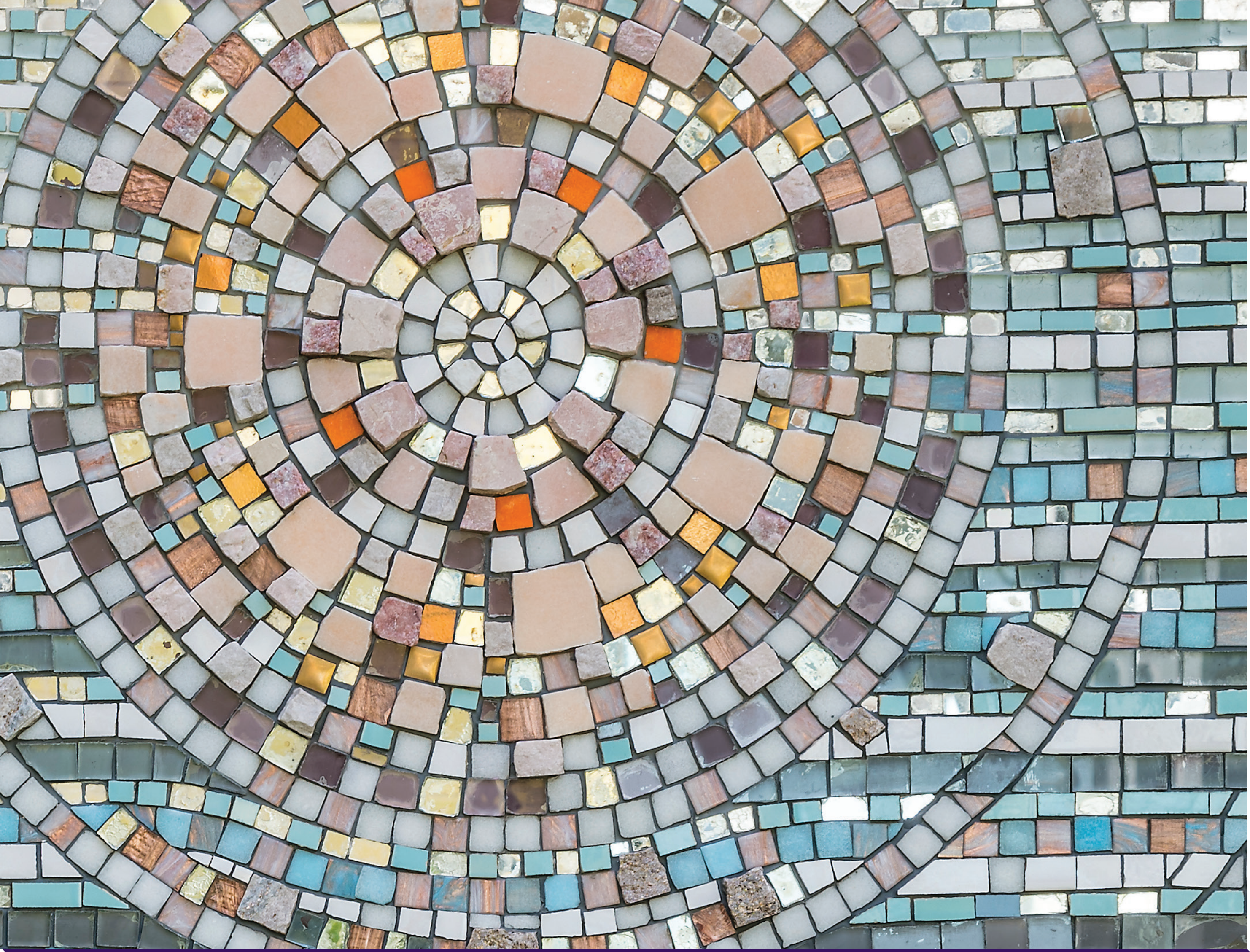

PM GLYNN INSTITUTE

A snapshot of palliative care services in Australia

AUSTRALIAN CATHOLIC UNIVERSITY

A snapshot of palliative care service in Australia

Cover image: Maery Gabriel 1939–2011, Australia
Illumination of the Waters, c1984
enamelled ceramic tiles, 182 x 113 x 7 cm
Acquired 1997
Australian Catholic University Art Collection

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FOREWORD

The publication of this report concludes a long-running policy research project undertaken by the PM Glynn Institute to investigate the provision of palliative care in Australia and how equitably it can be accessed by those who need it.

The Institute approached this task making no claims to specialised expertise in health policy or palliative care. As the public policy think-tank of Australian Catholic University, the Institute's focus was on the policy implications of the current state of provision and access in palliative care. This required drawing together into one place a large volume of publicly-available evidence on provision and access to see what it revealed. In addition to examining specialist reports and analysing the available data, the Institute sought advice from palliative care clinicians and practitioners, policy experts and advocates working in the area, both to clarify the implications of the findings and to develop substantive policy recommendations in response to them.

The report was not, of course, undertaken in a vacuum. It was informed by debates over the legalisation of euthanasia and assisted suicide, which have led to the legalisation of voluntary assisted dying in Victoria and Western Australia, and to serious consideration being given to the question by a number of other states. This report itself, however, focuses exclusively on the evidence concerning the provision of palliative care and access to it, and particularly on the important question of equity in provision and access.

This question is important in its own right, like the question of provision and access in any other area of healthcare. In the context of the debate over assisted dying, however, it is also important as a question of public policy. Considered strictly from a public policy perspective, there is a major argument to be made against the legalisation of assisted dying or euthanasia when access to palliative care for those at the end of life or suffering from life-limiting illnesses is neither universal nor equitable. This is especially so when the case for euthanasia and assisted suicide is advanced on the grounds of choice and autonomy.

If in some places and for some people there is no effective access to palliative care, it is difficult to see how a genuine choice is offered to a suffering person by giving them the option of assisted dying. If the choice is between assisted dying on the one hand, and the absence of effective pain and symptom control and accompaniment by family and carers on the other, it is a false choice and one which it is unjust to offer. If individual autonomy is the pre-eminent value here, offering such a choice pays no respect to it.

There are other grounds for opposing euthanasia and assisted suicide than the absence of genuine choice and real autonomy. They are two important grounds, but other considerations such as respect for life and the dignity of the person, solidarity with the weak and the vulnerable, and the nature and purpose of medical care, are much more important. They are among the decisive reasons for opposition to assisted dying, even with perfect choice and autonomy – and perfect provision and access in palliative care.

Clearly, arguments over euthanasia and assisted suicide will continue, and whether or not assisted dying is legalised is a matter for parliaments to decide – even if the laws they pass on a matter such as this may continue to be opposed and criticised afterwards. Out of respect for readers of this report, whatever their views on this question, it is important to be clear about the Institute's own position. This is part of the Institute's commitment to frank and open public discussion, most especially over questions where there are fundamental disagreements of principle.

The proposition that the Institute puts forward with this report, however, is really quite modest, and it is proposed in the spirit of seeking common ground and collaboration across divides whenever this might be possible. It is the proposition that before a community decides to take a momentous step such as legalising assisted dying, governments and law makers should ensure that everything possible has been done to address the significant gaps in provision and access to palliative care which this report highlights.

It is a proposition made simply as a matter of good public policy, taking into account the considerations of fairness, compassion and prudence to which the equitable and effective provision of palliative care gives rise, on its own merits, and especially in a policy context shaped by powerful arguments for legalising euthanasia and assisted suicide.

It could be argued that one of the drivers of demand for assisted dying – only one among a number of them – has been a failure of public policy to pay proper attention both to the effective and equitable provision of palliative care, and to fostering an accurate understanding of its nature and potential among the healthcare professions and the public. No one, least of all those with life-limiting illnesses or approaching the end of life, has anything to gain from compounding one public policy failure in this area with another, irrespective of whether assisted dying is legalised.

Whatever additional choices people may or may not want those at the end of life or with a life-limiting illness to have, it should be common ground that caring effectively and equitably for everyone in these circumstances means ensuring that everyone can access palliative care when it is needed. It is to this end that this report has been published, and I hope it will be helpful in achieving this goal.

Michael Casey
Director, PM Glynn Institute

ACKNOWLEDGEMENTS

This report was researched and written by Dr Cris Abbu, Policy and Projects Manager at the PM Glynn Institute. Analysis of data in this research was also undertaken by Dr Abbu, with assistance from Jude Lobo. Samantha Dunnicliff, Policy Researcher at the Institute lent invaluable assistance in editing the draft report and compiling the case studies on the integrative model of palliative care developed by the Royal Prince Alfred and Concord Hospitals in Sydney.

This report commenced with an extensive initial survey of some of the published data on palliative care compiled by Kerry Shearer at Mercy Health Australia. Her work formed an essential foundation in the development of the research, and the Institute is indebted to her, and to the CEO of Mercy Health Australia, Stephen Cornelissen, for his support for the project.

The Institute is particularly grateful to those experts, listed in the Appendix, who participated in the roundtable discussion of the report's findings and assisted in developing its recommendations. Thanks are also due to those experts who agreed to be interviewed and offered additional insights, and to a number of other people with expertise in the area who offered guidance and advice through the drafting process, and offered comments on the final draft.

1. Executive summary

The current debate on voluntary assisted dying (VAD) naturally prompts a discussion of the current state of palliative care in Australia. Palliative care, namely its provision, should be an important consideration in the debate on VAD. Ensuring access and equity, both underlying principles of social justice, is essential. This means that palliative care should not only be available to everyone who needs it, but also available to members of society who are more disadvantaged than others. In light of this, and with VAD having been legalised in Victoria in 2018, in Western Australia in 2019, and being under consideration in other states, it is important that before other parliaments follow suit, they first ensure that quality palliative care is accessible and equitable, and that gaps in provision are addressed. For these reasons, palliative care needs to be a primary factor in the current debate on VAD.

ABOUT THIS REPORT

The aim of this report is to provide an overview of palliative care services in Australia, by looking at it through the lens of the two aforementioned principles – access and equity. As such, this report:

1 Investigates and explores patterns in palliative care service provision, and in some cases, analyses and compares changes over time;
2 Identifies gaps in palliative care provision; and
3 Given the gaps, identifies areas for policy action.

This report relies heavily on the use of secondary data published by various agencies including the Australian Institute of Health and Welfare, Palliative Care Australia, the Department of Health and Ageing and the Australian Bureau of Statistics, with an emphasis on acute hospital care. The case studies mentioned in this report were extracted from de-identified cases provided to the PM Glynn Institute by the Department of Palliative Medicine at the Royal Prince Alfred Hospital in Sydney. The purpose of these case studies is to highlight what a successful integrative type of palliative care provision can look like, one of the key recommendations of this report.

THE ROUNDTABLE DISCUSSION ON PALLIATIVE CARE

A roundtable discussion was held at Australian Catholic University in May 2019, with the purpose of bringing together experts and advocates to discuss the implications of the findings in this report. The participants included palliative medicine specialists, representatives from service providers, ethicists, professionals and academics. A list of participants is provided in the Appendix. The observations, information and insights that resulted from the roundtable discussion informed the policy recommendations in this report.

KEY FINDINGS

Increasing rates of palliative care hospitalisation and the heavy burden on the public health system

In 2017–18, there were 79,932 palliative care hospitalisations across public and private hospitals, an increase of 3% from the previous year. This increase was not particular to 2017–18 alone. Palliative care hospitalisations have been increasing over time, at an average rate of 5% annually since 2003. This trend is likely to continue as Australia's ageing population continues to grow. Population statistics predict that there will be 7.8 to 11.3 million Australians aged 65 years and above in 2066, a significant increase from 3.9 million in 2018.

The incidence of chronic illnesses also continues to increase and is also projected to become a significant contributing factor in palliative care hospitalisations. In 2017–18, 80% of Australians aged 65 years old and above were diagnosed with one or more chronic conditions.

