



# Information gaps in Australia's palliative care:

**Reporting of activity and expenditure.**

Palliative Care Australia and KPMG

November 2021

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# Foreword

At Palliative Care Australia (PCA), it is our mission to influence, foster and promote the delivery of timely and quality palliative care for all who need it.

As a palliative care medicine specialist, I know the extraordinary benefits of access to timely, quality and person-centred palliative care.

Investment in palliative care means people can live well until their death in the place of their choice, with optimal management of symptoms, support and care.

In 2020 PCA commissioned health economics experts at KPMG to undertake a thorough investigation of the economic value of palliative care and make recommendations to better prepare Australia to meet the nation's rapidly escalating palliative care needs. *Investing to Save – The Economics of Increased Investment in Palliative Care in Australia* demonstrated that increased investment in palliative care can deliver lower end-of-life costs to Government as well as improving the health and social outcomes for people experiencing life-limiting conditions.

In order to better fund and plan for palliative care, it is important that we understand current activity and expenditure to determine if funding levels are sufficient and if there are any gaps or overlaps in service provision.

PCA has now commissioned KPMG to undertake an investigation into the transparency gaps in the reporting of palliative care activity and expenditure in Australia. KPMG has explored the existing evidence on palliative care funding and provision and consulted with key stakeholders in palliative care to better understand the key issues and complexities in reporting palliative care.

I extend my thanks to the KPMG team for their continued diligence both in the way they have explored the evidence and engaged with stakeholders to produce this report, keeping the needs of people with life-limiting illness and their families at the centre.

I also extend my thanks to everyone who contributed to this report and urge all Governments to study and implement the recommendations.

Doing so will deliver a more transparent view of the provision and funding of palliative care across Australia.



**Professor Meera Agar**  
Chair, Palliative Care Australia

# Introduction

**Over 50 years ago, former Australian Prime Minister Gough Whitlam, the then Leader of the Opposition, gave a speech to the Australian parliament which still resonates today:**

*“Mr Deputy Chairman, one of the problems in discussing health policy in Australia is the lack of reliable official information.”<sup>1</sup>*

— Mr Gough Whitlam (Leader of the Opposition)

Reproduced from the Hansard, 27<sup>th</sup> September 1967

This is particularly true for palliative care in Australia. As a country, we do not know who in our population has access to the palliative care services they need. There remains a ‘postcode lottery’ where the funding and delivery of palliative care services varies dramatically depending on where you live. We do not know how much we spend on helping Australians to live well in their last years, months and days of life, and if it is ‘enough’.

This report outlines what is routinely reported about the funding and provision of palliative care across Australia. The results are stark: across all funders and settings there are gaps that limit health service planning, investment and the delivery of person-centred palliative care. This is not to suggest Australia’s palliative care sector is poor by international standards. It is not, and with the routine measurement of outcomes in palliative care by Palliative Care Outcomes Collaboration (PCOC), Australia is in fact world leading. The Australian Institute of Health and Welfare (AIHW) report excellent statistics for specialist palliative care services provided in the inpatient and sub-acute settings. The AIHW’s Palliative Care and End-of-Life Data Development Working Group (PC EOL WG) is progressing a range of national data development activities including key performance indicators that will highlight access to specialist palliative care services across the population. But whilst this is an excellent start, there is room for improvement, particularly for palliative care services provided in the home, the community and residential aged care facilities. This report highlights actions to help routinely report the need, provision and funding of palliative care across these settings, so that gaps can be identified and addressed.

KPMG is proud to contribute to the ongoing discussion on palliative care reform, as we strive for a sector that is consumer-centric, evidence-based and equitable. We sincerely thank Palliative Care Australia for the opportunity to partner with them on this report. Our hope is that this report can fan the flames for better reporting of palliative care across Australia, as continued good policy development depends on data to inform it.



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# Acknowledgements

We would like to thank the key contributors to this report.

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## Stakeholder consultation

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**Organisation for Economic Co-operation and Development (OECD),** Directorate for Employment, Labour and Social Affairs – Cristian A. Herrera (Health Policy Analyst).

## Palliative Care Australia's acknowledgement and gratitude to The Snow Foundation

PCA has been able to commission this important work thanks to the generous support of the Snow Foundation.

Starting in Canberra, The Snow Foundation was established in 1991 by Terry Snow and his brother George to support people experiencing hardships and challenges. 30 years later, the Snow Foundation remains dedicated to the Canberra region coupled with a commitment to back key National initiatives supporting social entrepreneurship and stand out leaders with ambitious agendas for social change.

The Snow Foundation has been particularly generous in supporting people living with life-limiting illness. PCA has previously partnered with The Snow Foundation when they assisted financing *Investing to Save - The Economics of Increased Investment in Palliative Care in Australia*. The Snow Foundation continues to be an enthusiastic and willing partner in assisting to finance this follow up report which provides crucial information that will support better funding and planning for palliative care into the future. The Snow Foundation have recognised that for governments to make strategic changes and increase investment in palliative care for service delivery and data and evidence, governments need to have the facts clearly in front of them about gaps and inadequacies in the current arrangements.

The Snow Foundation are also generous benefactors to other organisations that offer care to palliative care patients and their families through their support of Clare Holland House in Canberra and the Violet Initiative (formally known as LifeCircle).

# Definitions

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## **Palliative care**

This report defines palliative care in accordance with The World Health Organization (WHO):

*“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.”*

Palliative care therefore:

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends neither to hasten or postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patient’s illness and in their own bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- Will enhance quality of life, and may also positively influence the course of illness; and
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

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## **End-of-life care**

This report defines end-of-life care in accordance with The Australian Commission on Safety and Quality in Health Care (ACSQHC) and is used in reference to those people likely to die within the next 12 months of life:

*“End-of-life care includes physical, spiritual and psychosocial assessment, care and treatment delivered by health professionals and ancillary staff. It also includes support of families and carers, and care of the patient’s body after their death. People are ‘approaching the end of life’ when they are likely to die within the next 12 months.”*

This includes people whose death is imminent (expected within a few hours or days) and those with:

- Advanced, progressive, incurable conditions;
- General frailty and co-existing conditions that mean that they are expected to die within 12 months;
- Existing conditions, if they are at risk of dying from a sudden acute crisis in their condition; and
- Life-threatening acute conditions caused by sudden catastrophic events.

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## **Person-centred care**

This report defines person-centred care in accordance with The Australian Commission on Safety and Quality in Health Care (ACSQHC):

*“Person-centred care is widely recognised as a foundation to safe, high-quality healthcare. It is care that is respectful of, and responsive to, the preferences, needs and values of the individual patient.”*

It involves seeking out, and understanding what is important to the patient, fostering trust, establishing mutual respect and working together to share decisions and plan care.

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# Disclaimer

This report has been prepared as outlined in the Scope Section. The services provided in connection with this engagement comprise an advisory engagement, which is not subject to assurance or other standards issued by the Australian Auditing and Assurance Standards Board and, consequently no opinions or conclusions intended to convey assurance have been expressed.

No warranty of completeness, accuracy or reliability is given in relation to the statements and representations made by, and the information and documentation provided by, Palliative Care Australia personnel and stakeholders consulted as part of the process.

KPMG have indicated within this report the sources of the information provided. We have not sought to independently verify those sources unless otherwise noted within the report.

KPMG is under no obligation in any circumstance to update this report, in either oral or written form, for events occurring after the report has been issued in final form.

The findings in this report have been formed on the above basis.

## **Third Party Reliance**

This report is solely for the purpose set out in the Scope Section and for Palliative Care Australia's information, and is not to be used for any other purpose without KPMG's prior written consent.

This report has been prepared at the request of Palliative Care Australia in accordance with the terms of KPMG's contract dated 24 September 2020. Other than our responsibility to Palliative Care Australia, neither KPMG nor any member or employee of KPMG undertakes responsibility arising in any way from reliance placed by a third party on this report. Any reliance placed is that party's sole responsibility.

The views expressed in this report are those of KPMG and not necessarily those consulted throughout the engagement.

