

National Palliative Care and End-of-Life Care Information Priorities

January 2022

Report produced by the
Australian Institute of Health and Welfare
in collaboration with the Palliative Care and
End-of-Life Care Data Development Working Group





Acknowledgments

We acknowledge Aboriginal and Torres Strait Islander peoples as the first inhabitants of this nation and the traditional custodians of the lands where we live, learn and work. Governments pay respect to all Aboriginal and Torres Strait Islander Elders, past and present from every nation.

We acknowledge the significant contribution of the Palliative Care and End-of-Life Care Information Priorities Authoring Group and from members of the Palliative Care and End-of-Life Care Data Development Working Group. We also acknowledge the individuals and organisations from the palliative care and end-of-life care sector who contributed to this document by providing feedback through the sector consultation or via committees.

Palliative Care and End-of-Life Care Information Priorities Authoring Group

Kate Swetenham	South Australian Department of Health (Chair)
Georgia Phillips	Australian Government Department of Health
Meera Agar	Palliative Care Australia
Belinda Rice	Victorian Department of Health
David Oats	Western Australian Department of Health
Laura Casey	PHN Brisbane South
Sushma Mathur	Australian Institute of Health and Welfare
Benjamin Ashton	Australian Institute of Health and Welfare

Contents

Acknowledgments	3
Contents.....	4
Foreword.....	5
Executive summary	6
Information priorities at a glance	7
Vision	7
Introduction.....	8
Definitions.....	10
Palliative care information landscape	12
Broader policy environment	15
Purpose of this document	16
Opportunities and challenges	17
National priorities for palliative care information development	19
People with a life-limiting illness.....	20
Families and carers.....	23
Workforce	26
Service and system planning and design.....	28
Service delivery and integration.....	30
Performance and public reporting	32
Understanding and public awareness	34
Making it happen	36
Potential data sources.....	37
Acronyms and abbreviations.....	38
Glossary	39
References	44

Foreword

Information is important infrastructure for effective delivery and promotion of palliative care and end-of-life care. Like other infrastructure, it requires long-term planning and prioritisation of investment.

The National Palliative Care and End-of-Life Care Information Priorities will be the first of its kind in the palliative care and end-of-life care sector. It will provide the strategic priorities for information development in government-funded palliative care and support services over the next decade.

Robust national palliative care and end-of-life care data is a key goal of the National Palliative Care Strategy (Australian Government 2018). Many of the Strategy's commitments require a more coordinated approach to national information, including better use of current national data, building new national data assets and new methods to monitor and report on the impact and outcomes of the sector.

These priorities, in conjunction with the National Palliative Care Strategy, are intended to guide planning, investment and action by governments and other stakeholders. They are not intended to be an implementation or investment plan. Many critical issues are beyond the scope of this document, including IT developments and the rapid expansion of private online health providers. Government health services need to work within this fast-changing environment, but this document cannot define the planning priorities for those sectors.

These draft information priorities have been developed by the Palliative Care and End-of-Life Care Data Development Working Group (PC EOL WG), which is a committee of the Australian Health Ministers Advisory Council (AHMAC)'s Health Services Principal Committee (HSPC). These committees reported to the Council of Australian Governments (COAG) Health Ministers. Please note, that following the cessation of COAG on 29 May 2020, the committee structures have been replaced by the Health Chief Executives Forum and the governance for the PC EOL WG is under review. The PC EOL WG includes representation from public and private health services, non-government organisations, and key national organisations involved in palliative care and end-of-life care policy, planning, data and reporting. This document has been informed by a broad public consultation, including submissions from a range of stakeholders. The PC EOL WG would like to thank all those who took part in the development of this document, including contributing views, experience, and expertise.



Kate Swetenham

Chair, Palliative Care and End-of-Life Care Data Development Working Group

Executive summary

The demographics of the Australian population are changing, with an increasing number of people living longer with illnesses that are chronic in nature. Palliative care is an approach that improves the quality of life of people—adults and children—and their families who are facing the problems associated with lifelimiting illness. With an ageing and growing population, it is projected that the demand for palliative care and end-of-life care will rise substantially.

Although there have been some advances in palliative care information, there is limited consistent, national data with full coverage of jurisdictions and care settings. The gaps in national data are likely to impact service planning and monitoring as the sector evolves in response to changing demand. With the increasing recognition of palliative care and end-of-life care as a key social and health issue, the development of comprehensive national information to inform policy and program development is essential.

This document outlines an aspirational vision for the future of national palliative care and end-of-life care information development over the next decade and articulates priorities aimed at supporting that vision. National information will support people with a life-limiting illness, their families and carers, health professionals, health services, policy makers, and governments to make informed decisions based on timely and comprehensive information. This will help to ensure that all people living with a life-limiting illness receive the care they need to live as well as possible for as long as possible.

The purpose of this document is to help guide efforts in palliative care and end-of-life care information development over the next 10 years. A set of aspirational priorities are outlined that will help to guide the development of national information and foster an information culture into the future. The document is a statement of common, national intent and an agreement to pursue the agreed directions to the extent that is possible for each of the parties. It is not a binding prescription for the parties concerned, and progressing the priorities will involve a collaborative effort between Australian governments.

This document is concerned with ‘national information’ development. This concept is used to refer to information that has national coverage and is comparable, consistent and relevant. It does not define how these priorities should be implemented, or any provision for funding. It is recognised that these priorities will require investment to progress.

The information priorities fall into seven categories: People with a life-limiting illness; Families and carers; Workforce; Service and system planning and design; Service delivery and integration; Performance and public reporting; and Understanding and awareness of palliative care. These are outlined in further detail below under ‘Information priorities at a glance’.

This document represents an initial step towards developing consistent national data. Progressing the priorities in this document will require cooperation between key stakeholders to develop a coherent national approach in line with this shared vision, along with dedication of resources to developing national data.

Information priorities at a glance

Vision	National information will support people with a life-limiting illness, their families and carers, health professionals, health services, policy makers, and governments to make informed decisions based on timely and comprehensive information.
Purpose	The purpose of this document is to help guide efforts in palliative care and end-of-life care information development over the next 10 years.
Priorities	People with a life-limiting illness <ul style="list-style-type: none"> • Patient-reported experience measures (PREMS) • Patient-reported outcome measures (PROMS) • Identifying and supporting people without carers • Conversations people are having and how they are planning for their future care
	Families and carers <ul style="list-style-type: none"> • Identifying who is providing care to Australians at their end of life • Identifying the needs of carers • Finding opportunities to understand carer experience
	Workforce <ul style="list-style-type: none"> • Complexity and capacity of the workforce supporting end-of-life care • Capacity across the workforce to deliver high-quality and person-centred care • Planning for future workforce requirements
	Service and system planning and design <ul style="list-style-type: none"> • Unmet need and demand for palliative care and end-of-life care to support system and service planning • Vulnerable populations • People’s preferences and actual place of care and death
	Service delivery and integration <ul style="list-style-type: none"> • Data capture on care at home and in the community • Ease of access, coordination and transition between services • Data sharing for appropriate and coherent care across services and care settings
	Performance and public reporting <ul style="list-style-type: none"> • Improve the quality of existing data • Identify the characteristics of people at the end of life • Monitor the quality and provision of palliative care in the system overall
	Understanding and awareness of palliative care <ul style="list-style-type: none"> • Data is easily understood and accessible to improve understanding • Data supports meaningful discussions and informed and shared decision making • Data is appropriately shared

Vision

The National Palliative Care and End-of-Life Care Information Priorities provides an aspirational vision for the future of national palliative care and end-of-life care information.

National information will support people with a life-limiting illness, their families and carers, health professionals, health services, policy makers, and governments to make informed decisions based on timely and comprehensive information. This will help to ensure that all people living with a life-limiting illness receive the care they need to live as well as possible for as long as possible.

Introduction

The experience of death and dying, and expectations of care services have changed considerably in Australia over the last century. In the early 1900s, dying at home was common. Social, economic, and carer circumstances have evolved, and with an increased life expectancy comes a greater prevalence of chronic conditions with complex symptoms and multi-morbidity. This has substantially influenced the dying experience, shifting a larger proportion of deaths into hospitals and residential aged care facilities (AIHW 2016).

Palliative care is an approach to treatment that improves the quality of life of patients and their families who are facing the problems associated with life-limiting illness (World Health Assembly 2014). Palliative care can be delivered by a wide range of health and community providers, is not limited to any specific condition, can be delivered at any stage of illness, and can accompany curative treatments.