Australia's public hospitals carry the heavier burden in the provision of palliative care. The number of palliative care hospitalisations in public hospitals has increased 6% annually since 2003. In 2017–18, 86% of all palliative care hospitalisations occurred in public hospitals. Comparatively, the number of palliative care hospitalisations in public hospital was six times more than the number in private hospitals.

Double digit rates of annual increase in paediatric palliative care hospitalisations

Palliative care hospitalisations among children and young adults have increased over time. The annual rates of increase have been in double digits since 2011. In 2016–17, there were 786 palliative care hospitalisations recorded for children aged 15 years or less, an increase of 18% from the previous year. When compared to the 2011–12 figure of 225 hospitalisations, the increase in 2016–17 was 3 times higher.

These double digit annual rates of increase highlight the increasing importance of paediatric palliative care and its emergence as a specialty. However, it is an area that is often overlooked simply because in absolute terms, the numbers are still small compared to the older cohorts.

Small number of palliative care hospitalisations for Indigenous Australians

In 2012–13, there were 1032 palliative care hospitalisations for Indigenous Australians and 60,564 palliative care hospitalisations for other Australians in public and private hospitals. Thus, palliative care hospitalisations for Indigenous Australians made up only 1.7% of palliative care hospitalisations for other Australians . This percentage has not increased significantly over time, increasing to just 2% in 2017–18, with 1,795 palliative care hospitalisations for Indigenous Australians and 78,137 palliative care hospitalisations for other Australians in both public and private hospital systems.

Number of residents in aged care facilities needing palliation and the need to treat this number with caution

In 2018–19, there were 242,774 permanent residents in Australia's residential aged care facilities, however only 2% were assessed as needing palliative care. An analysis of the changes over time reveals that the number of permanent residents in need of palliative care has fallen from 12,107 residents in 2012–13 to 4341 residents in 2018–19, a significant decrease of almost 64%.

Given the context of an ageing population and the sustained rise of chronic illnesses, this was an unexpected finding. Agencies such as the Australian Institute of Health and Welfare (AIHW) and Caresearch noted however that the application of new stricter measures in the Federal Government's Aged Care Funding Instrument (ACFI) may have caused this decline. ACFI is a tool for allocating subsidies to residential aged care providers for delivering care to their clients. The government also uses ACFI to assess the palliative care needs of residents in aged care facilities. Unfortunately, ACFI is not a palliative care planning tool, nor is it a palliative care assessment tool. Assessing residents who need palliative care through the use of what is essentially a funding tool is not likely to be an appropriate method and may result in an underestimation of the true figures of aged care residents needing palliative care.

Despite the growing need, the rate per 100,000 population of full time equivalent specialist palliative medicine physicians remained unchanged

Specialist palliative medicine physicians are essential to the effective functioning of any palliative care service. In 2017, there were 236 specialist palliative medicine physicians in Australia, This is equivalent to 0.9 full-time equivalent (FTE) specialist palliative medicine physician per 100,000 population. This ratio of 0.9 FTE per 100,000 population did not change much since 2013, with 0.7 FTE specialist palliative medicine physicians per 100,000 population in 2013 and 0.8 FTE per 100,000 population in 2014. Palliative Care Australia recommends a benchmark of 2.0 FTE specialist palliative medicine physicians per 100,000 population. Clearly there was a significant shortfall. In 2017 there were around 225 FTE specialist palliative medicine physicians, 39% less than the estimated requirement for Australia of 370 FTE palliative medicine specialists. Employed specialist palliative medicine physicians also comprised just 0.7% of all employed specialist medical practitioners and 0.25% of all employed medical practitioners.

In 2016, the average age of specialist palliative medicine physicians was 50.5 years, with almost a quarter aged 60 years old and above. Consequently, 42% signified an intention to retire within the next 10 years. The decreasing numbers of palliative medicine specialists, an ageing population and increasing incidence of chronic diseases are only some of the factors exacerbating the current shortages.

Shortfall in other areas of care

Palliative care nurses

The shortage of palliative care professionals was not confined to specialist palliative medicine physicians. There were 295,177 employed nurses in 2013. Of these, 1.1% were palliative care nurses. The number of employed nurses increased to 323,122 in 2017, but the percentage of palliative care nurses remained the same at 1.1%.

In terms of the rate per 100,000 population, there were 12.1 FTE palliative care nurses per 100,000 population in 2013. The figure remained essentially the same in 2017 at 12.0 FTE per 100,000 population. Even though there was an increased need for palliative care, the proportion of nurses trained in the area had been stagnant over time.

Similar to the findings for palliative medicine specialists, most of the palliative care nurses (53%) worked in hospitals across the country in 2017. Only 24% worked in community health services, 0.09% in Aboriginal health service setting, and 2% in residential care facilities.

GP palliative care related encounters

From 2013–14 to 2015–16, of all GP-patient encounters, 1 in 1000 was palliative-care related. This corresponds to 5 palliative care related GP encounters per 1000 population in 2013–14 and 6 encounters per 1,000 population in 2015–16. Although this represents an increase of 18%, this may be an underestimation. Any data collection on GP palliative care-related encounters suffers from problems related to its definition. It is difficult to ascertain what constitutes a palliative care-related encounter in general practice. Palliative care is not a medical diagnosis per se. It is a process that is related to a phase in the management of an illness. General practitioners may record the problems they manage but not the palliative care process itself.

GP knowledge of palliative care

The 2017 Department of Heath qualitative survey, “Research into awareness, attitudes and provision of best practice advance care planning, palliative care and end of life care within general practice”, noted that while some GPs were knowledgeable about palliative care and end of life care, a significant number were not. GP understandings of both concepts were fragmented with most GPs not differentiating between the two. Seventy-eight percent of GPs (nearly 8 in 10) perceived palliative care and end of life care – care for the incurable and terminally ill – to be the same thing. Conversely, only a small number (6%) of GPs adopted a whole-of-patient approach that included provision of emotional support, family advice and negotiation. Their understandings of palliative care and end of life care were reflected in their approach to patient care.

Low uptake of physician training in palliative care

There were 21,224 vocational medical trainees in 2016. The largest number was in general practice, which had 5689 trainees. The second largest group was in adult medicine (4934), followed by emergency medicine (2151) and paediatrics (1604). This trend has not changed over the years. The uptake for palliative medicine remains low, but not the lowest. Lower numbers were noted in oral and maxillofacial surgery, addiction medicine and sexual health medicine. By state or territory, Victoria registered the highest share of advanced palliative medicine trainees (38%), followed by Queensland (26%) and New South Wales (15%).

Palliative care is among the least preferred specialisations for future practice

In 2017, around 2100 graduating medical students ranked adult medicine as their most preferred specialty for future practice. General practice and surgery were ranked second and third, respectively. These three specialisations have remained the most commonly preferred since 2013. Palliative medicine was one of ten specialisations attracting less than 1% of graduands as their preference for future practice.

Lack of comprehensive national data on palliative care

One of the challenges encountered while undertaking this report was the lack of comprehensive data on palliative care. Data collection on palliative care provision is captured by episodes of hospitalisation rather than unique cases of palliative care utilisation. If supply and demand estimation or any econometric modelling is to be undertaken, it will be hampered by the lack of data on unique cases.

Capturing unique cases would be invaluable to improvement and innovation in service planning – factors that are essential in addressing issues related to quality, accessibility and equity in palliative care provision.

POLICY RECOMMENDATIONS

Develop innovative and integrated models of palliative care that address the problems of access, equity and fragmentation and move away from current reliance on hospital-based care

The need for palliative care services will continue to increase as Australia's ageing population increases, and given that the current burden of palliative care provision rests heavily on the public health system, mainly city-based hospitals, there is a need for innovative, integrated models of palliative care provision that move away from hospital-based care to community-based care.

This report presents an example of an integrative model that is currently adopted by the Royal Prince Alfred Hospital (RPA) and Concord Repatriation Hospital in Sydney. This model of care integrates the services of the hospitals, community services, locally-based general practitioners and a community based palliative care team. It also utilises the skills and time of a network of volunteers. The aim is to provide integrated and comprehensive support to individuals who need palliative care in their homes and in residential aged care, as well as to individuals in boarding houses and the homeless.

Develop a national policy framework or strategy for paediatric palliative care

While there are national strategies, guidelines and service development standards for palliative care in general, there is a lack of the same specific to palliative care for children and young people who may have chronic or life-limiting illnesses. Although the numbers of paediatric palliative care hospitalisations are still small compared to the older cohorts, their annual double-digit rates of increase point to the importance of adopting a similar national approach to palliative care provision for children and young people. Paediatric palliative care is dissimilar to adult palliative care. The provision of palliative care to children and young people can last for many years until they transition to adult palliative care, or it can be for a very short period of time. This unique characteristic alone warrants a strategy or a framework specific to paediatric palliative care.

Make advance care planning a basic part of routine clinical care

An advance care plan guides current and future treatment in the event of a deterioration in a patient's condition. However, it is more than just a treatment plans. It assists families and loved ones to prepare for the future when the patient reaches end of life. It involves information sharing and reflection both by families and clinicians. The case studies presented in this report highlight its necessity. The Institute supports the call by Caresearch, Advance Care Planning Organisation, the Royal College of Physicians, Catholic Healthcare Australia and other stakeholders and advocates for the adoption of Advance Care Planning early in a patient's illness.

Upskill residential aged care staff and increase specialist palliative care staff

Residential aged care staff lack the skills in providing palliative care. When a critical event happens that calls for the patient to be provided with palliation, the usual response is to admit the patient to a hospital for acute palliative care. The upskilling of staff in residential care can avoid this and help to ensure that quality palliative care is accessible in a timely manner. The presence and availability of skilled staff is essential in lessening the heavy reliance on hospitals for acute palliative care.

Concomitant to the upskilling of staff is the need to increase palliative care specialist staff in residential aged care and to address the low staff-to-patient ratio and high staff turnover rate. These gaps all need to be addressed.

Undertake a review of the aged care funding instrument

The Aged Care Funding Instrument (ACFI) evaluates the palliative care needs of residents in aged care facilities. It is the tool for government to allocate subsidies to aged care providers for the delivery of care. In 2016–17, the government implemented tighter funding criteria to residential aged care providers, envisioning savings of $1.2B over 4 years. The Australian Institute of Health and Welfare surmised that the decline in the number of residents appraised as needing palliative care was due to the stricter measures now used by ACFI.

Caresearch, Australia's network of resources on palliative care, contends that ACFI is a funding tool and not a comprehensive health planning tool. Hence, using what is essentially a funding tool to assess the palliative care needs of aged care residents is not appropriate and may result in an underestimation of the number of residents really needing palliation. This report recommends a review of ACFI for this reason.

Strengthen the role of general practitioners in palliative care provision in the community

Low numbers of GP-palliative care encounters emphasise that the role of GPs in the community must be strengthened. GPs play a crucial role in the provision of community-based palliative care services. The case studies in this report highlight their importance and show how a strengthened collaboration between GPs, community-based palliative care specialist teams and residential aged care staff in an integrative model of care can result in reducing the number of acute admissions in hospitals for palliation. Patients are cared for by a quality, integrated service network in their community. Hence, more liaison and collaborative partnerships between palliative care specialist teams, aged care teams and general practitioners in the community are called for.

There is also a need to address the knowledge gaps in general practitioners' understanding of palliative care. This is crucial in strengthening their role in delivering palliative care in the community. Most GPs believe that palliative care is end of life care and they do not distinguish between the two. As a result, they are less comfortable handling patients who need palliative care in their practices.