# Executive summary

## Background



**Need for palliative care is rising rapidly across Australia and the globe.** KPMG's 2020 'Investing to Save: Palliative Care' report highlighted the increasing need for palliative care services due to the ageing of the population and the growing prevalence of cancer and other chronic diseases that accompany ageing.<sup>5</sup> Australian governments have committed to addressing the palliative care needs of Australians through the National Palliative Care Strategy 2018.<sup>6</sup>



**Despite this, transparent and routine reporting of palliative care activity and expenditure ranges from excellent to non-existent.** Improved reporting has been acknowledged by the Commonwealth Department of Health (DoH) in the Senate Community Affairs References Committee as an "ongoing concern for the Commonwealth"<sup>7</sup>; by the Productivity Commission as a barrier "making it difficult or impossible to examine usage patterns, costs or outcomes"<sup>8</sup>; and by the Australian Institute of Health and Welfare (AIHW) as partly addressable through the use of "existing State and Territory Health information systems".<sup>9</sup>



**As a result, there is limited understanding of expenditure on palliative care.** This lack of transparency is important. It constrains the ability to identify if current levels of funding in palliative care are sufficient, if there are gaps or overlaps in service provision and if our endeavours are cost-effective. It also hinders the evaluation of progress over time and across Australia to better identify the people and regions who may require additional support, to recognise exemplary palliative care where we can, and to track movement toward more person-centred care as outlined in the National Palliative Care Strategy 2018.<sup>10</sup>

## Scope and methodology

KPMG was engaged by Palliative Care Australia (PCA) to highlight these transparency gaps in the reporting of palliative care activity and expenditure in Australia. To deliver on this, the methodology for this report involved three stages:

- 1. Evidence gathering**, which included reviews of existing literature on the provision of palliative care, case studies from alternative areas of health where transparency has been addressed, and the identification of industry stakeholders to consult during stage two;
- 2. Consultation and system mapping**, which included the development of a baseline system map of palliative care funding and reporting in Australia which was used to inform discussion with industry stakeholders and the identification of important information gaps across care settings; and
- 3. Final reporting**, which included the consolidation of findings into a concise report following several rounds of review and feedback from PCA and other stakeholders.

## Exclusions and limitations

This report does not aim to duplicate existing activities to improve national palliative care reporting, including those by the AIHW, the Palliative Care and End-of-Life Care Data Development Working Group (PC EOL WG) and all levels of government.

The scope of this report therefore does not include a: complete evaluation of all information gaps in the reporting of palliative care; or a complete whole-of-government plan for reform. Similarly, the scope of this report did not include any quantification or value judgement of the current level of funding or service provision, but focuses simply on whether or not it is adequately measured and reported.

Finally, the views expressed in this report are those of KPMG and not necessarily those consulted throughout the engagement.

## Results and findings

This report outlined what is routinely reported about the funding and provision of palliative care across Australia. The results were stark: across all funders and settings the gaps identified restricted health service planning, investment and the delivery of person-centred palliative care. See Table ES1.

Specifically, it was found that the data had difficulties in:

- Identifying provision.** There are major gaps in the reporting of the palliative care services provided in the community and residential aged care settings. General Practitioner (GP) related activity has had no systematic mechanism for reporting activity since the conclusion of Bettering the Evaluation and Care of Health (BEACH) survey in 2015-16; the Medicare Benefits Schedule (MBS) does not adequately capture palliative care-related activity provided by non-specialist personnel; the Pharmaceutical Benefits Schedule (PBS) excludes a range of essential medicines due to an outdated palliative medicine schedule, despite recent reviews to the palliative care schedule (2021);<sup>11</sup> and although reforms are impending, the Aged Care Funding Instrument (ACFI) data highlights only a fraction of the total provision of palliative care in residential aged care with its scope confined to the last days, rather than months and years, of life; and
- Identifying expenditure.** While expenditure on palliative care services in sub-acute settings is consistently reported through the component of hospitals’ Activity Based Funding (ABF), the identification of expenditure in palliative care elsewhere is hampered by difficulties in identifying provision, and government’s lack of systematic reporting of community funding. Despite the presence of some reporting in budget statements, partnership agreements and program evaluations, there is limited visibility of how equitably and efficiently palliative care funding in the community is actually spent, and in which areas (e.g. education, death literacy, or provision).

Many of the challenges in understanding palliative care data arise when consolidation, accessibility and consistency of reporting is poor. This is particularly evident with government, whose announcements of funding for palliative care programs and initiatives often vary from announcement-to-announcement, are isolated and/or buried within budget statements.

This ad-hoc reporting is in contrast with the AIHW’s reporting through the ‘Palliative Care Services in Australia’ web publication each year. This report consolidates and updates palliative care data for the admitted, residential aged care and community settings, patient outcomes, workforce, and supports the insights in each report with robust interpretation and information on the data sources used to generate them.<sup>12</sup>

The difference in reporting is crucial. The ‘one-stop-shop’ approach to reporting embodied by the AIHW improves the usability of palliative care data in Australia, and subsequently, its ability to inform palliative care investment and policy development.

Table ES1: System mapping of palliative care activity and/or expenditure reporting

Funders	Home and community	Residential aged care	Hospital
Commonwealth	P	P	P / ✓
State	✗	✗	P / ✓
Primary health networks	✗	✗	-
Consumers	✗	✗	✗ / P

Source: KPMG 2021

Key: ✗ Limited capture/reporting P Partial capture/reporting ✓ Good capture/reporting / Mixed between

## Opportunities

Five potential opportunities were identified to support quality, person-centred palliative care. The aim of these actions is to deliver a more transparent view of the provision and funding of palliative care across Australia today through improved consolidated reporting and remedy of the issues identified in this report. The opportunities included:

- 1. Support equitable and person-centred palliative care for home and community by estimating need, service capability, provision of services and consolidating expenditure reporting on palliative care.** This can be achieved by modelling palliative care need in our population areas through the Public Health Information Development Unit (PHIDU); expansion of the National Palliative Care Services Directory; survey of palliative care provision in the community (GP-related activity); and consolidation of data in Commonwealth and state government information systems to report palliative care-related expenditure within the AIHW's national reporting of palliative care each year. Improved reporting of this kind will allow for population-based decision-making that fairly allocates funding in the community and help to evaluate our effectiveness in servicing these needs over time;
- 2. Recognise the palliative care needs in residential aged care with systematic surveys of residential aged care facility's (RACFs) provision.** Until reforms to aged care take place, or where they fall short, surveys of RACF's level of palliative care provision will support understanding of whether the provision of palliative care in residential aged care is reaching those who need it most;
- 3. Provide palliative care patients with access to the medicines they need by regularly reviewing the palliative medicine schedule.** While the recent recommendations to include additional opioid medications in the palliative care schedule are welcomed, systematic reviews (e.g. every three years) are still required, and must displace the current 'set-and-forget' policy.<sup>13</sup> This will help ensure that the PBS data accurately represents the provision of palliative care medicines and that more Australians have adequate access to them;
- 4. Improve understanding of Australians' end-of-life discussions with annual reporting of uptake of Advance Care Plans through the AIHW.** National reporting of ACPs under the remit of the AIHW would provide consistent and accessible reporting of a key indicator of palliative care provision as identified in the National Palliative Care Strategy 2018. This will help to consolidate national reporting of palliative care-related information and improve the understanding of end-of-life discussions in our population over time; and
- 5. Increase our provision of high-value care to Australians through longitudinal measurement and reporting of the incidence of low-value care metrics in hospital.** Development and reporting of low-value care metrics can inform health care providers in a timely and useable manner to facilitate continuous improvement toward person-centred palliative care, and minimise the economic costs associated with low-value care such as preventable admissions, excessive intensive care unit use or emergency department presentations during the end-of-life.

# 1. Scope, limitations and methodology for this report

# 1. Scope, limitations and methodology for this report

## Introduction

Palliative care and end-of-life care is remarkably complex. It can be required by the very young up to the very elderly, must adapt to the spectrum of patients' needs across the lifespan, and be available in all settings of care.<sup>14</sup>

Responsibilities for the provision and funding of quality palliative care are shared across the health and aged care system. Funding and financial assistance are provided by the Commonwealth and state governments to support a range of palliative care initiatives and services across residential aged care, hospital and community settings. However, there is also a significant amount of palliative care that is unaccounted for due to the challenges in identifying both need and provision of palliative care – particularly in residential aged care and general practice.