This philosophical approach to palliative care is distinct from the services delivering palliative care in Australia. The term 'specialist palliative care' refers to both clinicians with specialised expertise in palliative care, and services that make up the designated specialist palliative care sector. These clinicians and services are defined by set criteria and are funded to deliver specialist care.

The term 'end-of-life care' shares many of the same components of palliative care; including physical, spiritual and psychosocial assessment and treatment. While the terms are sometimes used interchangeably, 'end-of-life care' refers to the care provided to people who are likely to die within the next 12 months. It is provided to those with advanced or incurable conditions, frailty and old age, and life-threatening acute conditions (ACSQHC 2015). This document includes both palliative care and end-of-life care information priorities throughout.

The use of each of these terms has many meanings to different people; however, this document uses established definitions outlined in the definitions section. There will need to be ongoing work in the palliative care sector to refine and build consensus about palliative care and end-of-life definitions.

The demographics of the Australian population are changing; the number of people who die each year is expected to rise substantially over the next 50 years, more people will have complex multi-morbidities that need to be managed and more people will die due to chronic progressive diseases. This will increase the demand for high quality palliative care and end-of-life care services to meet the needs and expectations of people with a life-limiting illness and their families.

The National Palliative Care Strategy (Australian Government 2018) articulates a vision and commitment by all Australian governments to ensure that people living with a life-limiting illness get the care that they need to live well. The Strategy recognises that the development of robust national palliative care and end-of-life care data is central to improvements in the palliative care system. Comprehensive, accurate, publicly available data will improve our understanding of the needs of people in palliative care and end-of-life care and support service planners and governments to provide services that deliver high quality care.

This document outlines a vision for national palliative care and end-of-life care information development over the next decade and articulates the priorities aimed at supporting that vision. This document is concerned with 'national information' development. This concept is used to refer to information that has national coverage and is comparable, consistent and relevant. It does not define how these priorities should be implemented, or any provision for funding. It is recognised that these priorities will be resource intensive to progress.

Definitions

Palliative care and end-of-life care are broad terms and may have different meanings depending on the context. There is significant variability in the language used in relation to palliative care and end-of-life care. This document uses the definitions below established for the Australian context in the National Palliative Care Strategy, which has been endorsed by all Australian governments. The glossary provides further information on definitions of key terms used within this document.

Palliative care

The World Health Organization (WHO) has defined palliative care as follows:

“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:

- *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 patients 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;*
- *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.”*

World Health Organization, 2017b. WHO Definition of Palliative Care. <http://www.who.int/cancer/palliative/definition/en/>. Accessed 24 February 2020.

End-of-life care

The Australian Commission on Safety and Quality in Health Care (ACSQHC) has defined end-of-life care as follows:

“End-of-life care includes physical, spiritual and psychosocial assessment, and 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*
- *life-threatening acute conditions caused by sudden catastrophic events.”*

Australian Commission on Safety and Quality in Health Care, 2015. [National Consensus Statement: Essential elements for safe and high-quality end-of-life care](#). ACSQHC, Sydney.

Palliative care services in Australia (technical definition)

In Australia, palliative care services have a nationally agreed definition for data collection purposes in hospitals, where services have the following characteristics:

“Palliative care is care in which the primary clinical purpose or treatment goal is optimisation of the quality of life of a patient with an active and advanced life-limiting illness. The patient will have complex physical, psychosocial and/or spiritual needs.

Palliative care is always:

- *delivered under the management of or informed by a clinician with specialised expertise in palliative care, and*
- *evidenced by an individualised multidisciplinary assessment and management plan which is documented in the patient’s medical record. The plan must cover the physical, psychological, emotional, social and spiritual needs of the patient, as well as include negotiated goals.”*

This definition of palliative care services has been agreed for use in admitted patient settings by all Australian governments through the Australian Health Minister’s Advisory Committee structure. It is also used for funding purposes by the Independent Hospital Pricing Authority (IHPA) as part of the Australian National Subacute and Non-Acute Patient (AN-SNAP) classification system. This definition is not adopted by the National Palliative Care Strategy.

Australian Institute of Health and Welfare 2019. METeOR ID 711010, 2019. Hospital service—care type, code N[N]. <https://meteor.aihw.gov.au/content/index.phtml/itemId/711010/>. Accessed 13 February 2020.

Palliative care information landscape

Palliative care and other end-of-life care forms a complex and fragmented system (SCARC, 2012), delivered across various government portfolios at both the Commonwealth and state and territory levels, with a range of services provided by government, private and not-for-profit providers. Service delivery models and language vary significantly between jurisdictions and sectors, with different services delivered through specialist and generalist providers. States and territories also have varying demographic and geographical remoteness profiles and, consequently, varying demands for particular types of services.









Palliative care and end-of-life care is provided in many health care settings in Australia, including, but not limited to specialist inpatient and community-based palliative care services, neonatal units, paediatric services, geriatric services, public and private acute hospitals, general practices, disability services, and residential and community aged care services. Care is also delivered to people in their own homes by some of these services. This care will vary according to the individual's needs but may include management of pain and other symptoms, care coordination, personal care, hotline support, respite services, equipment supply, emotional support, and bereavement support to families and carers.

The need for palliative care will be influenced by a number of factors, including diagnosis and the nature of illnesses, illness trajectories, and the complexity of individual needs. Palliative Care Australia (PCA) has conceptualised the population of people who are dying expected deaths as falling within three groups based on their needs for palliative care. These include people with straightforward and predictable needs, people with intermediate and fluctuating needs, and people with complex and persistent needs (PCA 2018a). Individuals may benefit from a range of support, and their preferred settings and services may change over time as their needs change.

The development, collection, and reporting of accurate, relevant and timely data about palliative care and end-of-life care is central to making informed, evidence-based decisions. The 2017 Productivity Commission inquiry report on reforms to human services noted “data that allow performance monitoring and evaluation of government activities are a fundamental starting point for improving the delivery of those activities to the community. Data on end-of-life care are no exception” (PC 2017). Under the two previous National Palliative Care strategies, national information on palliative care and end-of-life care in Australia has developed to include a number of data collections. Of particular note is the establishment of the Palliative Care Outcomes Collaboration (PCOC), which routinely reports on clinical outcomes for people receiving palliative care in specialised palliative care units and represents a significant achievement in national information. The Australian Institute of Health and Welfare (AIHW) publishes available national palliative care-related data through the annual Palliative Care Services in Australia online report. PCA also maintains the National Palliative Care Standards along with a self-assessment for service providers (known as Palliative Care Self Assessment [PaCSA]) to determine their level of service capability; however, results from self-assessments are not publicly available. This highlights the need to develop an action plan for quality improvement to support clinical and service development for providers. It is also a useful source of palliative care information and data.

Despite these achievements, data on palliative care and end-of-life care for national reporting purposes still has substantial gaps. National data should ideally be able to answer 6 questions summarised by Leginski et al (1989) as: 'who receives what services from whom, for what purpose, at what cost, and to what effect?'. As demonstrated in Figure 1 below, there are substantial gaps in the availability of national palliative care and end-of-life care data across settings of care and for each of these 6 questions. This figure reflects the broad availability of national data across select settings of care that are considered important for national development; however, this is not an exhaustive list of all settings where care may be delivered or where data may be useful, and does not reflect the relative priority of data development. Identifying palliative care and end-of-life care in existing data collections and across all health settings remains a significant challenge. Palliative care delivered in community, primary care, and residential aged care settings is largely absent from any national data. These gaps affect policy development and service planning to meet current and future demands for high quality, person and family-centred palliative care and end-of-life care. This information priorities document aims to identify opportunities to close these known gaps over the coming decade.

Figure 1: Availability of national data across select palliative care settings considered important for national data development

	Who receives	what services	from whom	for what purpose	at what cost	Consumer outcomes	Consumers and carer experience	to what effect
	 Consumer demographics	 Interventions	 Workforce	 Diagnosis	 Expenditure	 Consumer outcomes	 Consumers and carer experience	 Consumer safety
General Practice	P	P*	P	x	x	P	x	x
Residential aged care	P	x	P	P	P	P	x	x
Community nursing	x	x	P	x	x	P	x	x
Community based specialist palliative care services	P	x	✓	P	x	P	x	x
Ambulance	x	x	x	x	x	x	x	x
Emergency Department / other non-admitted hospital services	✓	x	✓	✓	P	x	x	P
Hospital outpatient clinics	P	x	P	x	P	P	x	x
Hospital based - admitted specialist palliative care	✓	✓	✓	✓	P	P	x	P
Hospital based - other admitted care	✓	P	✓	✓	P	P	x	P

Key: x No national information P Partial coverage ✓ National information available P* Palliative care listed medications through PBS

Broader policy environment

Improvement of palliative care information requires a multipronged approach with a range of initiatives including state and territory palliative care policies and frameworks, local level action plans, high level strategic planning and national policies, and government agreement to implement improvements. This document has been designed to align with and complement a range of existing strategies and policies that aim to improve palliative care and end-of-life care in Australia, including the National Palliative Care Strategy.