Prioritise systematic and comprehensive data collection on palliative care

In the course of undertaking this report, problems related to a lack of data on rates of palliation were encountered. The utilisation of palliative care services in hospitals is measured by episodes of hospitalisation rather than unique cases. This hinders estimation of demand or any econometric estimation of palliative care utilisation, as the data does not record individual cases but episodes of hospitalisation for palliation. The provision of care should be of high quality and should be based on evidence, but evidence requires data. The availability of a comprehensive set of data facilitates innovation and the continuous quality improvement in palliative care provision. Hence, there is a need to evaluate the method in which palliative care data is currently collected.

Actively encourage increased uptake of palliative care training

This report shows the low uptake in palliative care training by physicians and nurses. This is also reflected in the low preference for palliative care as a specialty amongst graduating medical students. There is a need to generate interest in the field. Incentives can take the form of government subsidies for palliative care training, increasing the number of fellowships that are available in the colleges and the availability of university scholarships for students wanting to specialise in the field. These steps can also address the problems of shortfalls in the supply of palliative care specialists and the problems related to an ageing palliative care workforce.

Develop strategies to foster a better understanding of palliative care among medical professionals and the public

There is a general misconception about palliative care that is not confined to the medical community alone. If GPs misconstrue palliative care as end of life care and associate it with death, how can the general public be expected to have a better understanding of palliative care? Palliative care is not the last resort for those who are dying. The need to educate and inform is vital to the timely provision of palliative care, both for ensuring that people who need it know it is available and know how to access it, and for encouraging early access to palliative care in the trajectory of an illness. This is particularly significant for chronic illnesses. Palliative care is not end of life care, although end of life care includes palliative care.

2. Introduction

The current discussions on voluntary assisted dying (VAD) as an option for people with life-limiting illnesses have prompted a new focus on palliative care. The two seemingly incompatible and antagonistic concepts (Dierickx et al. 2018) have a common underpinning of reducing human suffering (Hurst and Mauron 2006). Palliative care in itself is fraught with definitional problems and misconceptions. It is an area which is often poorly understood by the public (Brooksbank 2015; Patel and Kruczynski 2015) and even by the medical profession (Coulton and Boekel 2017). Often, it is associated with death or as a resort for those who are dying (World Health Organisation 2018) and evokes confusion in patients and their families (Chye 2015; Nyatanga 2005). These challenges in the understanding and practice of palliative care are aggravated by the competing ideological and ethical narratives on assisted dying (Zaman et al. 2017). Hence, palliative care cannot assume the position it should properly have in the current debate on VAD.

This paper argues for the re-positioning of palliative care in this debate. There is a need to understand where the gaps in palliative care provision are in terms of equity and access. These gaps must be addressed before any moves to consider legalising assisted dying as an option are even made. In the light of the 2017 Victorian Voluntary Assisted Dying Act and similar legislation being passed in Western Australia in 2019, other parliaments when deciding to consider legalising euthanasia must first ensure that everything possible has been done to achieve universal and equitable access to palliative care. This report is aimed at identifying the gaps that need to be addressed. There is an important argument against taking the momentous step of legalising euthanasia or assisted suicide when access to palliative care is neither universal nor equitable. In other words, is voluntary assisted dying a real choice when there are wide gaps in equity and access in palliative care provision? The paper also seeks to heed the call by the Australian Commission on Safety and Quality Health Care (ACSQHC 2013) for government agencies, academe and non-government organisations to contribute to the discussions on improving palliative care provision.

2.1 LIMITATIONS OF THIS RESEARCH

This report draws heavily on secondary data published by various agencies such as the Australian Institute of Health and Welfare, Palliative Care Australia, Department of Health and Ageing and the Australian Bureau of Statistics. One of the crucial findings of this report is the apparent lack of a comprehensive, integrated system of data collection on palliative care, which is essential for planning and evaluation. One of the significant implications of the lack of comprehensive national data, particularly on community-based palliative care, is that this report could only detail palliative care provision in acute hospital settings.

2.2 THE DEFINITION OF PALLIATIVE CARE

The World Health Organisation defines palliative care as an approach that improves the quality of life of patients and their families facing the problems related to a life-threatening illness. Palliative care is the prevention and relief of suffering by means of early identification and exemplary assessment and treatment of pain and other problems, including physical, psycho-social and spiritual (WHO 2019). The WHO outlines some key characteristics. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten nor 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 needed;
- 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.

2.3 PALLIATIVE CARE AS A HUMAN RIGHT

Palliative care is recognised under regional and international human rights law as an integral part of the human right to health. The right to health is embodied in Article 12 of the International Covenant for Economic, Social and Cultural Rights (ICESR). The obligation it places on its signatories, including Australia, should be understood as extending to the provision of palliative care (Gwyther 2014). The ICESR's monitoring body, the UN Committee on Economic, Social and Cultural Rights (CESCR), made this clear in adopting "The Right to the Highest Attainable Standard of Health", Article 12, General Comment 14, Specific Legal Obligation 34, which states that:

> "In particular, States are under the obligation to respect the right to health by, inter alia, refraining from denying or limiting equal access for all persons, including prisoners or detainees, minorities, asylum-seekers and illegal immigrants, to preventive, curative and palliative health services..." (Office of the High Commissioner on Human Rights 2000, p.12).

In 2014, the World Health Assembly ratified the first ever global resolution on palliative care. It urged member-countries to improve access to palliative care as a fundamental element of health systems, with particular emphasis on primary health care and community and home-based care (World Health Assembly 2014). The different international charters and resolutions governing palliative care are shown in Table 2.3.1.

Table 2.3.1 Resolutions and charters on palliative care as a human right.

Resolution/covenant	Specifics
International Covenant for Economic, Social and Cultural Rights (ICESR)	Commits signatories, including Australia, to meet the core of obligations of the right to health (Article 12), which extends to providing palliative care
UN Committee on Economic,Social and Cultural Rights (the monitoring Committee for ICESR)	General Comment 14 makes clear that respecting the right to health under Article 12 includes an obligation not to deny or limit equal access for all persons to preventive, curative and palliative health services
World Health Assembly	Palliative care recognised as a component of comprehensive care throughout the life course; urged signatories to develop and implement the comprehensive strengthening of health systems to integrate, evidence-based, cost-effective and equitable palliative care services, with focus on primary care, community and home-based care and universal coverage schemes

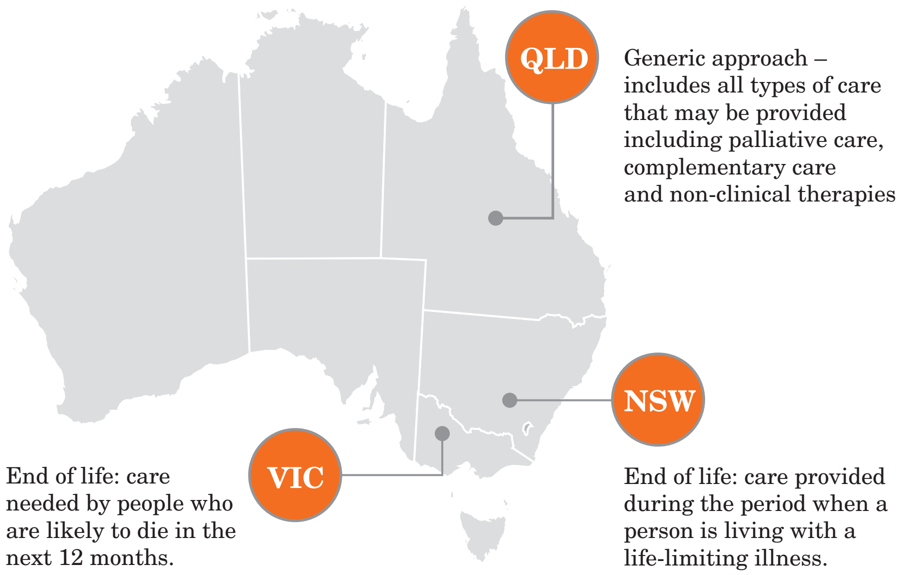
Sources: a) International Covenant Economic, Social and Cultural Rights 1966, “Joint declaration and statement of commitment on palliative care and pain treatment as human rights”, viewed 15 November 2018, www.apcp.com.pt/uploads/jdsc.pdf. b) World Health Assembly 2014, “Strengthening of palliative care as a component of comprehensive care throughout the life course”, viewed 15 November 2018, apps.who.int/gb/ebwha/pdf_files/WHA67/A67_R19-en.pdf.

2.4 END OF LIFE CARE: AN INTEGRAL PART OF PALLIATIVE CARE

There is a distinction between palliative care and end of life care, although the terminology used of both has been interchangeable over the last few years. End of life care is an integral part of palliative care for people who are nearing the end of life. The focus of end of life care is to assist people to live as well as possible and to die with dignity. It also pertains to the treatment and support during this time, including the care for their psycho-social, pastoral or spiritual needs and those of their families and friends (Caresearch 2017a).

The States in Australia have varied approaches to end of life care. For example, Victoria, New South Wales and Queensland distinguish between end of life care and palliative care. In Victoria, the term end of life care is used narrowly to describe care provided in a certain period of time. In NSW, the term incorporates non-specialist providers of care. In Queensland, the term is used broadly to include all types of care and all types of providers. See Figure 2.4.1.

Figure 2.4.1 Examples of the application/definition of end of life care



Generic approach – includes all types of care that may be provided including palliative care, complementary care and non-clinical therapies

End of life: care needed by people who are likely to die in the next 12 months.

End of life: care provided during the period when a person is living with a life-limiting illness.

Sources: a) NSW Ministry of Health 2019, "End-of-life care and palliative care framework 2019-2024", viewed 25 June 201, www.health.nsw.gov.au/palliativecare/Publications/eol-pc-framework.pdf. b) Department of Health and Human Services Victoria 2016, "Victoria's end-of-life and palliative care framework: A guide for high quality end-of-life care for all Victorians", viewed 25 June 2019, www2.health.vic.gov.au/hospitals-and-health-services/patient-care/endof-life-care/palliative-care/end-of-life-and-palliative-care-framework.

3. The policy frameworks

3.1 AUSTRALIA'S NATIONAL PALLIATIVE CARE FRAMEWORKS AND STANDARDS

The adoption of a palliative care policy framework is important as it provides a format for a consistent approach for national policies on palliative care to follow. A framework guides public policy and a government's course of action. It sets out the requirements for the development of policies and defines activities, roles and responsibilities (Tunny 2016). Inasmuch as a policy framework is the approach that guides policies, policies in themselves are declarations of intent in that they outline a program of goals and a line of action (Luyirika et al. 2016). A palliative care policy is therefore an intention and a broad guideline which elaborates government's goals and actions when it comes to implementation of palliative care services across all levels of the health system.

Australia has national palliative care standards and service development guidelines, a workforce development framework and a national strategy. Some of these were developed in the early 2000s but have undergone refinement to reflect the changing contexts in recent years. These frameworks are outlined in Table 3.1.1.

It is significant to note that while there is a national framework for palliative care in general, there is no national framework that is specific for paediatric palliative care. This is further discussed in subsection 7.3. Some States have also developed important palliative care frameworks. The New South Wales framework is set out as an example at Table 3.1.2.