As a result, transparent and routine reporting of palliative care activity and expenditure across care settings ranges from excellent to non-existent. Improved reporting been acknowledged by the Commonwealth DoH in the Senate Community Affairs References Committee (SCARC) in 2012 as an “ongoing concern for the Commonwealth”<sup>15</sup>; by the Productivity Commission (PC) as a barrier “making it difficult or impossible to examine usage patterns, costs or outcomes”<sup>16</sup>; and by the Australian Institute of Health and Welfare (AIHW) as partly addressable through the use of “existing State and Territory Health information systems”.<sup>17</sup>

This lack of transparency is important. It constrains the ability to identify if current levels of funding in palliative care are sufficient, if service provision is equitable across Australia, and if our endeavours are cost-effective. It also hinders the evaluation of progress over time to better identify the people and regions who may require additional support, to recognise exemplary palliative care where we can, and to track movement toward more person-centred care as outlined in the National Palliative Care Strategy 2018.<sup>18</sup>

## Scope

KPMG was engaged by PCA to highlight information gaps in the reporting of palliative care activity and expenditure in Australia. The scope of the engagement included:

- Review of the responsibilities for palliative care and the related reporting of activity and expenditure in Australia;
- Consultation with key stakeholders in palliative care to understand key issues in reporting palliative care and the complexities associated with addressing them; and
- Identification of opportunities to improve reporting that have a positive impact on transparency of reporting of palliative care and were in the spirit of those priorities set out in the National Palliative Care Strategy 2018.

## Exclusions and limitations

This report does not aim to duplicate existing activities to improve national palliative care reporting, including those by the AIHW, the Palliative Care and End-of-Life Care Data Development Working Group (PC EOL WG) and all levels of government.

The scope of this report therefore does not include a: complete evaluation of all information gaps in the reporting of palliative care; or a complete whole-of-government plan for reform. Similarly, the scope of this report did not include any quantification or value judgement of the current level of funding or service provision, but focuses simply on whether or not it is adequately measured and reported.

Finally, the views contained within this report are those of KPMG. This report does not speak for those consulted throughout the engagement.

## Methodology

The methodology used to deliver this report scope is comprised of three stages:

### **1. Evidence gathering.**

Stage one compiled research and data on palliative care funding, activity and expenditure to develop the evidence base for this report. This included the extensive research published by the government, peak bodies, academics and leading practitioners on palliative care in Australia; and data reported by organisations such as the AIHW, the Palliative Care Outcomes Collaboration (PCOC) and more.

Additional information regarding the specific research considered, and data sources evaluated, in the formulation of this report can be found in Appendix A.

### **2. Consultation and system mapping.**

Stage two included consultation with key palliative care organisations such as the AIHW, Commonwealth and state health departments, primary health networks, data development groups and international organisations such as the Organisation for Economic Co-operation and Development (OECD). In conjunction with the evidence gathering in stage one, these consultations were used to develop a system map of palliative care funding and reporting in Australia, identify information gaps across care settings and highlight potential opportunities to address them.

Additional information outlining the specific organisations and stakeholders consulted for this report can be found in Appendix B.

### **3. Final reporting.**

Stage three included the consolidation of findings into a compact report followed by several rounds of review and feedback from PCA and other stakeholders.

This report presents the results from the implementation of this methodology. Importantly, the views expressed in this report are those of KPMG and not necessarily those consulted throughout the engagement.

## 2. System mapping: palliative care activity and expenditure reporting

# 2. System mapping: palliative care activity and expenditure reporting

## Palliative care by setting and funder

This section maps the data identifying palliative care activity and expenditure to communicate transparency gaps by setting and funder. In this mapping, there are three broad settings: home and community; residential aged care; and hospital; and four funders: Commonwealth government; state governments; primary health networks (PHNs); and consumers.

Table 1 below highlights the key findings from this system mapping process.

In summary, it was found that across the settings where palliative care is provided, data is at best partially reported in the hospital setting, while in residential aged care, and home and community settings, there is stark lack of reporting of annual funding and service provision.

The sections that follow provide more detail to these findings including funding responsibilities, what is publicly reported in the data and what is not. The report then highlights potential opportunities for improved transparency despite these gaps and limitations in the data, inspired by related areas of health, other jurisdictions, and identified in consultation with key stakeholders in palliative care.

Additional information regarding the data sources used in this system mapping can be found in Appendix A.

Table 1: System mapping of palliative care activity and/or expenditure reporting

Funders	Home and community	Residential aged care	Hospital
Commonwealth	P	P	P / ✓
State	✗	✗	P / ✓
PHN	✗	✗	-
Consumers	✗	✗	✗ / P

Source: KPMG 2021

Key: ✗ Limited capture/reporting   P Partial capture/reporting   ✓ Good capture/reporting   / Mixed between

# Home and community

## How is it funded?

Palliative care in the home and community is partly funded by the Commonwealth government, as well as via state governments, PHNs, and consumer out-of-pocket costs.<sup>19</sup>

### Commonwealth government

The Commonwealth government does not specifically fund palliative care in the home. However, Commonwealth funding is provided for home and community care through Home Care Packages (HCPs) or Commonwealth Home Support Programme (CHSP). HCPs support older persons who have ongoing and/or complex needs with daily activities while at home, and may be accessed by an older person to support them as they are approaching the end of their life. CHSP provides lower levels of support, but likewise may also be accessed as older people reach the end of their life. Eligibility for HCP is assessed by an Aged Care Assessment Team (ACAT) and can range from level 1 (basic care needs) up to level 4 (high care need). Importantly, people receiving HCPs can also receive specialist palliative care services from their local health service.<sup>20</sup> Likewise, CHSP eligibility is assessed by Regional Assessment Services (RAS). CHSP delivers discrete care, which is less intensive than HCPs. Services that can be accessed through CHSP include personal care, meals, respite and allied health.

The Commonwealth government provides additional funding for palliative care programs and initiatives, including those under the National Palliative Care Projects (NPCPs), some of which are for the home and community.<sup>21</sup> Palliative medicine services (under group A24 of the Medicare Benefits Schedule (MBS)) and medicines (under the palliative care schedule of the Pharmaceutical Benefits Schedule (PBS)) are also subsidised by the Commonwealth government.<sup>22</sup>

Finally, funding from the Department of Veteran Affairs (DVA) is allocated for palliative care services as part of their community nursing services for eligible veterans, war widows/widowers, and dependants, where clinically required.<sup>23 24</sup>

### State governments

State governments as system managers of the public hospital system are responsible for allocating Commonwealth funding for palliative care through the subacute component of hospitals' Activity Based Funding (ABF). This includes the distribution of state funding to provide specialist palliative care services and non-admitted care across home and community settings.<sup>25</sup>

### Primary Health Networks

The Commonwealth government provides funding for PHNs to support the delivery of quality palliative care in the home and community for their respective regions. An example includes the Greater Choice for at Home Palliative Care (GCfAHPC) program which provides funding for coordinating palliative care through PHNs to improve access to at home palliative care, support existing services in the region, reduce unplanned hospital admissions, build death literacy and community capacity.<sup>26 27</sup>

### Consumers and other

Part of consumers' palliative care needs are self-funded with out-of-pocket costs from accessing palliative care services and medicines under the MBS and PBS, respectively, and fees while in receipt of home care packages and support programs.<sup>28</sup>

## What is captured? What is not?

Publicly available data identifying palliative care-related activity and/or expenditure in home and community include the Bettering the Evaluation and Care of Health (BEACH) survey, MBS, PBS, the Independent Hospital Pricing Authority (IHPA), PCOC, Commonwealth and state government reporting and AIHW GEN aged care data. Despite this information, there are significant limitations in using this

data to systematically identify palliative care activity and expenditure in the community, as highlighted below and summarised in table 2.