This document begins to address Goal 6 of the National Palliative Care Strategy – Data and Evidence and forms part of a strategic plan that acknowledges key development areas. It represents the first step towards a common goal of improving palliative care information in a complex environment with a range of diverse stakeholders.

Although this document complements the National Palliative Care Strategy, it articulates issues specific to national information improvement rather than the goals of the Strategy. This document is not intended to be an implementation or investment plan.

The development of national data is a shared responsibility, requiring cooperation from the Commonwealth, state and territory governments to achieve the common vision outlined in this document. The development of data infrastructure to support national information is resource intensive, requiring significant input from Governments. Wherever possible, new initiatives should leverage existing data systems and enable the Governments to undertake their roles as system managers.

Purpose of this document

The purpose of this document is to help guide efforts in palliative care and end-of-life care information development over the next 10 years. The primary audience for this document is intended to be Australian governments and health provider organisations; however, this document will also be of interest to people living with a life-limiting illness, their families and carers. It aims to provide a strategic vision about how Australia can shift from having minimal national data about the provision of palliative care and end-of-life care, to an environment where sector development is informed by a robust national data collection. This document outlines a set of aspirational priorities that will help to guide the development of national palliative care and end-of-life care information and foster an information culture into the future.

The document is a statement of common, national intent and an agreement to pursue the agreed directions to the extent that is possible for each of the parties. Specific actions are flexible and subject to change as new and innovative approaches are developed. It is not a binding prescription for the parties concerned, and progressing the priorities will involve a collaborative effort between Australian governments.

Scope

This document is concerned with 'national information' development. This concept is used to refer to information that has national coverage and is comparable, consistent and relevant. It will also encompass information that is cross-jurisdictional (Australian and state and territory governments, and other agencies, public and private) and that requires cooperation and coordination between jurisdictions and other stakeholders for health information activities to proceed on a cohesive basis. National information focuses on palliative care services and interventions that occur at an individual and population level; the consumers of those services, and their outcomes; palliative care service delivery to the population generally and of specific population groups; and the relationship between these elements. This document recognises that individual services, organisations, and state and territory governments will have richer and more detailed data.

This document is not about how information systems will be constructed or implemented, or how broader research should progress in the future, and it does not include a provision for funding for the priorities listed. It is recognised that substantial resources will be required to progress the national data landscape, however, this document only outlines approaches and recommendations for driving improvements in national information.

Opportunities and challenges

In order to progress palliative care and end-of-life care information development, Australia will need to both take advantage of opportunities and respond to challenges. Palliative care sits within the broader health services sector and will be affected by both systemic issues and system changes.

Some of the key opportunities and challenges for palliative care and end-of-life care information are:

Building national data infrastructure

Comprehensive national data on palliative care and end-of-life care has substantial gaps, including care delivered in community, residential care, and primary care settings, either by governments or private providers, along with information about the number and cost of the establishments delivering specialist palliative care services. Development of agreed national data infrastructure with coverage of all care settings is needed to support the increasing demands placed on the sector. A particular challenge in sourcing data will be the availability of consistent data from private sector service providers.

Building national data will be both a key challenge and opportunity for the palliative care sector.

Identifying patient pathways through the system

A major challenge is identifying palliative care and end-of-life care within the various health settings and patient pathways through the system. While activity that occurs in a specialist palliative care service can be readily identified as being 'palliative care' in nature, a large volume of palliative care and end-of-life care-related activity occurs outside of specialised palliative care settings. For example, activity could occur in a range of settings including primary care, oncology wards, geriatric wards, intensive care units, within the home, and residential aged care facilities. Capturing palliative care-related activity across the diverse service settings is a key challenge.

Currently there is little visibility of people with life-limiting illness in existing health system data. What little can be seen relates specifically to the provision of specialist palliative care, giving poor insight into service use of people with life-limiting illness. The challenge is to develop national data systems that help identify people with life-limiting illness across the spectrum of healthcare settings.

Developing national data about person and family-centred care

Person and family-centred care, including families of choice—which is tailored to the individual and their families, taking into account their choices and preferences—can pose a significant challenge in summarising sector performance at a national level, however, this is a significant priority. Palliative care is provided to people with a life-limiting illness; however, it is also intended to support the families of people with a life-limiting illness. Little data is available to facilitate insight into the supports provided pre and post-death to families and carers.

Taking advantage of the wider information technology environment

Advances in technology and service delivery models are transforming how care is delivered, and information systems are generally slow to adapt to this dynamic environment. Integrating these changes into information systems will be a key challenge for the palliative care and end-of-life care sector and the health sector more broadly. New data tools and infrastructure can facilitate powerful use of existing national data, such as the use of data linkage. This presents an opportunity to leverage these innovations to improve national information; determining the best way to use these innovations will be a key challenge.

Collecting information on social and spiritual support

The provision of psychological, spiritual, and social support is integral to managing suffering and distress of people with a life-limiting illness and their families, and managing problems related to the person's social and living circumstances, such as access to formal carers and maintenance of independence (PCA 2018a). Collecting information at a national level about these important aspects of care will be a key challenge.

Responding to diverse stakeholders

The palliative care sector has many key stakeholders, including people living with a life-limiting illness, their families and carers, clinicians, health professionals, advocacy organisations, government departments, and non-government organisations. The information needs of stakeholders are diverse and expanding and should be represented in the palliative care and end-of-life care information landscape.

Community capacity to support healthy approaches to death, dying and bereavement

Community capacity to support people approaching the end of life, their families, and informal carers adds an important dimension to the support that can be provided by health services. This includes understanding when a person with a life-limiting illness is approaching the end of life to ensure appropriate planning and care provision. A public health approach to death and dying, such as the international 'Compassionate Communities' movement could potentially build this capacity. Compassionate Communities are "naturally occurring networks of support in neighbourhoods and communities, surrounding those experiencing death, dying, caregiving, loss and bereavement" (Abel 2018).

National priorities for palliative care information development

This document outlines aspirational priority areas for national palliative care and end-of-life care information development over the next decade. The following priority areas are identified for action to the extent that is possible for each of the parties, with potential initiatives detailed in the rationale for each area:

- People with a life-limiting illness
- Families and carers
- Workforce
- Service and system planning and design
- Service delivery and integration
- Performance and public reporting
- Understanding and awareness of palliative care

People with a life-limiting illness

Understanding the experiences of people receiving palliative care is an integral and essential part of delivering high quality, person-centred care. The National Palliative Care Strategy states that it is vital that the experiences of people affected by life-limiting illnesses, their families and informal carers are included in regular monitoring and reporting. Further, there is also a need for greater focus on the design and collection of meaningful data, including data on outcomes and experiences, and data on vulnerable populations, including people who are:

- Aboriginal and Torres Strait Islander;
- culturally and linguistically diverse, particularly new migrants;
- lesbian, gay, bisexual, transgender and intersex;
- living with disability, including cognitive impairment such as dementia;
- experiencing homelessness;
- in long-term institutional care (including being incarcerated);
- ageing and frail; and
- living in rural and remote areas (DoH 2018).

Where possible, data collections should leverage existing collections and systems, to reduce additional data collection burden on people with a life-limiting illness.

Key areas for development of national information:

• Patient-reported experience measures (PREMs)

PREMs provide people living with a life-limiting illness and their informal carers with a voice to express their views about the care they have received and give health professionals important insight into treatment decisions. Measures could seek views on the accessibility of care, quality of services, and aspects of how health professionals interact with people with a life-limiting illness and their carers, such as how respected a person feels. Measures could also assess harder-to-measure aspects of care, such as spiritual care measures. This would facilitate an evaluation of the services people find most useful. Reporting experience of care at the service level will provide people living with a life-limiting illness, their families and carers with information to compare the quality of care between services, and provide services with feedback to monitor their impact and inform improvements. Future developments could build on established initiatives where possible.