Table 3.1.1 National frameworks and standards

Framework/ Standards	Year	Proponent	Brief description
The National Palliative Care Standards	2018 (precursor – 2005)	Palliative Care Australia	Intended to guide health services and health workers in delivering high quality palliative and end of life care and ensure that the services are person-focused and evidence-based
Palliative Care Service Development Guidelines	2018 – replaced earlier guidelines issued in 2003 ("Palliative Care Service Provision in Australia") and 2005 "Guide to Palliative Care Service Development: A population-based approach")	Palliative Care Australia	Sets out the expectations regarding the range of palliative care services that should be made available to people living with life-limiting illness, their families and carers. It also outlines the workforce and system capabilities that are needed to deliver an effective network of palliative care services, applying a population-based and geographic approach to service planning
National Palliative Care Workforce Development Framework	2016	The Palliative Care Education and Training Collaborative based at Queensland University of Technology, funded by the Commonwealth Department of Health	Developed as a guide for health care providers, health service managers and policy makers to guarantee that all health care providers are equipped with capabilities pertinent to their practice in palliative care
The National Palliative Care Strategy	2018	Commonwealth Department of Health	Describes elements that are essential for delivering safe and high quality end of life care, and sets out suggested practice for the provision of care in settings where acute care is provided

Source: a) Department of Health 2018, "The National Palliative Care Strategy," viewed 30 June 2018, www.health.gov.au/internet/main/publishing.nsf/Content EF57056BDB047E2FCA257BF0002061 68/$File/12291_PC-Strategy.pdf. b) Palliative Care Australia 2018a, "Palliative Care Service Development Guidelines",viewed 12 December 2018, palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/02/ PalliativeCare-Service-Delivery-2018_web2.pdf. c) Palliative Care Australia 2018b, "National Palliative Care Standards, 5th edition-2018", viewed 12 December 2018, palliativecare.org.au/wp-content/uploads/dlm_ uploads/2018/11/PalliativeCare-National-Standards-2018_Nov-web.pdf. d) Caresearch 2016, "National Palliative Care Workforce Development Framework", viewed 12 December 2018, www.caresearch.com.au/caresearch/ TabId/3781/ArtMID/6000/ArticleID/38/Palliative-Care-Workforce-Development.aspx.

Table 3.1.2 An example of a statewide palliative care framework: New South Wales

Framework	Proponent	Principles	Priority Areas
NSW Statewide Framework for Palliative Care and End of Life	NSW Agency for Clinical Innovation	Patient and family centred-care should be delivered in accordance with the wishes of the patient and family	Supported and informed patients, families and carers
		Population and needs based care-services are based on population distribution and disparities in health status between population groups are addressed	Supportive and supported primary care providers, medical specialists and other service providers
		Care as close to home as possible	Local needs based access to L1 specialist palliative care services for all NSW people*
		People approaching the end of their life have access to local primary care, needs-based access to level 1 specialist care	Networked needs-based access to L2 and L3 specialist palliative care service advice and support**
		Equitable access to needs-based care regardless of age, diagnosis, geography and culture	Networked services models of care designed around patient journeys; Patient and family focused models of care
		Primary services, specialist acute services and specialist palliative care services are integrated to enable seamless patient transfer based on needs assessment and clear referral and access protocols	State-wide specialist palliative care services network plan; Needs based assessment tools; Access protocols; Record linkage; Minimum data set development
		Safe and effective: That people receive health care without experiencing preventable harm; that people receive appropriate evidence-based care	Health services regularly participate in quality improvement programs including the following: National Safety and Quality Health Service Standards; National Standards Assessment Program; Palliative Care Outcomes Collaborative

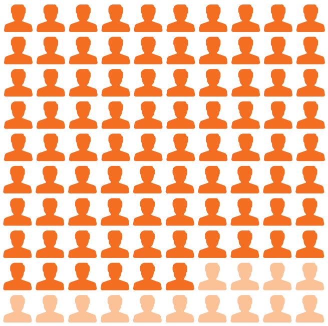
* L1 palliative care specialists provide palliative care consultation and direct care service to patients whose needs exceed the capability and resources of primary care providers.

** L2 palliative care specialists provide a specialist palliative care service with additional services such as providing support and consultation to Level 1 services within a local area for patients with complex problems, contributing to education to support Level 1 specialist providers, providing leadership in collaborative research activities. L3 palliative care specialists provide for the needs of patients with complex end of life care issues, undertake a lead role in education and research in palliative care, have formal links with academic units, and have the capability for registrar training under supervision of a Fellow.

Source: NSW Agency for Clinical Innovation 2013, "Framework for the Statewide Model for Palliative and End of Life Care Service Provision", viewed 19/02/2019, www.aci.health.nsw.gov.au/__data/assets/pdf_file/0019/184600/ACI-Framework-for-Statewide-Model-of- PEoLC-Service-Provision.pdf.

4. An overview of palliative care services in Australia

4.1 PROVISION OF PALLIATIVE CARE SERVICES IN AUSTRALIAN HOSPITALS



86%

of hospitalisations for palliative care occurred in public hospitals.

Source: Australian Institute of Health and Welfare (AIHW), Palliative care services in Australia, various years.

In 2017–18, there were 79,932 hospitalisations for palliative care in public and private hospitals, an increase of 3% from the previous year's total of 77,369 palliative care hospitalisations.

4.2 PALLIATIVE CARE HOSPITALISATION OVER TIME

Table 4.2.1 and Figure 4.2.2 show palliative care hospitalisations from 2003–04 to 2017–18. Overall, palliative care hospitalisations have been increasing, with an average annual rate of increase of 5% since 2003–04. Palliative care hospitalisations in public hospitals increased annually at 6% on average, while for private hospitals, the average annual increase was 3%. It is evident that the burden of provision fell on the public hospital system.

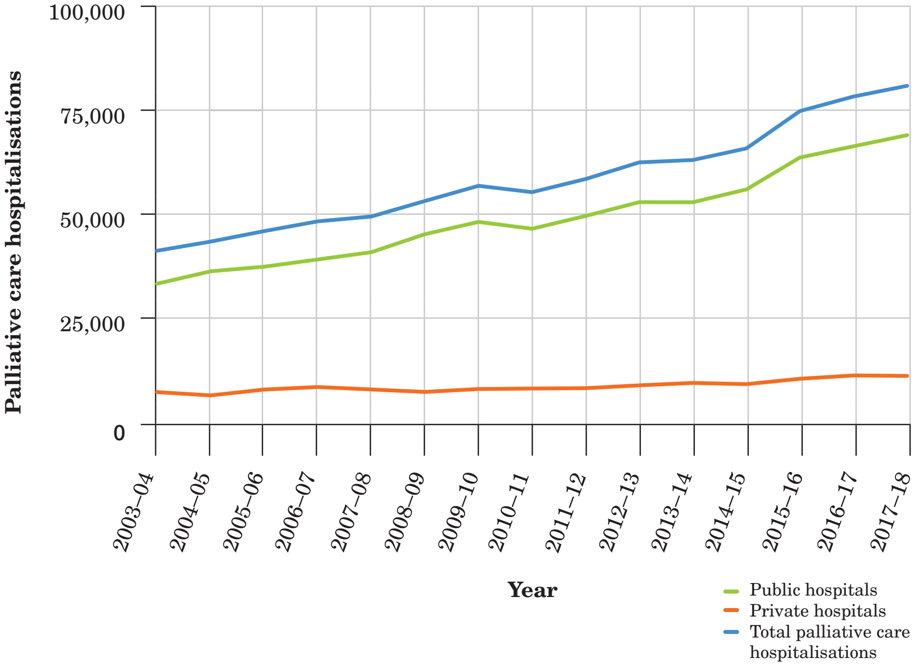
Table 4.2.1 Palliative care hospitalisation, annual rates of change, public and private hospitals, 2003–04 to 2017–18

	2003–04	2004–05	2005–06	2006–07	2007–08	2008–09	2009–10	2010–11	2011–12	2012–13	2013–14	2014–15	2015–16	2016–17	2017–18	Ave change*
Public hospitals	32542	35522	36623	38355	40096	44405	47345	45713	48772	52071	52058	55123	62776	65461	68128	
% change, public		9.16	3.10	4.73	4.54	10.75	6.62	–3.45	6.69	6.76	-0.02	5.89	13.88	4.28	4.07	6%
Private hospitals	7893	7100	8511	9117	8535	7942	8638	8753	8842	9525	10106	9816	11108	11908	11,804	
% change, private		–10.05	19.87	7.12	–6.38	–6.95	8.76	1.33	1.02	7.72	6.10	–2.87	13.16	7.20	0.87	3%
Total	40435	42622	45134	47472	48631	52347	55983	54466	57614	61596	62164	64939	73884	77369	79932	
% change, total		5.41	5.89	5.18	2.44	7.64	6.95	–2.71	5.78	6.91	0.92	4.46	13.77	4.72	3.3	5%

* Indicates average annual change or average annual rate of increase.

Source of basic data: Institute of Health and Welfare, “Palliative care services in Australia”, various years.

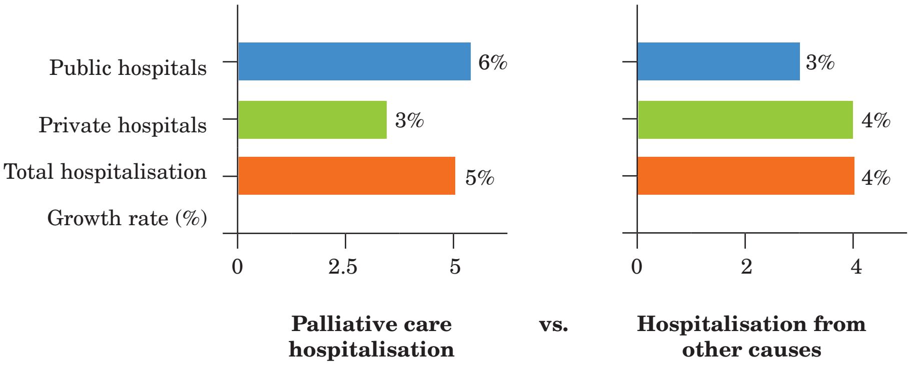
Figure 4.2.2 Palliative care hospitalisation, annual rates of change, public and private hospitals



Source: Institute of Health and Welfare, “Palliative care services in Australia”, various years.

The trend in palliative care hospitalisations that occurred in public hospitals followed the trend in palliative care hospitalisation overall, underscoring that the burden of provision was carried by the public health system. Eighty-six percent of all palliative care hospitalisations occurred in public hospitals. However, a more telling indicator of change over time would be the fastness or velocity (rate) of increase in palliative care hospitalisation, compared to the rate of increase in hospitalisation from other causes as shown in the next section.

Figure 4.2.3 Average annual rates of increase (%) in palliative care hospitalisation vs. hospitalisation from other causes, 2003–18



Source: Institute of Health and Welfare, “Palliative care services in Australia”, various years.

What Figure 4.2.3 shows:

- Although there were more hospitalisations from other causes than hospitalisations for palliative care, the latter increased faster (5% vs. 4%) from 2003–18 across public and private hospitals in Australia;
- In public hospitals, hospitalisation for palliation increased annually at 6%, while palliative care hospitalisation in private hospitals increased only at half this rate at 3%;
- The increase in hospitalisations for palliative care in public hospitals had overtaken the growth in hospitalisation from other causes, increasing twice as fast (6% compared to 3%).

5. Palliative care and an ageing population

5.1 STATISTICS OF AN AGEING POPULATION

The relatively high rates of increase in palliative care hospitalisation over time necessitate a closer look at Australia's ageing population, defined as 65 years old and over.