- The BEACH surveys report the estimated number of palliative care-related encounters by General Practitioners (GPs) in the Australian population from data on a random sample of 1,000 GPs each year. While this data provided a robust insight into the important role that GPs have in palliative care in the community, this survey was last administered in 2015-16. As a result, there is no systematic mechanism for reporting of GP provision of palliative care beyond 2015-16.<sup>29</sup>
- The MBS data (or the AIHW's analysis of it) reports the number of patients, services, and government expenditure for claim of palliative care-related services under group A24 of the MBS. This includes attendances and case conferences in the community provided by palliative medicine specialists. However, this data does not report if these services were provided in the community or residential aged care setting, nor consumers' aggregate contributions to these claims.<sup>30</sup> Since only palliative medicine specialists are able to provide these services, this data also fails to capture the palliative care services provided by GPs, or the wider range of services provided near the end-of-life (e.g. psychologist services). As there are no palliative care-specific items for GPs to claim, the provision of palliative care by GPs are likely captured among other MBS items such as those for chronic disease management and/or home visits.<sup>31</sup> The MBS data covers but a fraction of total activity of home and community-based palliative care as a result.
- The PBS data (or the AIHW's analysis of it) reports the number of patients, medicines, and government expenditure for claim of palliative care medicines under the palliative care schedule of the PBS. However, this data has similar problems to the MBS. The PBS data cannot identify between medications prescribed in community and residential aged care, nor consumers' aggregate contributions to these claims. The palliative care schedule is out-of-date and understates the number of, and expenditure on, medicines claimed with palliative intent as a result. This data also includes claim of palliative care-related medicines that are in use for other conditions or purposes such as chronic pain.<sup>32</sup>
- IHPA records non-admitted palliative care separations and expenditure under the Tier 2 classifications 20.13 and 40.35.<sup>33</sup> These events include care delivered to hospital outpatient clinics, community-based clinics and patients' homes.<sup>34</sup> However, this data does not support the disaggregation between hospital and community-based non-admitted palliative care service events.<sup>35</sup> The data therefore reports activity and expenditure related to non-admitted palliative care services, but cannot attribute it to the home and community setting.
- Data reported by PCOC includes near full coverage of specialist palliative care episodes and phases in the community settings including patients' homes and residential aged care facilities.<sup>36</sup>
- State funding of community palliative care services can provide information on the level of investment, and its time horizon. For example, South Australia's (SA) 2018-19 budget announced \$16 million over four years to extend palliative care community outreach services operating hours to 24/7;<sup>37</sup> Queensland's (QLD) 2019-20 budget announced \$17 million in funding over two years to support community based palliative care services;<sup>38</sup> and Western Australia's (WA) 2019-20 budget announced an additional \$41 million investment in enhanced community-based palliative care across the region.<sup>39</sup> Importantly however, state-based reporting of expenditure on palliative care is ad-hoc, inconsistent across the country, and do not represent what is actually spent.
- Despite recent efforts to evaluate the NPCPs, Commonwealth government's reporting of the funding for community palliative care supports similarly lacks consistency, consolidation, and understanding of actual expenditure.<sup>40</sup>
- Finally, data on recipient of and expenditure on home care packages by the Commonwealth government are report by AIHW GEN aged care data. However, this data does not specifically report which recipients were palliative or received palliative supports.<sup>41</sup> The data therefore does not identify any activity or expenditure on palliative care.

Table 2: Publicly available data identifying palliative care in the home and community

Source(s)	What is captured?	What is not?
<b>BEACH</b>	<ul style="list-style-type: none"> <li>✓ Estimated number of palliative care-related encounters.</li> </ul>	<ul style="list-style-type: none"> <li>✗ Based on sample data of palliative care activity provided by GPs.</li> <li>✗ Data collection has ceased – last year of data is for 2015-16.</li> </ul>
<b>GEN / National Aged Care Data Clearinghouse (NACDC)</b>	<ul style="list-style-type: none"> <li>✓ Recipients and expenditure on home care and support services.</li> <li>✓ Veterans receiving palliative care community nursing services.</li> </ul>	<ul style="list-style-type: none"> <li>✗ Does not capture palliative care (recipients or expenditure) of in home care data.</li> </ul>
<b>PCOC</b>	<ul style="list-style-type: none"> <li>✓ Near full coverage of specialist community palliative care episodes and phases.</li> <li>✓ Excellent range of patient related outcome measures in the community setting.</li> </ul>	<ul style="list-style-type: none"> <li>✗ Public data currently does not disaggregate between community and residential aged care episodes/phases, although we note there is opportunity to request more detailed data from PCOC.</li> </ul>
<b>IHPA</b>	<ul style="list-style-type: none"> <li>✓ Non-admitted palliative care separations and expenditure under the Tier 2 classifications 20.13 and 40.35.</li> </ul>	<ul style="list-style-type: none"> <li>✗ Data does not support the disaggregation between hospital and community-based non-admitted palliative care service events.</li> </ul>
<b>MBS/AIHW</b>	<ul style="list-style-type: none"> <li>✓ 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.</li> </ul>	<ul style="list-style-type: none"> <li>✗ Cannot identify between the services provided in community and residential aged care.</li> <li>✗ Cannot identify consumers' out-of-pocket expenditures.</li> <li>✗ Cannot attribute the wider range of services accessed with palliative intent to 'palliative care', including services provided by GPs and more.</li> </ul>
<b>PBS/AIHW</b>	<ul style="list-style-type: none"> <li>✓ 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.</li> </ul>	<ul style="list-style-type: none"> <li>✗ Cannot identify between the medications prescribed in community and residential aged care.</li> <li>✗ Excludes medicines such as private prescriptions, over-the-counter medicines, and those supplied to inpatients in public hospitals.<sup>42</sup></li> <li>✗ Includes prescribing of palliative care-related medicines for non-palliative purposes.</li> <li>✗ Cannot attribute the wider range of medicines accessed with palliative intent to 'palliative care', included new palliative care medicines.</li> </ul>
<b>Commonwealth programs and initiatives</b>	<ul style="list-style-type: none"> <li>✓ Total funding over investment period and some detail on distribution of money to states if applicable.</li> </ul>	<ul style="list-style-type: none"> <li>✗ Funding and attribution versus actual expenditure (e.g. education, provision, in the community).</li> <li>✗ Systematic public reporting post announcement is limited.</li> </ul>
<b>State programs and initiatives</b>	<ul style="list-style-type: none"> <li>✓ As above.</li> </ul>	<ul style="list-style-type: none"> <li>✗ As above.</li> <li>✗ Mention of palliative care in state budgets is often not guaranteed.</li> </ul>

Source: KPMG 2021

# Residential aged care

## How is it funded?

Palliative care in residential aged care is funded primarily by the Commonwealth government, in some cases via state governments and/or PHNs, and partly through consumer out-of-pocket costs.<sup>43</sup>

### Commonwealth government

The Commonwealth government determines funding for residential aged care providers for palliative support as residents reach the end of their life through the Aged Care Funding Instrument (ACFI) section 12 item 14. The funding enables support including intensive clinical nursing and/or complex pain management in the last weeks or days of life for a consumer in the residential aged care setting.<sup>44</sup> The DoH is trialling an alternative funding instrument: the Australian National Aged Care Classification (AN-ACC), however this is yet to be fully implemented across the sector.

The Commonwealth government also provide funding for palliative care programs and initiatives, including the NPCPs. A number of these specifically target residential aged care facilities (RACFs).<sup>45</sup> Subsidies are also available for palliative medicine attendances and case conferences under group A24 of the MBS and palliative care medicines under the palliative care schedule of the PBS.<sup>46</sup>

### State government

While state governments' roles and responsibilities for palliative care in residential aged care are limited, Commonwealth and state governments do collaborate to provide more integrated services for residents. For example, the Comprehensive Palliative Care in Aged Care agreement specifies a cost-sharing arrangement between Commonwealth and state governments to deliver "projects that expand existing models of care or support new approaches to the way care is delivered or commissioned by each state and territory for older Australians living in RACFs."<sup>47</sup>

### Primary Health Networks

The Commonwealth government provides funding for PHNs to support the delivery of quality palliative care in residential aged care in their respective regions. One example of this is in North Sydney, where Sydney North PHN has "commissioned HammondCare to provide palliative care training to nursing staff at 20 to 30 local RACFs".<sup>48</sup> Another example includes the Gold Coast PHN who allocated funding to establish a "Palliative Care Support Framework for health professionals supporting RACFs in clinical and coordination of palliative and end-of-life care patient management".<sup>49</sup>

### Consumers and other

Part of residents' palliative care needs are also self-funded through the out-of-pocket costs from accessing palliative care services and prescriptions under the MBS and PBS, respectively, and fees while in receipt of aged care packages.<sup>50</sup>

## What is captured? What is not?

Publicly available data identifying palliative care-related activity and/or expenditure in residential aged care are provided by the AIHW's analysis of the ACFI, MBS and PBS data, and via Commonwealth and state government reporting. As in the home and community, there are significant limitations in using this data to systematically identify palliative care activity and expenditure in residential aged care, as highlighted below and summarised in table 3.