• Patient-reported outcome measures (PROMs)

PROMs seek information from clinicians and people receiving care on aspects of their health and condition, such as levels of pain or symptom management. Information on palliative care outcomes and benchmarking is currently collected through PCOC. The current focus of the program is services that voluntarily participate, however, this could expand over time. National data can support improvements in service quality and safety by strengthening the focus on outcomes.

- **Identifying and supporting people without informal carers**

Families and carers are often critical to meeting the care needs of people with a life-limiting illness in their preferred location. People who do not have access to an informal carer are likely to require more support to receive high-quality care and meet their preferences for care. Between 3 and 3.5 million Australians are projected to be living alone in 2041, which will make up around a quarter of all Australian households in 2041 (ABS 2019). Information systems could help identify this cohort, and evaluate the quality of care received by people living alone to identify opportunities to improve that care, including an evaluation of the workforce requirements for this group, such as social workers. For people without carers (or a substitute decision-maker), Advance Care Planning and the documentation of an Advance Care Directive may be an important mechanism to ensure the person's preferences are known for a time when they lose decision-making capacity.

- **Conversations people are having and how they are planning for their future care**

Advance Care Planning (ACP) is a process whereby a person can communicate their preferences and values to others about their future care. These conversations may lead to the development of an Advance Care Plan (ACP); Advance Care Directive (ACD); or values-based, non-statutory advance care plan, which documents what is important to the person if the person is unable to speak for themselves due to illness or impaired cognition. Although ACPs and ACDs are not always solely focused on palliative care, their use forms an important piece of information about people with a life-limiting illness and their interaction with the health system.

- **Improving information on paediatric palliative care**

Paediatric palliative care differs from adult palliative care in many ways; including illness trajectories, support requirements for children living with a life-limiting illness and their families, specialist paediatric palliative care workforce requirements, and the unique considerations for advance care planning in paediatric populations. Comprehensive information on paediatric palliative care will be required to support service planning and delivery.

Our vision is national information should:

- Provide a set of nationally consistent PREMs developed in consultation with people with a life-limiting illness, their carers, and people from vulnerable populations to ensure that issues of importance to them are included. The set of PREMs should be suitable for implementation in a range of care settings, including hospitals, residential aged care facilities, at home, and in the community; and be available in various languages and take into consideration vulnerable populations. PREMs should cover all aspects of palliative care, including spiritual and psychological needs.
- Support improvements in service quality and safety by strengthening the focus on outcomes. An example is raising the profile of currently available outcomes data from PCOC as part of national monitoring and reporting.
- Provide insight into the varying needs of specific cohorts in palliative care and end-of-life care, such as people with complex comorbidities, vulnerable populations, and people with a life limiting illness without a carer.
- Enable services to use outcome and experience measurement, including linked data, to improve the delivery of palliative care and end-of-life care.
- Provide insight into how much people are talking about and planning for their future care and death, including ACP and the use of ACDs and values-based directives. This includes allowing for the evaluation and consultation of whether people's preferences are being met when discussing their illness trajectory, including treatment preferences, place of care, and place of death. Information about the assistance people are receiving to complete ACPs should also be collected.
- Improve national information on the provision of paediatric palliative care that takes into account the unique requirements of children with a life-limiting illness and their families.

Families and carers

National information relating to families, including families of choice, and carers has a range of challenges. These include identifying carers within information systems, particularly those that do not identify themselves as a carer or are an informal carer, potentially collecting information at an exceptionally difficult time, identifying the diverse services accessed outside an official caring role, and identifying the national information that is useful for improving the experience and support for families and carers.

Carers and families form an essential part of palliative care and end-of-life care provision, both in providing invaluable support and care for the person with life-limiting illness, and as people in need of support. Carers and families of people with life-limiting illness are a sub-set of the broader carer population and may either be considered formal (paid) or informal carers (unpaid). For the purposes of this document, the term 'carers' refers to unpaid carers. Carers are:

“people who provide personal care, support and assistance to people with a disability, medical condition (including terminal or chronic illness), mental illness, or frailty due to age. Carers include family members, friends, relatives, siblings or neighbours. Grandparents or foster carers providing care to a child with disability, medical condition (including terminal or chronic illness) or mental illness are included as carers.” (Australian Government 2011).

There is great diversity in the demographics of carers, with varying requirements depending on the challenges the carer faces, including challenges for themselves or the person they are caring for. Specific initiatives or information collections relating to families and carers may work to either address the entire carer population, or be targeted at the needs of carers of people with a life-limiting illness.

Many carers of people with a life-limiting illness may receive the majority of their support from their family, family of choice, or community. Initiatives such as Compassionate Communities or other public health approaches can form an integral support for families and carers outside the health system. Those with more complex needs may access support services through state and territory funded specialist palliative care services or broader health, mental health, disability and social service programs.

Key areas for development of national information:

• Identifying who is providing care to Australians at their end of life

Identifying informal carers of people with a life-limiting illness presents a unique challenge for national information, which is largely based on interactions of the health system with the patient. The supports for families and carers are diverse, ranging from informal community or online supports, to specialised bereavement services (PCA 2018b). Those providing informal care may not self-identify as a carer. This diversity is not conducive to routine collection of data on who is providing care and the supports available to them. Particular types of information that are of interest for development include the carers' role and involvement in care, and information on the services provided by governments. Substitute decision makers should also be identifiable in data systems, as they play an important and unique role in end-of-life decision making.

- **Identifying the needs of carers**

The needs of informal carers of people with life-limiting illness, both before and after the loss of someone with a life-limiting illness, are important to understand. Grief and bereavement can be complex and difficult to predict, with some carers requiring almost no formal support, while others need significant support. The needs of carers will vary over time, with the setting of care (such as residential aged care facilities or at home), and based on demographics (such as those caring for people under 18 years, and young carers). Carers will also have unique requirements at various stages of illness, locations and ages. Identifying the needs of carers in vulnerable populations will be important to ensure person-centred care, including barriers and stigma faced by carers in vulnerable groups. Identifying those at highest risk of complex grief and bereavement, such as those without strong community supports, is key to providing appropriate support. Identifying the types of grief and bereavement support and services being accessed is an important step in understanding how to improve the available supports, including understanding grief and bereavement care in aged care settings. The socioeconomic impact on carers should also be assessed.

- **Finding opportunities to understand carer experience**

The experience of carers and families, both before and after the death of a person with a life-limiting illness, varies greatly. Recording the experience of families and carers will help to ensure that the voices of families and carers are heard. The collection of this information should balance the desire of carers to have a voice, while balancing sensitivity to the emotional needs of carers without adding to an already stressful situation. Routine annual collection of data on carers may not be appropriate; rather, information can be gathered opportunistically, potentially through surveys and specific research projects.

Our vision is national information should:

- Include mechanisms to identify carers of people with life-limiting illness and the support services available to them, including after-hours support and respite care. Information should facilitate a greater understanding of culture or socioeconomic needs of families and carers to ensure adequate support. National data collections and linked assets could be used to investigate the reach and effectiveness of national carer support mechanisms, such as carer support payments.
- Collect data about the needs of carers and whether existing supports are meeting those needs to ensure that adequate supports are available, regardless of socioeconomic status or geographic location. The needs of carers in the different settings of care should be evaluated. This could include supporting targeted research projects into families and carers of people with a life-limiting illness, including pre-death and post-death grief and bereavement support services and resources accessed by families and carers. For example, the development of a national bereavement survey could assist with assessing the most effective grief and bereavement interventions and services offered and those that are most valued by families and carers.
- Look for opportunities to gain insight into the experience of carers, before and after the death of a loved one, to inform service delivery. This should include the identification of complex grief and bereavement. Approaches should consider the potentially vulnerable position of carers, particularly in the time immediately post-death, and should be suitable for implementation in the various care settings where palliative care and end-of-life care is delivered.
- Provide evidence of involvement of families and carers in policy development, service co-design and delivery to ensure issues of importance to them are reflected. This could include representation in health-service governance structures and committees.

Workforce

Workforce capability is a key priority in the National Palliative Care Strategy. Demand for palliative care and end-of-life care is expected to increase, and it is anticipated that there will be shortfalls in the palliative care workforce as demand increases. Comprehensive and timely workforce information at a national level, including the composition and skill level of the workforce, will help inform a strategic approach to address future workforce requirements for palliative care.