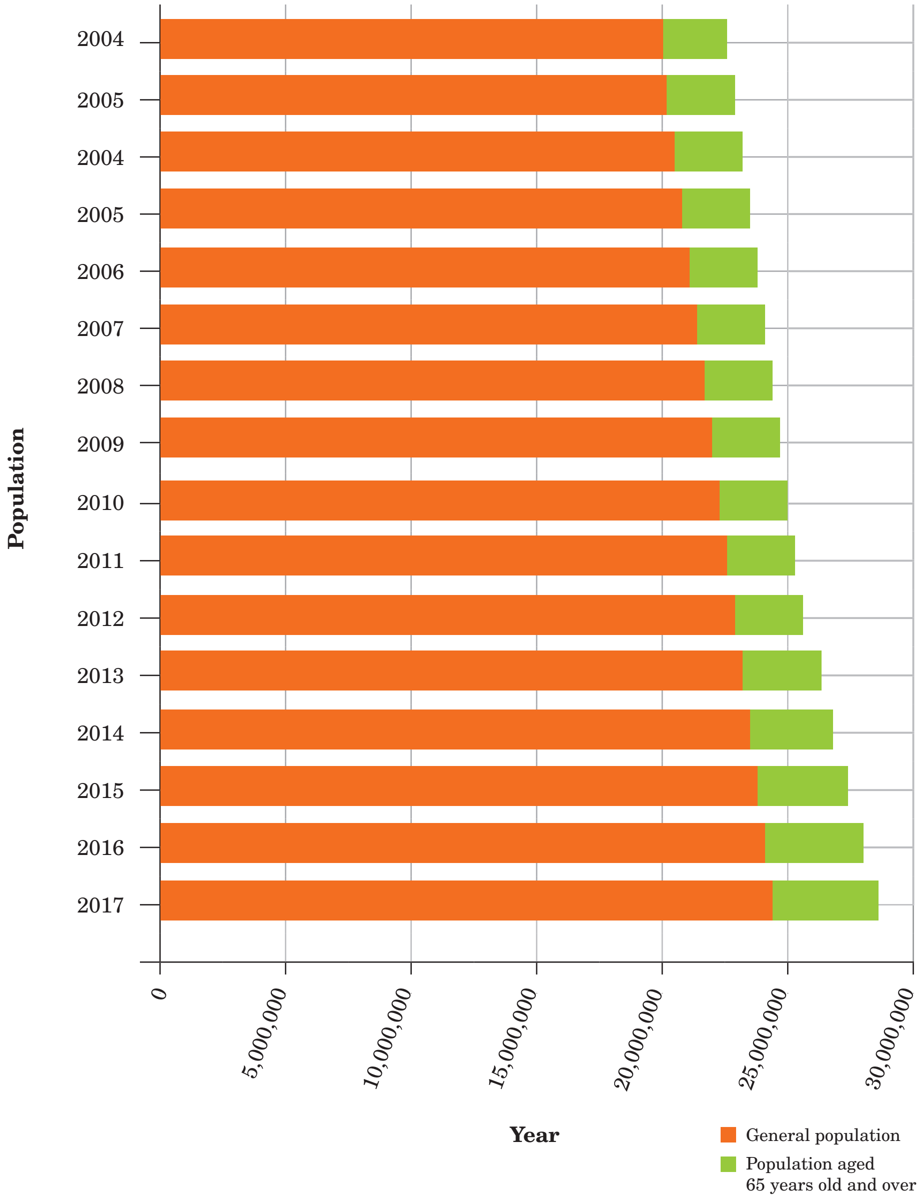
Figure 5.1.1 Statistics of an ageing population

	General population	Ageing population
As at year ending June 2014	**23.8 million** The population was 23,815,995	**3.4 million** or 15% of the population were aged 65 years and above
As at year ending June 2018	**24.9 million** The population was 24,992,369	**3.9 million** or 16% of the population were aged 65 years and above
Forecast: As at year ending June 2066	**37.4–49.2 million** The population is projected to increase to between 37.4 million to 49.2 million	**7.8–11.3 million** or from 21% to 23% of the total population will be aged 65 years and above

Source of basic data: a) Australian Bureau of Statistics, Australian Demographics Statistics Tables, various years. b) Australian Bureau of Statistics, Population projections, Australia, 2017 (base) –2066, viewed 20/02/2019, www.abs.gov.au/AUSSTATS/abs@.nsf/mf/3222.0.

Figure 5.1.2 Trends in the general population and population aged 65 years old and above, 2004–17.

Comparing the years...



Source of basic data: ABS, Australian Demographics Statistics Tables, various years.

Australia’s ageing population grew faster than the growth in the general population as shown by the following trends:

- The general population grew at an average rate of 1.6 % per year from 2004 to 2017.
- The ageing population grew at an average annual rate of 3%, double the growth in the general population from 2004–17.
- It is estimated that the ageing population will increase by up to 11.3 million by 2066 comprising 23% of the highest projected total population of 49.2 million.

5.2 FACTORS OTHER THAN AN AGEING POPULATION: THE RISE OF CHRONIC AND INCURABLE DISEASES

> “...Australia’s growing and ageing population- paired with a rise in chronic and incurable diseases- has broadened the type of patients requiring palliative care.” – AIHW 2016

- Older Australians are the most affected by chronic and incurable diseases – in 2017–18, 80% for those 65 years old and over, compared to 15% of people in the 0–26 years age bracket.
- Fifty percent (50%) of people aged 65–74 years have 5 or more chronic diseases, increasing to 70% for those 85 years and above.

Figure 5.2.1 Top 5 leading cause of death in older Australians by age group, 2014–16 (ranked)

	65–74 years old	**75–84 years old**	**85–94 years old**
1	Lung cancer	Coronary heart disease	Coronary heart disease
2	Coronary heart disease	Dementia and Alzheimer’s disease	Dementia and Alzheimer’s disease
3	Chronic obstructive pulmonary disease (COPD)	Cerebrovascular disease	Cerebrovascular disease
4	Cerebrovascular disease	Chronic obstructive pulmonary disease (COPD)	Chronic obstructive pulmonary disease (COPD)
5	Colorectal cancer	Heart failure and complications	Heart failure and complications

Source: Australian Institute of Health and Welfare 2018a, “Older Australia at a glance”, viewed 5/05/2020, www.aihw.gov.au/reports/older-people/older-australia-at-a-glance/contents/summary.

6. Measuring the burden of palliative care provision

The previous sections demonstrated that the increase in palliative care hospitalisations in public hospitals far outpaced the increase in total palliative care hospitalisations and palliative care hospitalisations in private hospitals. Table 6.1.1 shows the comparative burden by ratios.

Table 6.1.1 Comparison between total palliative care hospitalisation and total hospitalisation, public and private hospitals, 2003–04 and 2017–18

	2003–04	2017–18
Palliative care hospitalisations vs. total hospitalisations, all hospitals	**1:169** For every 169 hospitalisations, 1 was for palliation	**1:141** For every 141 hospitalisations, 1 was for palliation
Palliative care hospitalisations vs. total hospitalisations, public hospitals	**1:129** For every 129 hospitalisations in the public hospital system, 1 was for palliation	**1:99** For every 99 hospitalisations in the public hospital system, 1 was for palliation
Greater burden on public hospitals	**4x** Palliative care hospitalisations in public hospitals were 4x the number of palliative care hospitalisations in private hospitals	**6x** Palliative care hospitalisations in public hospitals were 6x the number of palliative care hospitalisations in private hospitals
Reduced burden on private hospitals	**20%** Palliative care hospitalisations in private hospitals made up 20% of all palliative care hospitalisations	**15%** There were fewer palliative care hospitalisations in private hospitals in 2017–18 than 2003–04

Source of basic data: Australian Institute of Health and Welfare, Palliative care services in Australia, various years.

7. Access to palliative care services

7.1 PALLIATIVE CARE HOSPITALISATION BY GENDER, 2009–18

Figure 7.1.1 Hospitalisation for palliation and other causes, by gender, 2009–18

Palliative care hospitalisation

54% males

Fifty-four percent of those accessing palliative care in both public and private hospitals were males. This percentage remained stable through time.

Hospitalisation from other causes

53% females

In contrast, there were more females (53%) who were hospitalised from other causes in both public and private hospitals.

Source of basic data: Australian Institute of Health and Welfare 2018a, “Australia’s Hospitals at a glance”; “Palliative Care Services in Australia”, various years

7.2 PALLIATIVE CARE HOSPITALISATION: TOP 3 AGE GROUPS, FROM 2011–12 TO 2017–18

Figure 7.2.1 Palliative care hospitalisation by age group

1

75–84 years old

Consistently the largest group since 2011, with 25,173 palliative care hospitalisations in 2017–18.

The average annual increase since 2011 was 6%.

2

85 years and over

This age group is ranked 2nd in the number of palliative care hospitalisations in 2017–18 with 20,179 hospitalisations.

The average annual increase since 2011 was 11%.

3

65–74 years old

This age group was 3rd in the number of palliative care hospitalisations in 2017–18 with 18,384 hospitalisations.

The average annual increase since 2011 was 5%.

Source of basic data: Australian Institute of Health and Welfare, “Palliative care services in Australia”, various years.

7.3 THE GROWING NEEDS FOR PAEDIATRIC PALLIATIVE CARE

In 2016–17, there were 17,533 individuals aged 65–74 years who were hospitalised for palliation. Hence, the Australian Government's Agency for Clinical Innovation's document "Palliative and End of Life Care – A Blueprint for Improvement" (2014) has underlined the need to focus on the 65–74 years age group, in addition to the 75–84 age group, after observing this substantial number. Taking the data further to compute for rates of increase by age groups (Table 7.3.1) provides a greater insight, particularly in relation to paediatric palliative care hospitalisations. Although the numbers were still small compared to the older cohorts, the annual percentage increases were in double digits for children less than 15 years old, with sporadic increases in the 15–24 years age group. This highlights the importance of the often overlooked area of paediatric palliative care. It is considered a growing specialty and an emerging field of practice (Royal College of General Practitioners 2014; Palliative Care Australia 2015).

Table 7.3.1 Palliative care hospitalisation, rates of change by age groups, 2011–12 to 2016–17

Patient age group	2011–12	2012–13	2013–14	2014–15	2015–16	2016–17
Less than 15 years	225	273	430	557	656	786
% change		21.33	57.51	29.53	17.77	19.82
15–24 years	166	152	227	218	311	344
% change		-8.2	49.34	–3.96	42.66	10.61
25–34 years	409	432	442	444	538	571
% change		5.62	2.31	0.45	21.17	6.13
35–44 years	1340	1358	1359	1439	1681	1571
% change		1.34	0.07	5.89	16.82	–6.54
45–54 years	4095	4082	4124	4181	4871	4888
% change		–0.32	1.03	1.38	16.5	0.35
55–64 years	9375	9223	9161	9444	10347	10589
% change		–1.62	–0.67	3.09	9.56	2.34
65–74 years	13716	14542	14629	15179	16921	17533
% change		6.02	0.60	3.76	11.48	3.62
75–84 years	16676	18168	17979	18655	21015	21788
% change		8.95	–1.04	3.76	12.65	3.68
85 years and over	11612	13366	13794	14822	17533	19299
% change		15.11	3.20	7.45	18.29	10.07

Source of basic data: Australian Institute of Health and Welfare, "Palliative care services in Australia", various years.

7.4 PALLIATIVE CARE HOSPITALISATION BY REMOTENESS OF RESIDENCE, 2017–18

As expected, most hospitalisations for palliative care across the country's hospital system (public and private) were for patients from major cities. In 2017–18, there were 53,478 palliative care related hospitalisations for patients whose usual residence was in major cities. This made up 66.9% of all palliative care hospitalisations. However, crude rates, which take into account the rate at which cases occur in a given population (incidence), show that for major cities, there were 30.3 palliative care hospitalisations per 10,000 population. This was lower than the rate for inner regional (39 palliative care hospitalisations per 10,000 population) and the rate for outer regional areas (38.3 palliative care hospitalisations per 10,000 population). The crude rate for remote and very remote areas was at 25.1 palliative care hospitalisations per 100,000 population, which was lower than the crude rates for regional areas. Given this lower crude rate for remote and very remote areas, it is important to take a closer look at access to palliative care services by Indigenous Australians. This is discussed in section 7.5.

Table 7.4.1 Palliative care hospitalisation and remoteness of residence, 2017–18

	Remoteness area	Palliative care hospitalisations	Crude rate*
Public hospitals	Major cities	44,873	25.4
	Inner regional	14,712	33.5
	Outer regional	7097	34.6
	Remote and very remote regions	1184	24.0
Private hospitals	Major cities	8605	4.9
	Inner regional	2390	5.4
	Outer regional	741	3.7
	Remote and very remote regions	48	0.9
All hospitals	Major cities	53,478	30.3
	Inner regional	17,102	39.0
	Outer regional	5380	38.3
	Remote/very remote regions	712	25.1

* Crude rates are the rates of cases that occur in a given population, hence, they are usually considered as the true rates. They are based on the preliminary Australian estimated resident population as at 30 June 2016 and are expressed per 10,000 population

Source of basic data: Australian Institute of Health and Welfare, "Palliative care services in Australia", various years.