- The AIHW's analysis of ACFI data reports the number of admissions and residents with an ACFI-appraised palliative care status.<sup>51</sup> However, ACFI data is unable to represent the actual number of, and expenditure on, palliative persons in residential aged care. Funding for palliative care through ACFI is only available for the last days and weeks of life, which excludes the majority of palliative

care provision (i.e. the last years of life); is often restricted by the need for directives and pain assessments before claim; and is unavailable where residents are on the maximum ACFI 12 claim.<sup>52</sup>

- The MBS and PBS data (or the AIHW's analysis of it) reports the number of patients, services, and government expenditure for claim of palliative care-related services and medicines, respectively. However, this data does not report if these claims were provided in a residential aged care setting, nor consumers' aggregate contributions to these claims.<sup>53</sup> While these schedules can have claim items for a specific setting of care (i.e. GPs in RACFs),<sup>54</sup> they do not completely isolate palliative versus non-palliative intent in the services or medicines provided. As in the home and community setting, this includes services provided by non-palliative medicine specialists that though part of the end-of-life process are not recorded in the data on palliative care.<sup>55</sup> For the PBS this includes claim of palliative care-related medicines that are in use for other conditions or purposes such as chronic pain, and the reverse, where palliative patients are prescribed medicines that are commonly used for palliative care but that are not included on palliative medicine schedule.<sup>56</sup>
- The Commonwealth DoH reports information each year related to their funding of palliative care initiatives and programs and partnership agreements with state governments.<sup>57</sup> <sup>58</sup> This reporting often includes Commonwealth contribution amounts over the length of investment, and where applicable the distribution of such funding across states. For example, in the Project Agreement for Comprehensive Palliative Care in Aged Care it was reported that the Commonwealth government would contribute \$55 million to the states and territories allocated between 2019-20 and 2023-24, with \$17 million, \$14 million and \$11 million going to New South Wales, Victoria and Queensland, respectively.<sup>59</sup> However, once announced, there is limited to no visibility or reporting of how this was actually expended, and in which areas.

Table 3: Publicly available data identifying palliative care in residential aged care

Source(s)	What is captured?	What is not?
<b>ACFI/ NACDC</b>	✓ Admissions and residents with an ACFI-appraised palliative care status.	✗ Does not capture the full scope of palliative care need (persons) or receipt (provision).
<b>MBS/AIHW</b>	✓ 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.	<ul style="list-style-type: none"> <li>✗ Cannot identify residential aged care from the services provided.</li> <li>✗ Cannot identify consumers' out-of-pocket expenditures.</li> <li>✗ Cannot attribute the wider range of services accessed with palliative intent to 'palliative care', including services provided by GPs and more.</li> </ul>
<b>PBS/AIHW</b>	✓ 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.	<ul style="list-style-type: none"> <li>✗ Cannot identify residential aged care from the medications prescribed.</li> <li>✗ Excludes medicines such as private prescriptions, over-the-counter medicines, and those supplied to inpatients in public hospitals.<sup>60</sup></li> <li>✗ Includes prescribing of palliative care-related medicines for non-palliative purposes.</li> <li>✗ Cannot attribute the wider range of medicines accessed with palliative intent to 'palliative care', included new palliative care medicines.</li> </ul>
<b>Commonwealth programs and initiatives</b>	✓ Total funding over investment period and some detail on distribution of money to states if applicable.	<ul style="list-style-type: none"> <li>✗ Funding and attribution versus actual expenditure (e.g. education, provision, in RACFs).</li> <li>✗ Systematic public reporting post announcement is limited.</li> </ul>
<b>State programs and initiatives</b>	✓ As above.	<ul style="list-style-type: none"> <li>✗ As above.</li> <li>✗ Mention of palliative care in state budgets is often not guaranteed.</li> </ul>

Source: KPMG 2021

## How is it funded?

Palliative care in hospital is primarily funded by Commonwealth and state governments, consumers' out-of-pocket costs, and private health insurance.<sup>61</sup>

### Commonwealth government

The Commonwealth government provides financial assistance to state governments to serve their role as "system managers of the public hospital system".<sup>62</sup> In addition to this funding the Commonwealth government subsidises claim of palliative medicine attendances in hospital or surgery as indicated under group A24 of the MBS and palliative care medicines under the palliative care schedule of the PBS.

### State governments

As system managers of the public hospital system state governments are responsible for allocating Commonwealth funding for palliative care in hospital through the subacute component of hospitals' Activity Based Funding (ABF), and for the distribution of state funding to provide specialist palliative care services and non-admitted care across hospital and community settings.<sup>63</sup>

### Consumers and other

Palliative care needs in hospital can also be privately funded through private health insurance and the out-of-pocket costs from accessing palliative care services and prescriptions under the MBS and PBS, respectively.<sup>64</sup>

## What is reported? What is not?

Publicly available data identifying palliative care-related activity and/or expenditure in hospital is provided by the National Hospital Morbidity Database (NHMD), IHPA, PCOC, MBS, PBS and state budgets or announcements. In general, the public hospital system is effective in measuring activity and subsequent expenditure on palliative care, largely due to the ABF approach.<sup>65</sup> Despite this, some gaps remain in the relevant data on palliative care in hospital, as highlighted below and summarised in table 4.

- The NHMD presented by the AIHW provides information on palliative care and end-of-life care episodes in public and private hospitals, including the number of episodes, patient days and average length of stay.<sup>66</sup> Similarly, IHPA reports the number of separations, average length of stay and total expenditure for palliative care-related hospitalisations in public hospitals. Both data use patient 'care type' to determine the supply of palliative care for a given episode/separation.<sup>67</sup> This understates the true provision of palliative care as it does not specifically identify the receipt of palliative care – excluding services provided routinely by non-specialist palliative care providers such as geriatricians, for example.<sup>68</sup> For IHPA data specifically, while reporting on expenditure in palliative care it does not capture the palliative care provided in private hospitals, which according to the NHMD data accounts for approximately 1 in 6 palliative care and end-of-life hospitalisations in Australia.<sup>69</sup> And since private health insurers are not obligated to publicly report this information, data on palliative care expenditure in private hospitals are limited/not captured.
- IHPA also records non-admitted palliative care separations and expenditure under the Tier 2 classifications 20.13 and 40.35.<sup>70</sup> These events include care delivered to hospital outpatient clinics, community-based clinics and patients' homes.<sup>71</sup> However, this data does not support the disaggregation between hospital and community-based non-admitted palliative care service events.<sup>72</sup> The data therefore reports activity and expenditure related to non-admitted palliative care services, but cannot attribute it to the hospital setting.
- PCOC data has near full coverage of specialist palliative care in the inpatient setting.<sup>73</sup>

- Unlike residential aged care and the community, palliative care attendances provided in hospital or surgery can be identified in group A24 items of the MBS.<sup>74</sup> However, the issues in fully identifying palliative care intent from MBS/PBS claims identified in the home, community and residential aged care settings are common to the hospital setting. For details regarding these issues, refer to the 'palliative care in home and community' and 'palliative care in residential aged care' sections of this report.
- State's funding for hospital palliative care services can provide information on the level of investment, and its time horizon, in palliative care. However, this reporting is typically irregular and/or vague which make it difficult to attribute expenditure to palliative care specifically. For example, the Tasmania (TAS) 2017-18 budget set aside \$329 million to help continue increased access to subacute services at the Mersey Community Hospital, across rehabilitation, pain management services, palliative and geriatric care.<sup>75</sup> These announcements are also not guaranteed, as was the case in South Australia's 2017-18 budget which had no mention of palliative care despite receiving significant parliamentary discussion.<sup>76</sup>