The workforce required at the end of life includes a mix of professionals, generally distinguished between specialist palliative care and generalist palliative care. The workforce includes, but is not limited to palliative care specialist nurses and doctors, other medical specialists, general practitioners, nurses, allied health professions, pharmacists, paramedics, residential aged care workers, Aboriginal and Torres Strait Islander Health Workers, community care workers, interpreters, spiritual and pastoral care workers, and volunteers. Allied health is a broad group of individual professions including, but not limited to, psychologists, occupational therapists, social workers, dietitians, physiotherapists, and speech and language therapists. Although this is not an exhaustive list, each profession plays a unique role in supporting people with a life-limiting illness to receive comprehensive, patient-centred care.

Key areas for development of national information:

- **Complexity and capacity of the workforce supporting end-of-life care**

Palliative care and end-of-life care has expanded from the specialist palliative care sector, and it is important to develop information that captures the full extent and complexity of the professions and workforce. Little is known about professionals delivering the care, such as their palliative care specific qualifications, work practices, continuing education and professional development. There is also general palliative care workers' comfort with providing palliative care and end-of-life care. Little is known nationally about the training and experience of paramedics in palliative care, but they perform a broad and significant front-line role in supporting people receiving palliative care. Information about the palliative care training requirements for residential aged care workers is needed.

- **Capacity across the workforce to deliver high-quality and person-centred care**

The level of professional understanding about the palliative approach among the wider health sector and the amount of collaboration with specialist palliative care providers is unknown; however, there has been an increase in broader awareness about palliative care over time (Urbis 2016). Clinician understanding of the physical, social, cultural, emotional, and advance care planning needs of people with a life-limiting illness is integral to care, as well as understanding the end-of-life care needs of vulnerable populations, intersectionality, and a trauma informed approach to care.

• Planning for future workforce requirements

Health services operate within environments of constrained resources. Using resources in the most efficient way by implementing more flexible models of care is a key priority for many health services. Information systems about workforce capability will need to adapt to diverse and evolving models of care, and should facilitate workforce planning for the full multidisciplinary workforce outlined above. This will help service providers, governments and educational institutions to plan and meet the continuing education needs of the workforce into the future. It is also important to evaluate what attracts professionals to work in palliative care, the supports available to them, job satisfaction, and the reasons they may choose to leave the profession.

Our vision is national information should:

- Provide complete and up to date information on the palliative care workforce, including a distinction between generalist and specialist palliative care workforces, paediatric and adult workforce, and geographical location to facilitate planning. Data development should also be informed by consultation with the multidisciplinary workforce, and ensure the reporting burden on clinicians is not increased.
- Improve workforce planning data including the collection of setting of work data, employment conditions (permanent vs temporary), postgraduate education, training, addition of multiple clinician specialties and sub-specialties, and improved data on allocation of time (e.g. clinical, training, time allocated to palliative care). Development should be informed by workforce initiatives commissioned by the Department of Health, including the National Palliative Care Workforce Action Plan.
- Inform workforce capability in the palliative approach outside the specialist palliative care workforce, including general practitioners, paramedics, nurses, other relevant specialties, aged care, and allied health workforce.
- Monitor capacity to deliver culturally sensitive care in the palliative care workforce, such as through patient-reported experience measures and other surveys.
- Provide insights into the continuing education requirements and uptake of training of the workforce to allow them to meet the changing workforce requirements.
- Collect volunteer workforce data to ensure the work of this group is better understood and their needs can be addressed.
- Capture data on the collaboration between specialist and generalist palliative care providers. Monitor the geographical distribution, skill levels and numbers of professionals in line with projected need to inform and plan for a workforce capable of supporting evolving and future models of care. This should be informed by initiatives such as PCA's Service Development Guidelines to provide insight into workforce training requirements.

Service and system planning and design

With the expected increase in demand for high quality, accessible palliative care, there is a strong requirement for national information to facilitate effective system and service planning and design. Australian, state and territory governments share responsibility for funding and delivering services across the health system and all governments require timely and relevant national information to integrate with local knowledge and intelligence. It is essential that information and data supports jurisdictions with system planning and design, and that national information provides useful, high level information to inform decision making. A strategic and informed approach is required in the development of models of service delivery to ensure equitable and timely access to services and equipment.

There are known variations in service provision, such as between urban and regional areas; most specialist palliative care services delivered in metropolitan areas, reflective of population density (Urbis 2016). However, not all variation is bad; as local level planning that leads to variation that is customised to a particular region can be both appropriate and beneficial.

Key areas for development of national information:

- **Unmet need and demand for palliative care and end-of-life care to support system and service planning**

Understanding the level of need and demand for palliative care in the population is a complex and essential part of service planning. Various factors affect the need and demand for palliative care, including diagnosis and the nature of illnesses, illness trajectories, and the complexity of individual needs. Different cohorts can benefit most from care in different types of settings (inpatient, consultancy, outreach, community-based, residential care, or via telehealth). Setting of care should be captured in data systems, along with the stage in the illness trajectory where referral to specialist palliative care occurs. Although there have been research studies estimating the need for palliative care, there is currently no nationally consistent collection of data or methodology to establish either need or unmet need amongst Australians. The identification of people receiving palliative care in existing data sets is difficult, particularly outside admitted hospital settings. This is a major challenge, which will need to be overcome to fully understand the population need for palliative care. Novel methods could be considered in assessing unmet need, for example, the ICD-10 code for cachexia (wasting of the body due to chronic illness) could be used to identify unmet inpatient palliative care needs.

- **Vulnerable populations**

There are a range of factors that reduce equitable access, such as geographic variation and specific vulnerable populations. Cohorts with specific needs and challenges in accessing services must be taken into account in service planning. Information about these groups in national data is limited, and data should facilitate the identification of vulnerable populations.

• People's preferences and actual place of care and death

Preferences for place of death and actual place of death are considered important in evaluating the effectiveness of palliative care and end-of-life care in meeting the wishes of people at the end of life (Ali et al. 2019). However, there is significant complexity in considering the effectiveness of care using these as an indicator of quality. Preferences for place of death can change over time (Gomes et al. 2013), and changes in the location of death when compared to preferences at an earlier stage may have a patient-centred basis and not represent a system failure. An understanding of preferred outcomes, how and why preferences for place of death change, and the ultimate acceptability of the place of death by the person with a life-limiting illness and their carer would help to contextualise national reporting. However, there is currently no national data on preferred or actual place of death. The location of care is also considered an integral piece of information to evaluate quality of life over a longer period. Together, data on these aspects would help form a more complete picture of where people with a life-limiting illness are cared for when living with their life-limiting illness, where they would like to die, and where they actually die.

Our vision is national information should:

- Provide information about population need for palliative care to support service and system planning and design. This should include either an agreed methodology to support jurisdictions or a description of the key components of 'need for palliative care'. This should include all the components of palliative care (physical, psychosocial, and spiritual).
- Improve visibility of vulnerable populations, including better identification of vulnerable groups within national data sets, to inform the level of unmet need and service delivery requirements.
- Allow evaluation of whether service delivery is meeting the wishes of people with a life-limiting illness, such as preferred and actual place of death and location of care. Information on place of death should include enough detail to meaningfully understand the location.
- Collect information on factors affecting high-quality person-centred care in the home and in the community, such as availability of community-based palliative care; access to telephone support; medication access and use; need and use of aids; and the increasing role of technology in palliative care, including the use of emerging technologies, telehealth and in-home supports.

Service delivery and integration

People with a life-limiting illness may move between care settings, as their needs and preferences change. Multidisciplinary palliative care has been successfully integrated into the broader health system over the last few decades; however, an important part of efficient care is the ease with which people living with a life-limiting illness are able to move between services, limiting the number of transitions where possible, and the continuity of their care during transitions.

In the 2016 review of the National Palliative Care Strategy (2010), the fragmented nature of the palliative care system was identified as a significant barrier to accessing services (Urbis 2016). Data on transitions between service providers should be collected and reported, and this should be supported by information on palliative care provided external to the specialist sector. More information about care delivered in the community, including consultation outreach services and rapid response services, will be required.

Key areas for national information development:

- **Data capture on care at home and in the community**

Palliative care and end-of-life care will increasingly be delivered outside the specialist admitted palliative care setting. There is currently incomplete data about care delivered in non-admitted settings for people living at home, and in residential aged care. The provision of community supports, such as allied health, can decrease avoidable hospitalisations, but these services are not captured in national data. More information is required on the use of Emergency Departments after hours for people with a life limiting illness receiving care in the community or residential aged care to ensure service delivery is effective. Collection of data on care at home and in the community will be an essential part of developing a more complete picture of palliative care and end-of-life care delivery.