7.5 PALLIATIVE CARE HOSPITALISATION BY INDIGENOUS POPULATION

Indigenous Australians make up 3.3% of the total population. There are a number of factors which are important in considering the needs of Indigenous communities for palliative care and their access to it.

Indigenous Australians have a younger age profile than the rest of the community, with a median age of 23 years (compared to almost 38.8 years for the non-Indigenous population), and only 4% are 65 years or older, compared to 16% for other Australians (Australian Institute of Health and Welfare 2019). However, life expectancy is significantly lower. In 2015–17, there was a gap of 8.6 years between Indigenous and non-Indigenous men (71.6 years compared to 80.2 years) and 7.8 years between Indigenous and non-Indigenous women (75.6 years compared to 83.4 years) (Department of the Prime Minister and Cabinet 2020). One consequence of lower life expectancy is that Indigenous people are significantly more likely than non-Indigenous people to access aged care services earlier in life (Australian Institute of Health and Welfare 2020).

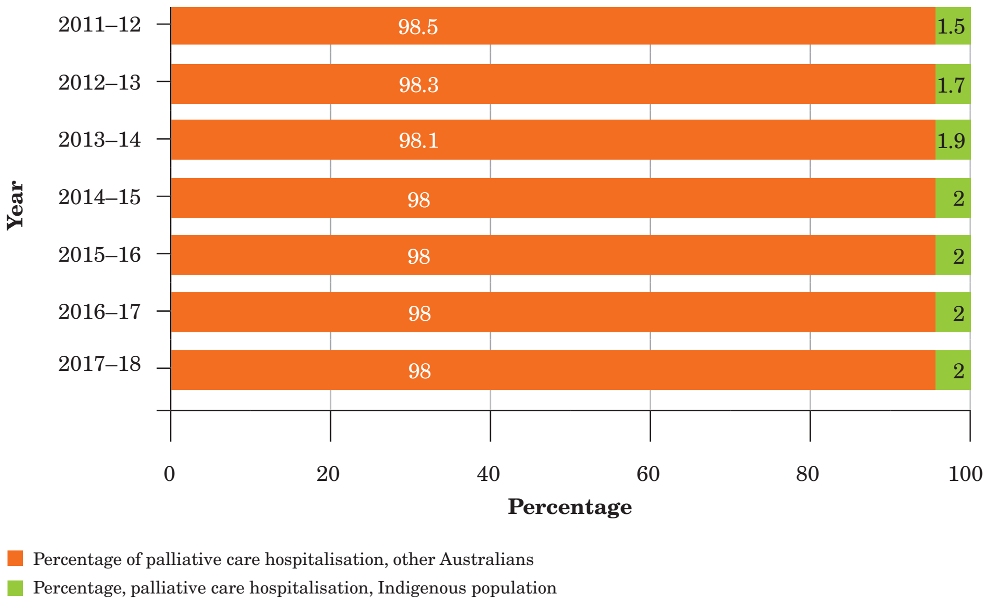
Mortality rates for Indigenous Australians are improving, but still at a significant gap compared to the non-Indigenous population. In 2018, the age-standardised mortality rate for Indigenous Australians was 927 per 100,000 population. The rate for other Australians was 539 per 100,000 population. Circulatory diseases and cancer are the main causes of death for Indigenous people, with cancer becoming the leading cause of death in 2017 and the gap between Indigenous and non-Indigenous cancer mortality widening (Department of the Prime Minister and Cabinet 2020). Indigenous Australians also have a burden of disease 2.3 times higher than that for the rest of the population, with chronic conditions such as cardiovascular diseases, mental and substance use disorders, cancer, chronic kidney disease and diabetes, helping to account for 70% of this gap (Australian Institute of Health and Welfare 2016). The life-limiting nature of these conditions underscores the importance of effective provision of palliative care for Indigenous Australians.

Most Indigenous people (81% or 4 out of 5) live in non-remote areas, but 19% live in remote/very remote areas, compared to 1.5% of non-Indigenous people, and they make up almost half the population in very remote areas (Australian Institute of Health and Welfare 2019). The higher proportion of Indigenous people living in remote/very remote areas combined with their lower life expectancy, higher mortality rates and higher levels of disease burden, highlights the significant equity issues in access to palliative care in these areas, particularly in the light that crude rate of palliative care hospitalisation in remote/very remote areas was the lowest (25.1 per 100,000 population as shown in Figure 7.4.1).

7.5.1 PERCENTAGE OF INDIGENOUS AUSTRALIANS ACCESSING PALLIATIVE CARE

In 2017–18, out of 79,932 palliative care hospitalisations in public and private hospitals, 1795 were for Indigenous Australians. This comprised only 2% of all palliative care hospitalisations. As shown in Figure 7.5.1, this percentage did not change significantly from 2011–12.

Figure 7.5.1 Palliative care hospitalisations: Indigenous population, 2011–12 to 2017–18



Source of basic data: Australian Institute of Health and Welfare, “Palliative care services in Australia”, various years.

The next section looks at palliative care in residential aged care. It assesses the trends and composition of palliative care services, including access by Indigenous Australians in residential care.

8. Palliative care in residential aged care

Residential aged care facilities receive funding from the government for older Australians under their care. It has been noted that facilities often have to surmount challenges in the provision of palliative care to its residents because often residents needing palliative care have dementia and other complex needs. Added to these is the high prevalence of chronic diseases (Australian Institute for Health and Welfare 2016).

The numbers

The need in residential aged care

1 in every 56 residents

In 2018–19, there were 242,774 permanent residents in Australia's residential aged care. Of these 4,341 or 1.8% were appraised to be in need of palliative care.

Regional rates

Crude rates: highest for inner and outer regions*

In 2018–19, the number of permanent residents requiring palliative care in residential aged care facilities was highest among those from inner regional areas (30.2 per 100,000 population) and outer regional areas (15 per 100,000 population) compared to major cities (14.9 per 100,000 population) and remote/very remote areas (3.8 per 100,000 population and 2.5 per 100,000, respectively).

Indigenous status

Only 0.8% were Indigenous

In 2018–19, of the permanent residents in residential aged care requiring palliative care, only 0.8% were Indigenous.

* Crude rates are based on the preliminary Australian estimated resident population as at 30 June 2018 and are expressed per 100,000 population.

Source: Australian Institute of Health and Welfare (AIHW), Palliative care services in Australia – palliative care in residential aged care, 2020.

* For more information see agedcare.health.gov.au/tools-and-resources/aged-care-funding-instrument-acfi-reports.

Sources: a) AIHW, Palliative care services in Australia – palliative care in residential aged care, various years.
b) Caresearch 2017b, viewed 16/04/2019, www.caresearch.com.au/caresearch/tabid/2535/Default.aspx.

Gender

53 percent were females

In 2018-19, there were 2,302 (53%) females requiring palliative care in residential aged care compared to 2039 males.

Age

Majority in 85+ age group

As expected, the majority of the permanent residents in aged care facilities requiring palliative care were in the 85 years plus age group comprising 57% of the total, followed by those aged 80–84 years at 18%. The lowest number were in the less than 65 years old group at 3%.

Trend

A downward trend of aged care residents needing palliative care, 2012–13 to 2018–19

On the recorded figures, the number of aged care residents requiring palliative care declined significantly over this period. Residents who required palliative care fell from 12,107 in 2012–13 to 4341 in 2018–19. This is a decline of almost 64%. The Australian Health and Welfare Institute surmised that this must be due to the application of the Government's Aged Care Funding Instrument (ACFI), which has stricter criteria for appraising residents in need of palliative care.

In particular, ACFI is a tool for government to allocate subsidies to aged care providers for delivering care. It uses a series of questions that determine funding across three domains: Activities of Daily Living; Behaviour Domain; and, Complex Health Care*. The greater the assessed need in each domain, the higher the basic subsidy for the resident. In 2016, the government tightened funding to residential aged care providers and envisioned a savings of $1.2B over 4 years by changing the scoring matrix that determined a resident's classification in the Complex Health Care domain. Caresearch (2017) contends that ACFI uses standardised tools to assess the need for palliative care but ACFI is a funding tool and not a comprehensive assessment or care planning tool for palliative care.

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* The 3 domains of ACFI: Activities of Daily Living domain focuses on nutrition, mobility, personal hygiene, toileting and continence; Behaviour domain relates to cognitive skills, wandering, verbal behaviour, physical behaviour and depression; Complex Health Care domain focuses on medication and complex health care procedures.

9. The critical workforce

Australia's palliative care workforce consists of specialist medicine physicians, palliative care nurses, general practitioners, general nurses, pharmacists, other medical specialists, health workers and other support staff.

9.1 SPECIALIST PALLIATIVE MEDICINE PHYSICIANS

Different reports give varying figures for the number of specialist palliative medicine physicians, and this is noted below. According to the Australian Institute of Health and Welfare, there were 236 specialist palliative medicine physicians in 2017. This was an increase of 4% from the previous year, 2016. On average, the annual percentage increase from 2013 to 2017 was 8%, from a total of 174 specialist palliative medicine physicians in 2013 to 236 in 2017.

In terms of full-time equivalent staff (FTE), there were 225 employed FTE palliative medicine specialists in 2017. This was an increase of 1.4% from the previous year's total of 222 employed FTEs. Translated to FTE per 100,000 population, there was 0.9 FTE specialist palliative medicine physician per 100,000 population in 2017. This rate did not increase substantially from 2013. Industry benchmarks suggest that 2.0 FTE specialist palliative medicine physicians are required per 100,000 population (Palliative Care Australia 2018a). Clearly, there is a shortfall in the number of specialist palliative care physicians. In numbers, in 2017 the national shortfall was about 145 specialist palliative medicine physicians, given that the estimated requirement nationally was 370 full-time equivalent specialists.

Table 9.1.1 Employed specialist palliative medicine physician, 2013–17

	2013	2014	2015	2016	2017
Specialist Palliative Medicine Physicians	174	192	208	226	249
% change, annual		10.3	8.3	8.7	4.4
Full-time equivalent (FTE)	167	183	205	222	225
% change, annual		8.5	11.9	8.3	1.4
FTE/100,00 population	0.7	0.8	0.8	0.9	0.9

Sources: a) Australian Institute of Health and Welfare 2020, "Palliative care services in Australia – Workforce, 2013–17", viewed 06/07/2020, www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/contents/palliative-care-workforce. b) Palliative Care Australia 2018a,"Palliative Care Service Development Guidelines", viewed 12/05/2020, palliativecare.org.au/wpcontent/ uploads/dlm_uploads/2018/02/PalliativeCare-Service-Delivery-2018_web.pdf.

9.2 COMPARISON WITH OTHER SPECIALISTS AND MEDICAL PRACTITIONERS

Table 9.2.1 Employed specialist palliative medical physicians as a percentage of all employed medical practitioners

Specialist palliative medical physicians	2013	2017
Percentage of specialist palliative medical physicians of all specialist medical practitioners	0.60%	0.70%
Percentage of specialist palliative medical physicians of all medical practitioners	0.21%	0.25%

Source of basic data: Palliative care services in Australia – Workforce 2017, viewed 3/07/2020, www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-inaustralia/contents/palliative-care-workforce.

Throughout 2013–17, physicians with specialisation in palliative medicine made up less than 1% of specialist medical practitioners. They made up even less (0.25%) of all medical practitioners.