Table 4: Publicly available data identifying palliative care in hospital

Source(s)	What is captured?	What is not?
<b>NHMD/AIHW</b>	<ul style="list-style-type: none"> <li>✓ Public and private reporting of palliative care and end-of-life care episodes.</li> <li>✓ Patient days and average length of stay.</li> </ul>	<ul style="list-style-type: none"> <li>✗ Data is episode-based and uses 'care type' to identify palliative care so it does not capture the full scope of palliative care need (persons) or receipt (provision).</li> </ul>
<b>Private Health Establishments Collection</b>	<ul style="list-style-type: none"> <li>✓ Specialist palliative care inpatient units (in private acute and psychiatric hospitals) beds and patient days.</li> </ul>	<ul style="list-style-type: none"> <li>✗ Collection ceased in 2016-17.</li> </ul>
<b>IHPA</b>	<ul style="list-style-type: none"> <li>✓ Count, expenditure and average length of stay for palliative care-related separations in public hospitals.</li> <li>✓ Non-admitted palliative care services under the Tier 2 classifications 20.13 and 40.35.</li> </ul>	<ul style="list-style-type: none"> <li>✗ As in row 1 (NHMD/AIHW).</li> <li>✗ Only captures public hospital activity.</li> <li>✗ Data does not support the disaggregation between hospital and community-based non-admitted palliative care service events.</li> </ul>
<b>MBS/AIHW</b>	<ul style="list-style-type: none"> <li>✓ Number of patients, services and total benefits paid for palliative care items in hospital or surgery: 3003, 3005, 3014, 3010, 3015.</li> </ul>	<ul style="list-style-type: none"> <li>✗ Cannot identify consumers' out-of-pocket expenditures.</li> <li>✗ Cannot attribute the wider range of services accessed with palliative intent to 'palliative care', including services provided by GPs and more.</li> </ul>
<b>PBS/AIHW</b>	<ul style="list-style-type: none"> <li>✓ 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.</li> </ul>	<ul style="list-style-type: none"> <li>✗ Cannot identify hospital from the medications prescribed.</li> <li>✗ Excludes medicines such as private prescriptions, over-the-counter medicines, and those supplied to inpatients in public hospitals.<sup>77</sup></li> <li>✗ Includes prescribing of palliative care-related medicines for non-palliative purposes.</li> <li>✗ Cannot attribute the wider range of medicines accessed with palliative intent to 'palliative care', included new palliative care medicines.</li> </ul>
<b>PCOC</b>	<ul style="list-style-type: none"> <li>✓ Near full coverage of specialist inpatient palliative care episodes and phases.</li> </ul>	
<b>State programs and initiatives</b>	<ul style="list-style-type: none"> <li>✓ Total funding over investment period and some detail intended scope (i.e. improve access to specialist palliative care).</li> </ul>	<ul style="list-style-type: none"> <li>✗ Funding and attribution versus actual expenditure (e.g. education, provision, in RACFs).</li> <li>✗ Systematic public reporting post announcement is limited.</li> <li>✗ Mention of palliative care in state budgets is often not guaranteed.</li> </ul>

Source: KPMG 2021

## Summary: limitations in the reporting of palliative care activity and expenditure

The system mapping exercise highlighted significant limitations in the data on palliative care activity and expenditure in Australia. Overall, it was found that the data had difficulties in:

- **Identifying provision.** There are major gaps in the reporting of the palliative care services provided in the community and residential aged care settings. GP-related activity has had no systematic mechanism for reporting activity since the conclusion of the BEACH survey in 2015-16; the MBS does not adequately capture palliative care-related activity provided by non-specialist personnel; the PBS excludes a range of essential medicines due to an outdated palliative medicine schedule, despite recent reviews to the palliative care schedule (2021);<sup>78</sup> and although reforms are impending, ACFI highlights only a fraction of the total provision of palliative care in residential aged care with its scope is confined to the last days and weeks, rather than months and years, of life; and
- **Identifying expenditure.** While expenditure on palliative care services in sub-acute settings is consistently reported through the component of hospitals' ABF funding, the identification of expenditure in palliative care elsewhere is hampered by difficulties in identifying provision, and a lack of systematic reporting of community funding. Despite the presence of some reporting in budget statements, partnership agreements and program evaluations, there is limited visibility of how palliative care funding in the community is actually spent, and in which areas (e.g. education, death literacy, or provision).

Many of the challenges in understanding palliative care data arise when consolidation, accessibility and consistency of reporting is poor. This is particularly evident with government, whose announcements of funding for palliative care programs and initiatives often vary from announcement-to-announcement, are isolated and/or buried within budget statements.

By contrast, organisations such as the AIHW deliver a web publication specific to 'Palliative Care Services in Australia' each year. This report consolidates and updates palliative care data for the admitted, residential aged care and community settings, patient outcomes, workforce, and supports the insights in each report with robust interpretation and information on the data sources used to generate them.<sup>79</sup>

The difference in reporting is crucial. The 'one-stop-shop' approach to reporting embodied by the AIHW improves the usability of palliative care data in Australia, and subsequently, its use to understand how palliative care 'works' and how it can be improved.

# 3. Opportunities and concluding remarks

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## Opportunities

One of the core pillars in the National Palliative Care Strategy 2018 emphasises the need to develop excellent data, evidence and consistent reporting to support the delivery of quality, person-centred palliative care in Australia. The previous section has demonstrated that across all care settings our data has several limitations which inhibit the attainment of such a goal, and in effect, of all other goals outlined in the National Palliative Care Strategy 2018.

This final section aims to briefly highlight the potential opportunities to support quality, person-centred palliative care for more Australians through improved consolidated reporting and remedy of the issues identified in this report. This includes the opportunity to:

1. Support equitable and person-centred palliative care for home and community;
2. Recognise the palliative care needs in residential aged care;
3. Provide palliative care patients with access to the medicines they need;
4. Improve understanding of Australians' end-of-life discussions; and
5. Increase our provision of high-value care to Australians in hospital.

### 1. Support equitable and person-centred palliative care for home and community

Palliative care services in the community have been referred to as a 'postcode lottery' where access to services are determined more on the basis of where you live than your level of need.<sup>80</sup> There are major gaps in the reporting of palliative care service provision in the community and residential aged care settings – particularly in GP-related activity. Information on government funded palliative care programs and initiatives in the community are often confined to budget line items with little subsequent reporting on actual expenditure and in which areas. The result is that access to palliative care in the home and community settings is unequal across regions, and that there is very limited robust and consistently reported data to identify which areas are which.

The implication of poor data is the sub-optimal allocation of funding to support population-based person-centred palliative care. The AIHW and the PC EOL WG have acknowledged they are aiming to improve this reporting in their 'National Palliative Care and End-of-Life Care Information Priorities' consultation draft document stating that national information should:

*"Include national data collection about state and territory funded and run specialised palliative care services; this could include information about establishments, beds, patient days, expenditure, staff and salaries. "and "...mechanisms to collate and report data from the private sector, non-government organisations, and community providers of palliative care, where it is not collected by state and territory health services."*<sup>81</sup>

Specifically, there are four key opportunities to improve reporting of palliative care in the home and community:

- **Estimate need.** Develop a palliative care index that models palliative care need using population projections, disease prevalence and demographic factors by geography (i.e. by PHN) each year. The Public Health Information Development Unit (PHIDU) have done much of this work already in their modelling of the prevalence of selected chronic diseases and conditions by PHN, Local Government Areas (LGA), remoteness areas (RA) and socio-economic indexes for areas (SEIFA) in the Australian population.<sup>82</sup> This would provide much needed information to providers about the likely palliative care needs in their community to make informed decisions about how to address them.

- **Identify service providers.** Expand and fund the existing National Palliative Care Services Directory to systematically capture information on the number of palliative care services in a given region (e.g. PHN), their capability (e.g. 24/7 support), workforce capacity (e.g. palliative medicine specialist), and annual throughput (i.e. service volume). In conjunction with estimates of need, this information would support population-based decisions about the funding of old and the implementation of new palliative care services in the community.
- **Measure provision.** Develop a survey to systematically report on palliative care provision in the home and community that are out-of-scope of current data collections. This has been done by RACGP Rural who conducted a Palliative Care Survey of members in 2015 to examine the extent of and demand for GP-led palliative care services in rural and remote communities. See Boxout 1. This information would allow the Commonwealth government to see some of the activity resulting from their funding, and if captured frequently, help evaluate if non-specialist palliative care needs are being adequately met. This is critical for evaluating the equity of palliative care provision across Australia, and the identification of unmet need.
- **Track expenditure.** Consolidate data captured in Commonwealth and state governments' information systems to report expenditure under the national reporting of palliative care by the AIHW. This reporting should highlight (a) how much palliative care funding was allocated, (b) it's intent (i.e. education, training, provision, death literacy), (c) in which regions, and (d) be updated retrospectively to highlight when (or if) funding was spent, each year.

Under the standard reporting of the AIHW, this will allow us to develop and monitor macro-level metrics (e.g. such as expenditure on specialist palliative care services per capita, which is likely to be endorsed by the AIHW and the PC EOL WG pending approval from governance committees) to understand if funding is sufficient for a given level of need and how effectively it is being serviced.<sup>83</sup>

#### **Boxout 1:** RACGP Rural palliative care survey

To determine the extent of, and demand for, GP-led palliative care services in rural and remote communities an online survey of National Rural Facility (NRF) members (practising GPs in ASGC-RA 2-5) was conducted on 20 April 2015.

522 responses were received and reported on the service provision across community, residential aged care and hospital settings, whether there was unmet need in their rural community and key barriers to addressing this need by demographic factors such as workforce age profile, rurality, and career stage.