- **Ease of access, coordination and transition between services**

The ease of access, coordination, and transition between services depends not only on adequate planning, but also on the integration of palliative care across the health system and communication between services. The role of various parts of the workforce is likely to change as models of care change, including increased use of paramedics with increases in palliative care service delivery in the community. Information on the workforce requirements for transitions of care will be important. Coordination services to ensure person-centred and effective care are vital but challenging. It is important for information to provide insights into the reasons for transitions between care settings and how these are managed.

- **Data sharing for appropriate and coherent care across services and care settings**

Information needs to support existing efforts to coordinate care for individuals to ensure that care is delivered in the most appropriate place and that efforts are not being duplicated, including transitions between settings as individual care needs change across the care continuum and lifespan. National linked data assets can be used to develop a greater understanding of intersections between service providers and pathways of care.

Our vision is national information should:

- Provide nationally consistent and comprehensive information about funded palliative care and end-of-life care delivered at home and in the community, including any location considered home, such as residential aged care or disability care. This will initially require the development of a nationally consistent dataset for the community setting, including consultation and hospital outreach services.
- Be used to support the development of local area care pathways, including transitions across the continuum of care and across the lifespan, as individual care needs change. Related information, such as costs associated with transitions are also important to capture. Linked data sets could be used to investigate pathways to and through palliative care and end-of-life care.
- Provide information about the communication between services to ensure the system is working together to ease transitions and consistency of service.
- Provide information about access to services, including whether people with a life-limiting illness and their carers are able to access the services required. Information about the timing of access is also important.
- Contribute to and enable data sharing policies and protocols to ensure all providers have access to information to provide appropriate and coherent care. Information regarding the wishes of people with a life-limiting illness, including ACPs and ACDs, should be accessible across care transitions to maximise opportunities for their wishes to be respected. This could be informed by the use of My Health Record to upload planning documents.

Performance and public reporting

Nationally consistent data is integral to building a sound evidence base to inform the future of the palliative care sector. A key goal of the National Palliative Care Strategy is the improvement of population level evaluation and monitoring. As summarised in the *Palliative care information landscape* section of this document, national data should ideally be able to answer 6 questions: 'who receives what services from whom, at what cost, and with what effect?'. As demonstrated in Figure 1, most of these questions cannot be answered with current national data.

Improvements in national data will provide important insight into palliative care and end-of-life care, including demographic information (including all age groups), diagnoses (including multiple diagnoses to reflect co-morbidity), interventions, provider information, expenditure, and outcomes and experiences. Public reporting of structural, process, and outcomes data will facilitate continuous improvement in care, and private reporting at an organisation and service level is integral to identify local level improvements. Data should also distinguish between specialist and generalist providers of palliative care services.

Key areas for development of national information:

- **Improve the quality of existing data**

Existing data can be improved through the establishment of processes for developing, agreeing and maintaining national classification systems to ensure consistent coding practices, such as in place of death data, and provide a clear indication where there is variation in coding. Collaborative approaches across all levels of government is key to improving transparency in the underlying data and calculation methods to ensure the validity and completeness of national data. Improvements in national data should leverage existing systems where possible, to reduce any additional data burden on providers.

- **Identify the characteristics of people at the end of life**

Dying is poorly recognised at the time of care, however, markers of death are often apparent in retrospect. Better markers to identify care preceding death will help to improve evidence-based treatments for end-of-life care.

- **Monitor the quality and provision of palliative care in the system overall**

At present, there is limited ability to monitor the quality and provision of palliative care in the system overall, and the lack of consistent collection and reporting of national data has been highlighted as a key area for improvement. National Minimum Data Sets (NMDSs) provide one mechanism for collating, analysing and reporting data that is comparable across all states and territories, and can potentially be linked to other existing data sources. These should consider the needs of all stakeholders. National linked data assets can be used to enhance the utility of the national data, and improvements in linked data should be a key priority to address gaps in national data.

Our vision is national information should:

- Be developed in consultation with people with a life-limiting illness, carers, and vulnerable populations, to ensure information is representative of what is important to person-centred care.
- Be improved, including better coding of palliative care episodes; transparency in variation of coded data; systematic coding of place of death; introduce information on place of care and improve consistency and links between existing national data sources.
- Use retrospective analysis to find end-of-life markers in order to improve identification of people who may have particular care needs as they approach the end of life. This could include evaluating how needs are recognised, assessed, and met.
- 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. This could also be expanded to include national data on investment in palliative care by Governments in palliative care, end-of-life care, and bereavement support.
- Include national data about community palliative care services, home based care, residential aged care facilities, outpatient care, hospital outreach into the community, improved hospital data for patients not coded as palliative, information about services delivered by General Practitioners, ambulance data, pharmacy support and medication use, and age specific coverage; such as specific paediatric palliative care collections.
- Include 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.
- 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.
- While Voluntary Assisted Dying (VAD) is not part of palliative care (PCA 2019), it is acknowledge that this is an important health and social issue that would benefit from regular reporting.

Understanding and public awareness

Public awareness and understanding of palliative care and end-of-life care has been widely identified as an important factor in the management of a life-limiting illness (McIlfatrick et al 2014). Information at the national level is an important component of public understanding and awareness; and high quality national data should support broader initiatives to increase informed discussion around palliative care and end-of-life care, including policy development and public health initiatives. A low level of public understanding about palliative care and end-of-life care may have negative consequences for equity of access to services and care quality. Public and professional awareness of palliative care is integral to supporting health professionals and people living with a life-limiting illness to have meaningful discussions and make informed decisions about palliative care and end-of-life care choices.

The availability of appropriate information can support people living with a life-limiting illness, health professionals, and families to have Advance Care Planning and goals of care discussions, understand the available options for palliative care and end-of-life care, plan for future care needs, and make informed decisions about care.

National data can inform regional level understanding of service gaps, duplication and areas of need. Equally, it can inform people with life-limiting illness and their families and carers of options in their local area, and key metrics of those services, such as outcomes and experience measures.

Key areas for development of national information:

- **Data is easily understood and accessible to improve understanding**

All of the priorities detailed in this document will help to build accurate and nationally comparable information. Easily understood, accessible, up to date, and consistent public reporting of national data will help to accurately inform public messaging around palliative care and end-of-life care, and inform policy development and targeted health promotion. It will also help to generate a deeper understanding about palliative care and end-of-life care, and inform the public and health professionals, facilitating an understanding of the sector that is not possible without accurate, nationally comparable information.

While this document does not detail health promotion actions, national information should be easily accessible and comprehensible, including tailored strategies for vulnerable populations, in order to support the development of health promotion interventions.

- **Data supports meaningful discussions and informed and shared decision making**

Public and professional awareness of palliative care is integral to supporting health professionals and people living with a life-limiting illness to have meaningful, values-based discussions and evidence-informed shared decision-making. The development of national data should be informed by both clinicians and people with a life-limiting illness to ensure that national information supports these purposes.

- **Data is appropriately shared**

The 2017 Productivity Commission review into Human Services recommended that “data should be published, shared between governments and made available to researchers in accordance with the framework for data sharing and release outlined in the Commission’s report on data availability and use” (PC 2017). It is crucial that palliative care information is nationally consistent and locally relevant.

Our vision is national information should:

- Be publicly available in a range of formats that are suitable for use by the public, palliative care professionals, and the broader health workforce to support the promotion and understanding of palliative care and end-of-life care.
- Published at the lowest possible geographical level to facilitate local use and to support increased understanding of local care options for people with life-limiting illness, and their families and carers.
- Be informed by Governments working collaboratively and cooperatively to ensure that public reporting meets the needs of all stakeholders, including people with a life-limiting illness, carers, and the multidisciplinary palliative care workforce.
- Support people living with a life-limiting illness, health professionals, and families to have discussions about palliative care and end-of-life care.
- Include methodologies for establishing national measures around public and professional awareness and understanding of palliative care and end-of-life care.
- Be supported by guidelines, protocols and standards for data development, collection, compilation, analysis and publication; including common protocols for access to jurisdictional data to promote their use for research and analysis and increasing the range of data available.

Making it happen

Progressing the priorities in this document will require cooperation between key parties to develop a cohesive national approach. The development of national information infrastructure is a significant undertaking (AIHW 2007), requiring investment of resources, time, and agreement between stakeholders to develop data collections. Ongoing collaboration between the Australian Government and states and territories will be fundamental to its success. Therefore, this document articulates a vision and set of priorities that the relevant parties can progress together, rather than specifying detailed actions and their implementation.