9.3 PALLIATIVE MEDICINE PHYSICIANS BY WORK SETTING, 2017

Table 9.3.1 Work setting, palliative medicine physicians, 2017

Work setting, 2017	Number*	Percent (%)
Solo practice, private	8	3.4
Group private practice	7	3.0
Other community health care service	18	7.6
Hospital	174	73.7
Outpatient service	15	6.4
Residential aged care facility	3	1.3
Tertiary educational facility	7	3.0
Other Government agency/department	0	0
Other, not specified	5	2.1
Total	236	100.0

* There may be differences between the data here and that published elsewhere due to differences in calculation or estimation methodology or extraction dates. In 2017, 74% of palliative medicine physicians worked in hospitals. Community-based palliative care specialists comprised only 8% and only 1% were working in residential aged care facilities.

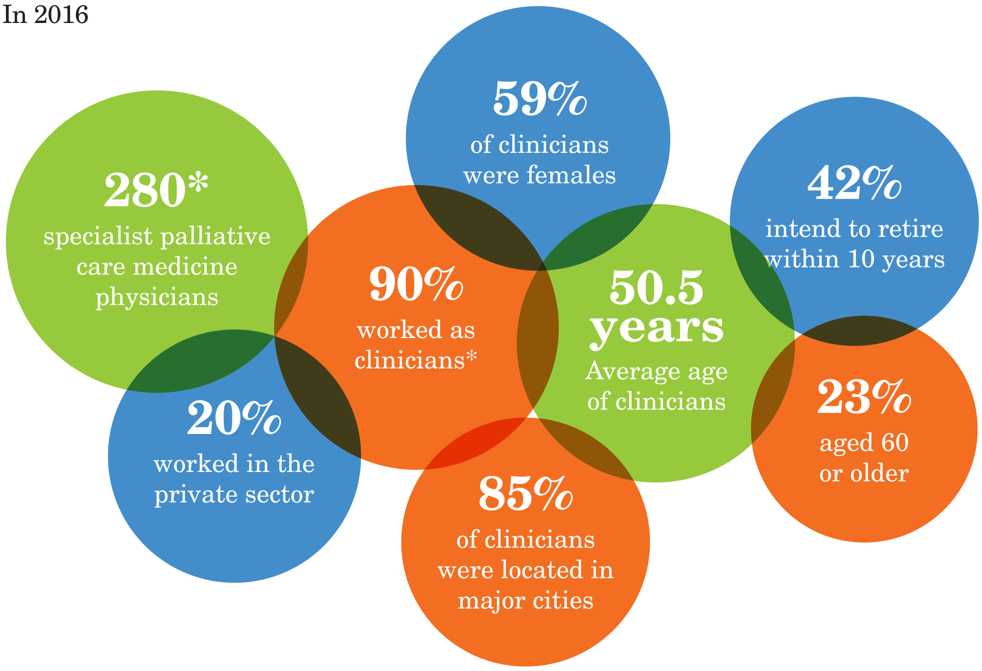
Source of basic data: National Health Workforce Data Set 2017, Palliative care services in Australia – Workforce, 2019, viewed 1/7/2020, www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-inaustralia/contents/palliative-care-workforce.

In 2017, 74% of palliative medicine physicians worked in hospitals. Community-based palliative care specialists comprised only 8% and only 1% were working in residential aged care facilities.

9.4 PALLIATIVE MEDICINE SPECIALISTS: OTHER CHARACTERISTICS

Figure 9.4.1 Palliative medicine specialists, other characteristics, 2016

In 2016



* Note: There may be differences in the number of specialist palliative care medicine physicians reported here and that published elsewhere due to differences in methodology or calculation. The National Health Workforce Dataset (NHWDS) consists of de-identified registration and survey data for health practitioners from the fourteen health professions regulated by the Australian Health Practitioner Regulation Agency (AHPRA) under the National Registration and Accreditation Scheme (NRAS).

Sources: a)Department of Health 2016, "Palliative medicine 2016 factsheet", National Health Workforce Dataset, viewed 04/02/2019, hwd.health.gov.au/webapi/customer/documents/factsheets/2016/Palliative%20medicine.pdf.
b) Department of Health, 2017a, "The National Health Workforce Dataset, 2016 Medical Workforce Factsheet", viewed 14/04/2018, hwd.health.gov.au/webapi/customer/documents/factsheets/2016/Medical%20Practitioners%20factsheet%202016docx.

Consistent with the data that most palliative medicine specialists worked in hospitals in 2016, 85% of the palliative medicine specialists were located in major cities. The average age was 50.5 years, with almost a quarter aged 60 years and above. Consequently, 42% signified an intention to retire within 10 years. The implication is obvious – the palliative medicine workforce is ageing. To compare, the average age of the medical workforce is 46 years, 5 years younger than the average age of palliative medical specialists (Department of Health 2017a).

9.5 PALLIATIVE CARE NURSES

There were 295,177 employed nurses in 2013 and palliative nurses made up 1.1% of this total. In 2017, the number of employed nurses increased to 323,122 but the percentage remained the same at 1.1% for palliative nurses. There were 12.1 full-time equivalent palliative nurses per 100,000 population in 2013. The figure remained the same in 2017 at 12.2 FTE per 100,000 population. See Table 9.5.1.

Table 9.5.1 Employed palliative care nurse, 2013 and 2017

Palliative care nurses	2013	2017
Percentage of palliative nurses to total employed nurses	1.1 %	1.1 %
Full-time equivalent per 100,000 population	12.1 FTE	12.0 FTE

Source: Palliative care services in Australia – Workforce, 2019, viewed 20/04/2020, www.aihw.gov.au/reports/palliative-careservices/palliative-care-services-in-australia/contents/palliative-care-workforce.

9.6 PALLIATIVE CARE NURSES BY WORK SETTING/MAIN JOB

In 2017, 53% of palliative care nurses worked in hospitals across the country, as shown in Table 9.6.1. Palliative care nurses who worked in community health services made up 24% of the total while 14% worked in hospices. Only 0.09 % worked in Aboriginal health service setting. GP practice made up of only 0.23% while residential care facilities' share was only 2%.

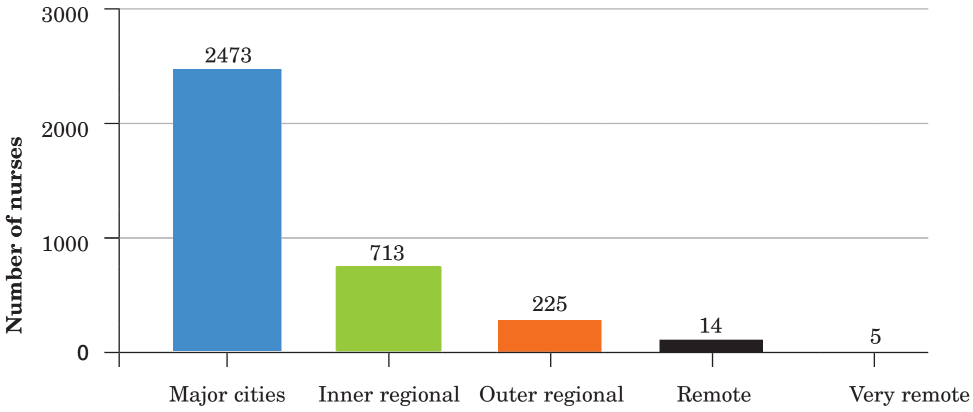
Table 9.6.1 Palliative care nurses: Work setting/main job, 2017

Work setting	Number	Percent (%)
GP practice	11	0.32
Independent private practice	20	0.58
Other private practice	15	0.44
Aboriginal health service	3	0.09
Community health service	808	23.56
Hospital	1829	53.32
Outpatient service	56	1.63
Residential care facility	82	2.39
Hospice	487	14.20
Tertiary educational facility	24	0.70
School	0	0
Other educational facility	3	0.09
Correctional service	3	0.09
Other government department	8	0.23
Other	82	2.39
Total	3430	100

Source: Palliative care services in Australia – Workforce, 2017, viewed 6/07/2020, www.aihw.gov.au/reports/palliative-careservices/palliative-care-services-in-australia/contents/palliative-care-workforce.

9.7 BY REMOTENESS OF MAIN JOB, NUMBER OF PALLIATIVE NURSES, 2017

Figure 9.7.1 Remoteness of main job, palliative nurses, 2017



Seventy-two percent (or 2473) palliative care nurses worked in major cities in 2017. There were 713 (21%) palliative care nurses working in the inner regions and 225 (7%) working in outer regions. There were only 5 (0.2%) palliative care nurses who were working in very remote areas and 14 (0.4%) nurses in remote areas. In terms of FTE staff, there were 12 palliative care nurses per 100,000 population in major cities compared to 2 palliative care nurses per 100,000 population in very remote regions. Nationally, there were 12 FTE palliative care nurses per 100,000 population. Compared to all nurses, the number of FTE palliative care nurses per 100,000 population was very small as indicated in Table 9.7.1.

Table 9.7.1 Remoteness by FTE per 100,000 population, 2017

Remoteness	Palliative nurses, FTE per 100,000 population	All Nurses FTE per 100,000 population
Major cities	12	1164.9
Inner regional	14	1130.5
Outer regional	9.7	1085.0
Remote	5.0	1281.6
Very remote	1.9	1339.8
Total (national)	12	1154.9

Source: Australian Institute for Health and Welfare, Palliative care services in Australia- Workforce, 2019.

9.8 GENERAL PRACTITIONERS AND PALLIATIVE CARE ENCOUNTERS

It is important to note that there is no consistent collection of data on general practitioners providing palliative care. The information cited here is taken from the University of Sydney Family Medicine Research Centre BEACH Survey.* The Survey recorded close to 2 million GP-patient encounters. It remains to date the most valid, reliable GP dataset in Australia.

Table 9.8.1 Palliative care encounters, 2013–14 to 2015–16

	2013–14	2014–15	2015–16
Total GP encounters, palliative care related	0.1% or 1:1000	0.1% or 1:1000	0.1% or 1:1000
Estimated number of palliative care related encounters	114,000	122,100	144,500
Rate of increase in palliative care related encounters	–	7.1%	18.3%
Estimated no. of palliative care related encounters per 1.000 population	4.9	5.2	6.0
Indigenous Australians (%)	nil	3.1	1.3

Sources: 1) Australian Institute for Health and Welfare, Palliative care services in Australia, various years. 2) University of Sydney, Family Medicine Research Centre Bettering the Evaluation and Care of Health (BEACH), viewed 30/01/2019, sydney.edu.au/medicine/fmrc/beach.

* Bettering the Evaluation and Care of Health (BEACH) Survey collected data on primary care and general practice activities. It began in 1998 and ended in early 2017 and administered by the University of Sydney.

From 2013–14 to 2015–16, of all GP encounters, 1 in 1000 encounters was palliative-care related. Translated into a rate per 1000 population this corresponds to 5 palliative care related GP encounters per 1000 population in 2013–14 and 6 encounters per 1000 population in 2015–16. This demonstrated an increase, indicating a rate of increase of 18% in 2015–16. Those seen by GPs for palliative care were mostly females and those aged 65 years and above (53% and 90% in 2015–16, respectively). Indigenous Australians comprised only 1.3% of all palliative care encounters in 2015–16.

9.9 PALLIATIVE CARE RELATED GP ENCOUNTERS BY REMOTENESS

Table 9.9.1 GP palliative care encounters by remoteness*

	2013–14	2014–15	2015–16
Major cities	53.2%	51.5%	50.8%
Inner regional	30.1%	32.9%	38.3%
Outer regional	15.4%	15.6%	10.9%
Remote/Very remote	1.3%	nil	nil

Source: Australian Institute of Health and Welfare, "Palliative care services in Australia", various years.

* Based on Family Medicine Research Centre (University of Sydney) 2017 analysis of BEACH Survey.