The results of the survey highlighted that 63% of participants indicated the need for more GP-led palliative care services in their community and that the largest barrier for improving the provision of more services was time constraints and inadequate palliative care education.

Source: RACGP (2018). *RACGP Rural palliative care survey*. [online] Racgp.org.au. Available at: <https://www.racgp.org.au/the-racgp/faculties/rural/advocacy-and-research/research-projects/racgp-rural-palliative-care-survey>

## 2. Recognise the palliative care needs in residential aged care

As a result of the Royal Commission into Aged Care Safety and Quality, it is likely that significant reform will occur in aged care. In a welcome move, the DoH is already trialling a replacement funding mechanism to ACFI. Structural and policy-based impediments inherent in ACFI have constrained effective provision and measurement of palliative care in residential aged care.<sup>84</sup> These flaws are most evident by the fact that while nearly all people who enter RACFs spend their last days there, only 1 in 50 access palliative care under ACFI.<sup>85</sup>

These issues are known. It is expected that these reforms may include a 'rethink' to palliative care and allow for administrative reporting that better identifies need and receipt of palliative care in residential aged care. Importantly, it is also acknowledged that these potential changes will be only a part of the total reforms to aged care, and will take the better part of a decade, or decades, to have the desired impact.

Until such time, gaps in understanding of palliative care in residential aged care will persist. Alternative solutions that can help satisfy this gap until reforms are rolled out or where reforms fall short must be supported. Solutions of this kind have been implemented in US nursing homes using surveys of care providers to assess the degree that staff provide palliative care. See Boxout 2.

The resulting information from a survey of providers would add new data and insights on the provision of palliative care in the residential aged care setting previously out-of-scope of ACFI reporting that will help to understand if our provision of palliative care in residential aged care is reaching those who need it most.

**Boxout 2:** Surveys assessing palliative care provision in US Nursing Homes.

The purpose of this study was to evaluate the psychometric properties of the Palliative Care Survey (PCS) for use in nursing homes. Support was obtained for a 51-item PCS made up of two constructs, Palliative Care Practice and Palliative Care Knowledge.

The PCS measures the extent to which the nursing home staff engage in palliative care practices and have knowledge consistent with good end-of-life care. Both practice and knowledge are an essential foundation to providing good end-of-life care to nursing home residents. Efforts to improve care for the dying in nursing homes have been slowed by an absence of measurement tools that capture care processes, a gap that the PCS reported here helps fill.

Source: Thompson, S., Bott, M., Boyle, D., Gajewski, B., & Tilden, V. P. (2011). A measure of palliative care in nursing homes. *Journal of pain and symptom management*, 41(1), 57-67.

### 3. Provide palliative care patients with access to the medicines they need

Palliative care patients are recommended a range of medicines to treat end-of-life symptoms. In 2004, the palliative medicines care schedule was introduced as a subsection of the PBS to “improve access to essential and affordable medications for patients receiving palliative care”.<sup>86</sup> With nearly two decades gone, the schedule has failed to keep pace with the availability of new medications and updated evidence for dosing in existing medicines to effectively treat palliative care.<sup>87</sup> Patients have access to some, but not all, of the medicines required to treat palliative care as a result.

Updates to the palliative care schedule have been supported widely by PCA National Clinical Advisor and Palliative Care Nurse Practitioner Kate Reed, the RACGP and the Pharmaceutical Benefits Advisory Committee (PBAC).<sup>88</sup> While the recent recommendations to include additional opioid medications in the palliative care schedule are welcomed, there is still a significant opportunity to ensure reviews do not follow ‘set-and-forget’ policies of the past, and are instead conducted routinely (e.g. every three years).<sup>89</sup>

This will help mitigate barriers to patients’ access to core medicines through reduced costs and fewer claim rejections, and simultaneously improve the administratively reported data. At present, PBS data on palliative care medicines does not cover the full range of medicines accessed for palliative care.<sup>90</sup> This review, and subsequent reviews, will therefore ensure that the data more accurately represents the provision of palliative care medicines and that more Australians have adequate access to them.

### 4. Improve our understanding of Australians’ end-of-life discussions

Advance care planning (ACP) is central to person-centred palliative care and is often part of our first discussions regarding the end-of-life. The Commonwealth government and the National Palliative Care Strategy 2018 understand this and have funded Advance Care Planning Australia to educate, advocate, advise, and commission research on the subject. This includes research “to deliver the 'Prevalence of Advance Care Planning Documentation in Australian Health and Residential Aged Care Services' study. This study has collected a national dataset on the uptake of advance care planning documents across jurisdictions, sectors, medical conditions and services. The findings of this study have implications for policy makers, stakeholder organisations, service providers and the community within Australia and internationally.”<sup>91</sup>

Despite the advent of this national dataset, the study of it, and our commitment to ACP under the National Palliative Care Strategy 2018 and its implementation plan (Action Area 3), the reporting of ACP documentation and concordance is not yet business-as-usual.<sup>92</sup> Such key statistics need to be collated and reported routinely and officially, just as the ABS and the AIHW report on key economic and health statistics.

There is an opportunity to bring this dataset into a national reporting framework of the AIHW. This has been similarly implemented with My Health Record where statistics on registrations, document uploads, and prescription/dispense documents are reported each month under the remit of the AIHW and the Australian Digital Health Agency. See Boxout 3 for additional information.

Consolidated national reporting under the AIHW would provide researchers, policymakers and providers with a 'one-stop-shop' for palliative care-related data that is consistent, transparent and accessible. This reporting of palliative care in Australia will improve the understanding of the end-of-life (including end-of-life discussions) in our population over time.

**Boxout 3:** My Health Record statistics.

The Australian Digital Health Agency publishes a range of statistics about how My Health Record is being used by healthcare provider organisations and patients. The statistics are reported every month and include information about registrations, document uploads and prescription/dispense documents.

For example, as at October 2020 there were over 22 million total My Health Records and over 2.3 billion documents uploaded, including medical histories, blood tests, pathology reports, advanced care plans and vital health information. Approximately 94%, 88%, 84% of public hospitals, pharmacies and GPs were recorded using My Health Record, respectively.

The Australian Institute of Health and Welfare (AIHW) has been appointed as the Data Custodian to manage the use of My Health Record system data for research and public health purposes, while protecting the privacy and security of that data. All applications for data will need to meet strict privacy, assurance and risk mitigation requirements to be considered. The AIHW has a remit to make information and statistics available that can help shape and improve health in Australia through better services and programs.

Sources: Australian Digital Health Agency. (2020). *My Health Record statistics*. Australian Digital Health Agency. <https://www.myhealthrecord.gov.au/statistics>; Australian Digital Health Agency. (2020). *Choose how your data is used for research*. Australian Digital Health Agency. <https://www.myhealthrecord.gov.au/for-you-your-family/howtos/choose-how-your-data-is-used-for-research>

## 5. Increase our provision of high-value care for Australians in hospitals

Hospitals' reporting of palliative care activity and expenditure is relatively robust, consistent and transparent, but its understanding of the low-value care provided to inpatients is not. In KPMG's 2020 report on the economics of increased investment in palliative care it was noted that although there are national standards for hospitals around comprehensive care at the end-of-life (e.g. Actions 5.15-5.20 of the National Safety and Quality Health Service Standards), the incidence of low-value care remains high.<sup>93</sup> The National Palliative Care Strategy 2018 similarly emphasises this in its demands for a health system that understands and recognises palliative care need and adequately supports it in all settings of care.<sup>94</sup>

Regular measurement and reporting of low-value care in end-of-life hospital admissions would ensure a focus on actioning these standards, priorities in the National Palliative Care Strategy 2018, and allow us to track progress towards reducing low-value care in hospitals. According to the OECD, simple metrics of low-value care, including the rate of unplanned hospital admissions, presentations to the emergency department and time spent in intensive care units in the end-of-life, can be powerful for assessing this progress and comparing performance across countries.<sup>95</sup>

While there have been academic papers reporting the incidence of low-value care in Australia, there is need for consistent and longitudinal reporting of low-value care metrics.<sup>96 97</sup> The AIHW and the PC EOL WG have acknowledged this in their 'National Palliative Care and End-of-Life Care Information Priorities' consultation draft document stating that national information should:

*“Establish nationally agreed and publicly available indicators relating to palliative care services. This could include systems to feed results back to health care providers in a timely and useable manner, facilitating continuous improvement activity”.*<sup>98</sup>

One opportunity to implement this type of reporting is through existing registries such as the Registry of Older South Australians (ROSA) which captures and reports information of 16,000 South Australians undergoing aged care eligibility each year, including the identification of unwanted variation in care. See Boxout 4.