The committees that previously sat under the Australian Health Ministers Advisory Council (AHMAC) were made up of diverse representatives and provided the infrastructure for national efforts to work towards the vision in this document. Any replacement structure will drive the implementation of the priorities, through collaboration and commitment of time and resources. It is acknowledged that governance structures may evolve over time and this work will continue to be embedded in future structures.

The priorities include activities that will need to be jointly managed by the Australian Government and the states and territories as well as activities that will need to be solely managed by each party.

Collectively, all parties will need to work together in setting directions, developing the framework for action and investing the necessary resources required by the work program. States and territories will carry responsibility for the implementation of agreed concepts and systems within public health services under their control. The Australian Government's role is to create an enabling environment by establishing national infrastructure, contributing funding to priority projects and facilitating coordination and action where a national approach is required.

In progressing the aspirational goals outlined in this document, the PC EOL WG, in conjunction with key stakeholders, will guide the prioritisation and actions from the recommendations in the document.

Potential data sources

Data sources can be broadly classified as being either administrative or research data (Connelly et al. 2016). Administrative data refers to data collected in the course of service delivery for purposes such as registration, transaction and record management; while research data, including observational and experimental designs, are collected primarily for a research purpose. Each type of data has various benefits and challenges, and the development of both will be required to progress the information priorities in this document.

- There are a number of methods for developing data sources to address the information priorities, including:
 - the improvement of existing datasets,
 - development of new data sources, such as population surveys, National Minimum Data Sets, and data from general practice; and
 - data linkage, such as the AIHW's National Integrated Health Services Information Analysis Asset (NIHSI AA).

Where possible, new data sources should be developed using the lessons learned from established collections and linkage projects.

Acronyms and abbreviations

Acronym / Abbreviation	Description
ACD	Advance Care Directive
ACP	Advance Care Planning
ACSQHC	The Australian Commission on Safety and Quality in Health Care
AHMAC	Australian Health Ministers Advisory Council
AIHW	Australian Institute of Health and Welfare
AN-SNAP	Australian National Subacute and Non-Acute Patient classification system
CALD	Culturally and linguistically diverse
COAG	Council of Australian Governments
HSPC	Health Services Principal Committee
IHPA	Independent Hospital Pricing Authority
NIHSI-AA	National Integrated Health Services Information Analysis Asset
NMDS	National Minimum Dataset
PaCSA	Palliative Care Self Assessment
PCA	Palliative Care Australia
PC EOL WG	Palliative Care and End-of-Life Care Data Development Working Group
PCOC	Palliative Care Outcomes Collaboration
PREM	Patient-reported experience measure
PROM	Patient-reported outcome measure
VAD	Voluntary assisted dying

Glossary

For the purposes of this document, the key terms below have the following meanings.

Aboriginal (adjective): A person of Aboriginal descent who identifies as Aboriginal and is accepted as such by the community in which he [or she] lives (the original inhabitants of the Australian continent and surrounding islands).¹

Advance care planning: “A process of planning for future health and personal care whereby the person’s values, beliefs and preferences are made known to guide decision-making at a future time when that person cannot make or communicate their decisions. Registered and non-registered health practitioners have a role in advance care planning and require capability to facilitate these conversations effectively. The National Quality Standards for aged care, general practice and health services all promote advance care planning. Individuals can also choose to engage in advance care planning with other non-health practitioners, such as friends or family.”²

Advance care plan: (Including but not limited to: Advance Care Plans, Statements of Choice; Statement of Choices – No Legal Capacity) “documents that capture an individual’s beliefs, values and preferences in relation to future care decisions, but which do not meet the requirements for statutory or common law recognition due to the person’s lack of competency, insufficient decision-making capacity or lack of formalities (such as inadequate person identification, signature and date). An Advance Care Plan for a non-competent person is often very helpful in providing information for substitute decision-makers and health practitioners and may guide care decisions but are not legally binding. An Advance Care Plan may be oral or written, with written being preferred. A substitute decision-maker named in an Advance Care Plan is not a statutory appointment.”³

Advance care directive: (Including, but not limited to: Advance Care Directives, advance health directive, advance personal plan, health direction, enduring powers of attorney, enduring guardian, medical treatment decision maker or any other similar Advance Care Directives in legislation) “Advance Care Directives is used as a catch-all term to refer to the instruments which are recognised in each jurisdiction under advance care directive legislation or common law. They are voluntary, person-led documents completed and signed by a competent person that focus on an individual’s values and preferences for future care decisions, including their preferred outcomes and care. Advance Care Directives are recognised by specific legislation (statutory) or under common law (non-statutory). They come into effect when an individual loses decision-making capacity. Advance Care Directives can also appoint substitute decision-makers who can make decisions about health or personal care on the individual’s behalf. Advance Care Directives are focused on the future care of a person, not on the management of his or her assets.”⁴

1 Australian Government, 2018

2 Australian Government, 2021

3 Australian Government, 2021

4 Australian Government, 2021

Bereavement: “refers to the event of death of a person with whom there has been an enduring relationship.”⁵

Carers: “people who provide personal care, support and assistance to people with a disability, medical condition (including terminal or chronic illness), mental illness, or frailty due to age. Carers include family members, friends, relatives, siblings or neighbours. Grandparents or foster carers providing care to a child with disability, medical condition (including terminal or chronic illness) or mental illness are included as carers.”⁶

Chronic conditions: “have complex and multiple causes; may affect individuals either alone or as comorbidities; usually have a gradual onset, although they can have sudden onset and acute stages; occur across the life cycle, although they become more prevalent with older age; can compromise quality of life and create limitations and disability; are long-term and persistent, and often lead to a gradual deterioration of health and loss of independence; and while not usually immediately life threatening, are the most common and leading cause of premature mortality.”⁷

Culturally and linguistically diverse: “a broad and inclusive descriptor for communities with diverse language, ethnic background, nationality, dress, traditions, food, societal structures, art and religion characteristics.”⁸

Data linkage Data linkage is an element in the process of data integration. Data linkage creates links between data from different sources based on common features present in those sources. Also known as ‘data linking’ or ‘data matching’, data are combined at the unit record or micro level.

End of life: “the period when a patient is living with, and impaired by, a fatal condition, even if the trajectory is ambiguous or unknown. This period may be years in the case of patients with chronic or malignant disease, or very brief in the case of patients who suffer acute and unexpected illnesses or events, such as sepsis, stroke or trauma.”⁹

End-of-life care: “includes physical, spiritual and psychosocial assessment, and 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; life-threatening acute conditions caused by sudden catastrophic events.”¹⁰

5 CareSearch, 2017

6 Australian Government, 2011

7 Australian Health Ministers’ Advisory Council, 2017 Page 6

8 Ethnic Communities’ Council of Victoria, 2012, Page 1

9 Australian Commission on Safety and Quality in Health Care, 2015, Page 33

10 Australian Commission on Safety and Quality in Health Care 2015, page 33

Governments The Australian Government as well as state and territory governments.

Grief: “is how bereavement affects us personally, with effects across several domains - emotional, cognitive, social, physical, financial and spiritual.”¹¹

Indicator A quantitative measure that is used to assess the extent to which a given objective has been achieved.

Integrated care: “Integration is a coherent set of methods and models on the funding, administrative, organisational, service delivery and clinical levels designed to create connectivity, alignment and collaboration within and between the cure and care sectors. The goal of these methods and models is to enhance quality of care and quality of life, consumer satisfaction and system efficiency for people by cutting across multiple services, providers and settings. Where the result of such multi-pronged efforts to promote integration leads to benefits for people, the outcome can be called integrated care.”¹²

Life-limiting illness: “a person with life-limiting illness may die prematurely. This term is often used for people living with a chronic condition that may seem life-threatening but can continue for many years or even decades.”¹³

Non-Government Organisation sector: The Non-government Organisation sector provides community-based support services that help keep people well in the community.