**Boxout 4:** Measuring and reporting low-value care through ROSA

A registry to capture 16 000 South Australians/year undergoing an aged care eligibility assessment was designed. ROSA will contain information captured by the Commonwealth and South Australian state Health Authority, linked by two data integrating authorities, and housed on a secured data platform. ROSA will contain information on the sociodemographic, health, function, psychological, social, home and safety assessment and concerns characteristics, aged care services, general health services, and mortality of people receiving aged care services. Registered participants will be prospectively monitored until their death and yearly updates of their aged care and healthcare services information will be added to the registry.

ROSA will longitudinally monitor the services provided to a population that puts costly demands on the state healthcare and aged care systems, identify unwanted variation, and underpin future research. ROSA's expected outputs include an annual report, a research agenda that focuses on high burden conditions and potentially economically impactful questions, educational materials, and risk profiling tools.

Source: Inacio MC, Bray SCE, Whitehead C, et al. Registry of Older South Australians (ROSA): framework and plan. *BMJ Open* 2019;9:e026319. doi:10.1136/bmjopen-2018-026319

## Concluding remarks

This report outlined what is routinely reported about the funding and provision of palliative care across Australia. The results were stark: across all funders and settings the gaps identified restricted our understanding of need, provision and funding of palliative care services in Australia.

This lack of transparency is important. It constrains the ability to identify if current levels of funding in palliative care are sufficient, if service provision is equitable and if our endeavours are cost-effective. It also hinders the evaluation of progress over time to better identify jurisdictions or cohorts that may require additional support, to recognise exemplary palliative care where we can, and to track movement toward key priorities outlined in the National Palliative Care Strategy 2018.<sup>99</sup>

It is acknowledged that these limitations are truly challenging to rectify, and that in fact Australia is a world-leading provider of palliative care across the globe.<sup>100</sup> But we also recognise that our palliative care system needs more timely, consistent and consolidated reporting to inform decision-making. This is demonstrated by the commitment of organisations such as the AIHW, PC EOL WG, PCOC and others to developing our national information systems; the DoH's implementation of the National Palliative Care Strategy 2018; the PC's inquiry into end-of-life care reforms; and our present-day review of the entire aged care system.

The need for palliative care is not slowing, but growing with ageing of the Australian population and the rise in the prevalence of cancer and other chronic diseases that accompany ageing.<sup>101</sup> Improved routine reporting of need, provision and funding of palliative care across home and community, residential aged care and hospital settings, is required to support evidence-based decision-making for our palliative care sector.

# Appendices

# Appendix A: Evidence base

## Key research and policy papers

Table 5: Key past reports and inquiries

Year	Author and Title
2020	<b>Palliative Care and End-of-life Care Data Development Working Group</b> National Palliative Care and End-of-Life Information Priorities: Consultation draft <sup>102</sup>
2019	<b>URBIS and the Department of Health</b> Evaluation of the National Palliative Care Projects <sup>103</sup>
2019	<b>Queensland Health</b> Palliative care services review <sup>104</sup>
2018	<b>University of Technology Sydney</b> Palliative care in residential aged care: Identifying and funding palliative care needs in Australia <sup>105</sup>
2018	<b>Department of Health</b> National Palliative Care Strategy 2018 <sup>106</sup>
2018	<b>Department of Health and Human Services, Victoria State Government</b> Palliative care funding model review <sup>107</sup>
2017	<b>Productivity Commission</b> Introducing competition and informed user choice into human services: Reforms to human services. Chapter 3: End-of-life care in Australia <sup>108</sup>
2012	<b>Senate Community Affairs Reference Committee</b> Palliative care in Australia <sup>109</sup>

Source: KPMG 2021

## Key data collections

Table 6: Key public sources of palliative care data.

Data	Description	Link
<b>BEACH Survey</b>	The BEACH survey of general practice activity was undertaken annually by the Family Medicine Research Centre at the University of Sydney between 1998 and 2016.	<a href="#">AIHW</a>
<b>AIHW GEN aged care data</b>	GEN gives access to the data and information from the National Aged Care Data Clearinghouse (NACDC) which is managed by the Australian Institute of Health and Welfare (AIHW). GEN is a comprehensive “one-stop shop” for data and information about aged care services in Australia. It reports on capacity and activity in the aged care system focusing on the people, their care assessments and the services they use.	<a href="#">GEN</a>
<b>PCOC</b>	The Australian Palliative Care Outcomes Collaboration (PCOC), established in 2005, is a national palliative care outcomes and benchmarking program. The data are reported at the patient-level, episode-level and phase-level.	<a href="#">AIHW</a>
<b>IHPA</b>	The National Hospital Cost Data Collection (NHCDC) Report, infographics and articles present the results from the Round 22 NHCDC (financial year 2017-18). These documents describe the hospital costs submitted by jurisdictions for the following activity streams: <ul style="list-style-type: none"> <li>• admitted acute care</li> <li>• non-admitted care</li> <li>• emergency care</li> <li>• mental health care</li> <li>• sub-acute and non-acute care.</li> </ul>	<a href="#">IHPA</a>
<b>MBS/AIHW</b>	The Australian Government Department of Services Australia collects data on the activity of all persons making claims through the MBS and provides this information to the Australian Government Department of Health. Information collected includes the type of service provided (MBS item number) and the benefit paid by Services Australia for the service.	<a href="#">AIHW</a>
<b>PBS/AIHW</b>	The Australian Government Department of Human Services (DHS) processes all prescriptions dispensed under the PBS/RPBS and provides this data to the Australian Government Department of Health. Information collected includes age, sex and postcode of the patient, details of the medication prescribed (for example, location).	<a href="#">AIHW</a>
<b>ACFI/AIHW</b>	Data on palliative care in residential aged care come from the AIHW’s National Aged Care Data Clearinghouse. This Clearinghouse contains information gathered via a number of data collections. Data collected from the Aged Care Funding Instrument (ACFI) are used to inform palliative care in residential aged care.	<a href="#">AIHW</a>
<b>NHMD/AIHW</b>	The NHMD includes administrative data, demographic information on patients, and clinical information including diagnoses and procedures performed. This annual collection is compiled and maintained by the AIHW, using data supplied by state and territory health authorities. Information from almost all hospitals in Australia is included in the database: from public acute and public psychiatric hospitals, private acute and psychiatric hospitals, and from private free-standing day hospital facilities	<a href="#">AIHW</a>
<b>Commonwealth / state initiatives and programs</b>	Funding for palliative care initiatives or programs reported in annual budgets, partnerships agreements or announcements.	Multiple sources

Source: KPMG 2021

## Appendix B: Stakeholder consultations

Importantly, the views expressed in this report are those of KPMG and not necessarily those consulted throughout the engagement.

Table 7: Organisations and stakeholders consulted for this engagement

Organisation	Stakeholder(s)
<b>Australian Institute of Health and Welfare (AIHW)</b>	<b>Centrelink Strategies Unit</b> Sushma Mathur (Centrelink Strategies Unit Head) and Benjamin Ashton (Palliative Care Team Leader).
<b>Commonwealth Department of Health</b>	<b>Primary Health and Palliative Care Branch</b> Nicole Fitzgerald (A/g Assistant Secretary), Georgia Phillips (A/g Director Palliative Care Section) and Toni Smith (Assistant Director, Palliative Care Section).
<b>State Department of Health</b>	<b>Department of Health Tasmania – Primary, Rural and Palliative Care and Health Planning, Policy, Purchasing, Performance and Reform)</b> Ian Bell (Manager).
<b>Primary Health Networks</b>	<b>Central Queensland, Wide Bay, Sunshine Coast PHN</b> Jane Campbell (Manager Clinical Engagement) and Paige Martinez (Health System Improvement Manager).  <b>North Western Melbourne PHN</b> Jesse Osowicki (Manager, Integration).
<b>Palliative Care and End-of-Life Data Development Working Group (PC EOL WG)</b>	<b>Palliative Care and End-of-Life Data Development Working Group</b> Kate Swetenham (Chair).
<b>Organisation for Economic Co-operation and Development (OECD)</b>	<b>Directorate for Employment, Labour and Social Affairs</b> Cristian A. Herrera (Health Policy Analyst)

Source: KPMG 2021



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