Palliative care: an approach that improves the quality of life of patients and their families facing the problems associated with life-limiting 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:

- 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;
- 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.”¹⁴

11 CareSearch, 2017

12 World Health Organization, 2016, page 3

13 Department of Health and Human Services, 2016, Page 29

14 Based on World Health Organization, 2017b

Palliative care services in Australia (technical definition): “Palliative care is care in which the primary clinical purpose or treatment goal is optimisation of the quality of life of a patient with an active and advanced life-limiting illness. The patient will have complex physical, psychosocial and/or spiritual needs. Palliative care is always: delivered under the management of or informed by a clinician with specialised expertise in palliative care; and evidenced by an individualised multidisciplinary assessment and management plan which is documented in the patient’s medical record. The plan must cover the physical, psychological, emotional, social and spiritual needs of the patient, as well as include negotiated goals.”¹⁵

Paediatric palliative care: “Palliative care for children is the active total care of the child’s body, mind and spirit, and also involves giving support to the family. It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease. Health providers must evaluate and alleviate a child’s physical, psychological, and social distress. Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.”¹⁶

Person-centred care: Person-centred care “is a philosophy that sees doctors, nurses and health services treating people the way they want to be treated. It allows people to make choices about the type of health services and care they access, and how and when it is delivered.

With person-centred care, each person is treated as a complete human being with their own life story, values, culture, interests and beliefs. Support from others is tailored to meet the person’s individual situation, unique needs and goals.”¹⁷

Primary care Primary care providers include general practitioners, nurses, allied health professionals, pharmacists, and Aboriginal and Torres Strait Islander health workers.¹⁸

Quality of care: “the extent to which health care services provided to individuals and patient populations improve desired health outcomes. In order to achieve this, health care must be safe, effective, timely, efficient, equitable and people-centred.”¹⁹

Specialist palliative care: “Services provided by clinicians who have advanced training in palliative care. The role of specialist palliative care services includes providing direct care to patients with complex palliative care needs, and providing consultation services to support, advise and educate non-specialist clinicians who are providing palliative care.”²⁰

Substitute decision-maker: “A collective term for a person appointed or identified by law to make substitute decision(s) on behalf of a person whose decision-making is impaired. A substitute decision-maker may be appointed by the person, appointed for (on behalf of) the person, or identified as the default decision-maker within legislation. Substitute decision-makers listed in Advance Care Directives are statutory appointments. Substitute decision-makers listed in advance care plans are not.”²¹

15 AIHW, 2019

16 World Health Organization, 2017a

17 Australian Government, n.d

18 Australian Institute of Health and Welfare, 2018a

19 World Health Organization, 2017c

20 Australian Commission on Safety and Quality in Health Care 2015, page 35

21 Australian Government, 2021

Terminal: the stage of an illness when death is likely within days.²²

Torres Strait Islander: A person of Torres Strait islander descent who identifies as a Torres Strait Islander and is accepted as such by the community in which he [or she] lives (the original inhabitants of the Torres Strait Islands).²³

Vulnerable populations: There are population groups that are considered vulnerable, in that these groups generally face additional barriers in accessing services, and the information available on these groups use of services is generally poor. Vulnerable populations include people who are:

Aboriginal and Torres Strait Islander

- culturally and linguistically diverse, particularly new migrants
- lesbian, gay, bisexual, transgender and intersex
- living with disability, including cognitive impairment such as dementia
- experiencing homelessness
- in long-term institutional care (including being incarcerated)
- ageing and frail
- living in rural and remote areas.²⁴

22 Australian Institute of Health and Welfare, 2018a

23 Australian Government, 2018

24 Australian Government, 2018

References

Note: resources referred to throughout this document have been used as examples and may not have full national endorsement. See specific resources for details on their level of endorsement.

Abel, J., Kellehear, A. and Karapliagou, A., 2018. Palliative care-the new essentials. *Annals of Palliative Medicine*. 7(Supp 2): S3-S14.

Ali M, Capel M, Jones G, et al. 2019. The importance of identifying preferred place of death. *BMJ Supportive & Palliative Care*. 9:84-91.

Australian Bureau of Statistics 2019. Household and Family Projections, Australia, 2016 to 2041. Catalogue no. 3236.0. Canberra: ABS.

Australian Commission on Safety and Quality in Health Care 2015. National Consensus Statement: Essential elements for safe and high-quality end-of-life care. ACSQHC, Sydney.

Australian Government 2021. National Framework for advance care planning documents.

Australian Government 2018. National Palliative Care Strategy. Canberra.

Australian Government 2011. National Carer Strategy. Canberra.

Australian Government n.d. Person-centred caring. <https://www.carergateway.gov.au/person-centred-caring>. Accessed 5 September 2019.

Australian Health Ministers' Advisory Council 2011. National Framework for Advance Care Directives. AHMAC, Canberra.

Australian Health Ministers' Advisory Council 2017. National Strategic Framework for Chronic Conditions. AHMAC, Canberra.

Australian Institute of Health and Welfare 2019. METeOR ID 711010, 2019. Hospital service—care type, code N[N]. <https://meteor.aihw.gov.au/content/index.phtml/itemId/711010/>. Accessed 13 February 2020.

Australian Institute of Health and Welfare 2019. Palliative care phase code N. <https://meteor.aihw.gov.au/content/index.phtml/itemId/681032>. Accessed 5 September 2019.

Australian Institute of Health and Welfare 2018. Australia's health 2018. Australia's health series no. 16. AUS 221. Canberra: AIHW.

Australian Institute of Health and Welfare 2016. Australia's health 2016. Australia's health series no. 15. Cat. no. AUS 199. Canberra: AIHW.

Australian Institute of Health and Welfare 2007. A guide to data development. AIHW Cat. no. HWI 94. Canberra: AIHW.

CareSearch 2017. Bereavement and Grief. <https://www.caresearch.com.au/caresearch/ClinicalPractice/PsychologicalSocialSpiritual/BereavementandGrief/tabid/1345/Default.aspx>. Accessed 5 September 2019.

Connelly R, Playford CJ, Gayle V & Dibben C 2016. The role of administrative data in the big data revolution in social science research. *Social Science Research* <http://dx.doi.org/10.1016/j.ssresearch.2016.04.015>.

Department of Health and Human Services 2016. Victoria's end of life and palliative care framework. DHHS, Melbourne.

Ethnic Communities' Council of Victoria 2012. ECCV Glossary of Terms. ECCV, Melbourne.

Gomes, B., Calanzani, N., Gysels, M., Hall, S. and Higginson, I.J. 2013, 'Heterogeneity and changes in preferences for dying at home: a systematic review', BMC Palliative Care, vol. 12, <http://dx.doi.org/10.1186/1472-684X-12-7>.

Leginski W, Craze C, Driggers J, Dumpman S, Geersten D, Kamis--Gould E, Namerow J, Patton R, Wilson N and Wurster C. 1989. Data Standards for Mental Health Decision Support Systems: A Report of the Task Force to Revise the Data Content and System Guidelines of the Mental Health Statistics Improvement Program, National Institute of Mental Health, US Department of Health and Human Services, Washington.

McIlpatrick, S., Noble, H., McCorry, N.K., Roulston, A., Hasson, F., McLaughlin, D., Johnston, G., Rutherford, L., Payne, C., Kernohan, G. and Kelly, S. 2014. Exploring public awareness and perceptions of palliative care: a qualitative study. *Palliative Medicine*, 28(3), pp.273-280.

Palliative Care Australia (PCA) 2019. Position Statement – Palliative Care and Voluntary Assisted Dying. Canberra.

Palliative Care Australia (PCA) 2018a. Palliative Care Service Development Guidelines. Canberra.

Palliative Care Australia (PCA) 2018b. Policy Statement – Grief and Bereavement. Canberra.

Productivity Commission (PC) 2017. Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services, Report No. 85, Canberra.

Senate Community Affairs References Committee (SCARC) 2012. Palliative care in Australia. Report to the Senate, Australian Government. Canberra: Senate Community Affairs References Committee.

The Royal Australian & New Zealand College of Psychiatrists 2020. Voluntary assisted dying, position statement 67. RANZCP, Melbourne.

Urbis 2016. Evaluation of the National Palliative Care Strategy 2010 Final Report. Urbis, Sydney.

World Health Assembly 2014. Strengthening of palliative care as a component of comprehensive care throughout the life course. WHA, Geneva.

World Health Organization 2017a. Palliative Care fact sheet. <http://www.who.int/mediacentre/factsheets/fs402/en/>. Accessed 5 September 2019.

World Health Organization 2017b. WHO Definition of Palliative Care. <http://www.who.int/cancer/palliative/definition/en/>. Accessed 24 February 2020.

World Health Organization 2017c. What is Quality of Care and why is it important? http://www.who.int/maternal_child_adolescent/topics/quality-of-care/definition/en/. Accessed 5 September 2019.

World Health Organization 2016. Planning and implementing palliative care services: a guide for programme managers. WHO, Geneva.