The majority of the palliative care related encounters in general practice occurred in major cities at an average of 52% of all encounters from 2013–14 to 2015–16. Inner regional made up on average 33% while the numbers were small for outer regional areas. GP palliative care-related encounters were insignificant in number (nil when rounded off) for remote and very remote regions.

9.10 THE CHALLENGES IN COLLECTING INFORMATION IN GENERAL PRACTICE

What constitutes a palliative care related encounter?

Due to its rigorous methodology developed over 30 years at the University of Sydney, the BEACH Survey is by far the most reliable GP dataset in Australia. However, any data collection on GP palliative care-related encounters suffers from problems related to its definition. It is difficult to ascertain what constitutes a palliative care-related encounter in general practice. Palliative care is not a medical diagnosis per se but is a process that is related to a phase in the management of an illness. A GP may record the problems they manage as part of the palliative care process but not the palliative care process itself. Hence, the figures on palliative care-related encounters in general practice may be underestimations. A study commissioned by the Commonwealth Department of Health in 2017 noted that palliative care-related consultations were actually higher and account for about 1 in every 100 GP consultations. The difference between this ratio and that of the BEACH data (1 in every 1,000) can be attributed to the differences in methodologies, the composition of respondents and how palliative care-related encounter was defined.

GPs’ conception of palliative care

The 2017 Department of Heath qualitative survey, “Research into awareness, attitudes and provision of best practice advance care planning, palliative care and end of life care within general practice”, noted that while a cohort of GPs were knowledgeable about palliative care and end of life care, a significant number were not. GP understandings of both concepts were fragmented with most GPs not differentiating the two. Palliative care was seen by 78% (nearly 8 in 10 GPs) as end of life care for the incurable and terminally ill. Conversely, only a small number (6%) adopted a holistic, whole-of-patient approach that included provision of emotional support, family advice and negotiation. These diverse views of both palliative care and end of life care were reflected in different approaches to best practice care.

10. Provision of palliative care: Catholic agencies

10.1 CATHOLIC HEALTH AND AGED CARE SERVICES AND PALLIATIVE CARE

The Catholic Church operates 80 hospitals, 17 of which are located in rural and regional locations. It also operates more than 550 residential aged care facilities (or more than 25,000 residential aged care beds) and 7000 senior dwelling units. To encourage care-in-the-home initiatives, the Church also supports 36,500 home care and support consumers (Catholic Health Australia 2018). Given this wide breadth of Catholic health care services, which accounts for 10% of all health care services in Australia, the Church is a major provider of palliative care. The following statistics are of significance:

Figure 10.1.1 The wide breadth of Catholic palliative care services

In 2015–16,

13% of all palliative care related hospitalisations, public and private, occurred in Catholic hospitals.

6% of all palliative care related hospitalisations occurred in Catholic public hospitals.

53% of all palliative care related hospitalisations in Catholic hospitals were in private hospitals.

52% of private palliative care inpatient beds were provided by Catholic hospitals.

30% of palliative care hospitalisations in Catholic private hospitals were in regional areas.

18% of palliative care hospitalisations in Catholic public hospitals were in regional areas.

Sources: a) Catholic Health Australia 2018, “Fighting for quality of life”, Health Matters Magazine, Spring 2018, viewed 4/02/2019, www.cha.org.au/images/Media_Releases/2018/HealthMattersMagazine_Spring2018PalliativeCareForum.pdf. b) Catholic Health Australia 2019, "Palliative care in the Catholic sector", viewed 17/07/ 2019, www.calvarycare.org.au/wpcontent/uploads/2019/03/CHA030_PalliativeCareInTheCathSector_A4_REPORT_LR_Embargoed.pdf.

11. Training and education

11.1 VOCATIONAL MEDICAL TRAINING IN AUSTRALIA

Australia's medical training system is complex and the process is arduous. Its delivery entails elaborate funding and organisational structure that involves state and Commonwealth governments, private agencies and non-government entities (Department of Health 2014). Given this complex system of agencies in the delivery and funding of medical training, planning for the workforce is very difficult (Department of Health 2014).

Figure 11.1.1 Australia's medical training system, as of 2014.

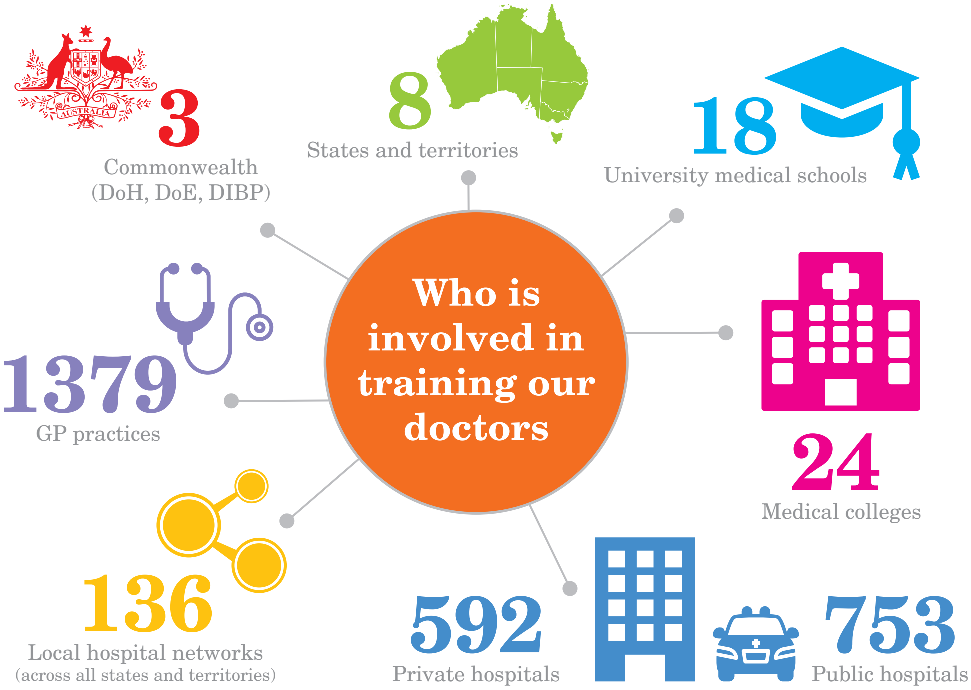


Chart inspiration sourced from Health Workforce Australia's "2014:Australia's future Health Workforce-Doctors", www.health.gov.au/internet/main/publishing.nsf/Content F3F2910B39DF55FDCA257D94007862F9/$File/AFHW%20- %20Doctors%20report.pdf.

The majority of medical graduates, following completion of university medical education and internship, pursue specialist medical practice. They must complete a recognised medical specialty training program through a specialist medical college. In the case of general practice, this is done through training programs that are accredited with the Australian Medical Council (Department of Health 2016). In order to gain entry into a training program, medical graduates must undergo a highly competitive selection process for a fixed number of training positions in an accredited facility. The number of trainee positions is also dependent on the health services' capacity to accept trainees.

Each state or territory has the responsibility of managing vocational training. However, they all work with the medical colleges to address particular needs, such as improving trainee supervision in public hospitals, planning workforce needs and developing statewide training programs. Although some specialist medical colleges distinguish between basic and advanced vocational training programs, where required, basic training is the entry point for specialist training. Its full completion is a prerequisite for advanced training. Those in advanced training programs work in a series of training positions, in which they are trained and mentored by qualified specialists (Department of Health 2016).

11.2 TRAINING IN PALLIATIVE CARE

The Chapter of Palliative Medicine (AChPM), a Chapter of the Royal Australasian College of Physicians (RACP) Adult Internal Medicine Division, provides two types of training: the Palliative Medicine Advanced Training Program and the Clinical Diploma in Palliative Medicine Program.

The Palliative Medicine Advanced Training Program requires three years of full-time equivalent training, undertaken at an accredited training site. It provides specialised training in the management of patients with active, progressive and far-advanced disease. Trainees are under supervision for their eventual independent practice as a palliative care consultant.

The Clinical Diploma in Palliative Medicine is a six-month qualification aimed at training medical practitioners in palliative care as part of their vocational training and continuing professional development (CPD). It is an in-depth specialisation training in the management of patients with active, progressive and far-advanced disease, for whom the prognosis is limited. This qualification recognises expertise in palliative care medicine but does not confer eligibility for specialist recognition in palliative care medicine; and so under the Medical Board of Australia's specialist register, upon completion of the diploma training, trainees cannot use the title "Specialist Palliative Medicine Physician".

Number of trainees by medical specialty

Table 11.2.1 through to Table 11.2.3 show the number of trainees by medical specialty as well as the proportion by medical specialty and by state/territory. Table 11.2.1 shows that in 2016, there were 21,224 vocational trainees. The largest number was in general practice, which had 5689 trainees. The second largest group was in adult medicine (4934), followed by emergency medicine (2151) and paediatrics (1604). This trend has not changed through the years. The number was low for palliative medicine, but not the lowest. Lower numbers were noted in oral and maxillofacial surgery, addiction medicine and sexual health medicine. By state/territory, Victoria registered the highest share of advanced palliative medicine trainees (38%), followed by Queensland (26%) and New South Wales (15%).

Table11.2.1 Number of vocational trainees by medical specialty in 2016

Medical specialty	Basic trainees	Advanced trainees	Total college trainees
Addiction medicine	–	27	27
Adult medicine	2933	2001	4934
Anaesthesia	539	698	1237
Anaesthesia – pain medicine	29	37	66
Clinical radiology	–	422	422
Dermatology	48	55	103
Emergency medicine	727	1424	2151
General practice	–	5689	5689
Intensive care	203	282	485
Medical administration	–	110	110
Obstetrics and gynaecology	372	150	522
Occupational and environmental medicine	–	84	84
Ophthalmology	55	91	146
Oral and maxillofacial surgery	–	35	35
Paediatrics	806	798	1604
Palliative medicine*	–	39	39
Pathology	–	283	283
Pathology and RACP (jointly)	–	269	269
Psychiatry	789	733	1522
Public health medicine	–	82	82
Radiation oncology	–	95	95
Rehabilitation medicine	–	199	199
Sexual health medicine	–	13	13
Sport and exercise medicine	42	42	42
Surgery	1065	1065	1065
Total	7608	14723	22331

* Includes chapter trainees only. Excludes chapter trainees in Clinical Diploma in Palliative Medicine as the training program does not lead to fellowship of RACP or AChPM.

Source: Department of Health 2017b, “Medical Education and Training in Australia: National Medical Training Advisory Network”, First edition, viewed 20/7/2019, hwd.health.gov.au/webapi/customer/documents/MET%20 1st%20edition%202016.pdf.

Table 11.2.2 Proportion (%) of advanced trainees by medical specialty and state/territory, 2016

Medical specialty	NSW	VIC	QLD	SA	WA	TAS	NT	ACT
Addiction medicine	51.9	11.1	7.4	7.4	14.8	3.7	3.7	0
Adult medicine	31.0	30.9	17.4	8.2	8.0	1.5	0.8	2.0
Anaesthesia	28.8	25.5	23.5	7.4	9.5	1.7	1.1	2.4
Anaesthesia – pain medicine	32.4	24.3	16.2	13.5	8.1	2.7	0	2.7
Clinical radiology	31.5	23.0	20.9	10.7	9.5	1.7	0	2.8
Dermatology	30.9	32.7	25.5	7.3	3.6	0	0	0
Emergency medicine	28.8	22.8	24.8	6.4	11.5	2.2	2.2	1.3
General practice								
– AGPT program*	32.1	19.3	22.8	8.6	10.9	2.8	3.5	–
– ACRRM Independent pathway*	28.2	11.7	36.2	2.5	14.1	1.8	4.3	1.2
– RVTS*	39.5	14.5	23.4	2.4	10.5	2.4	7.3	0
Intensive care	35.8	24.8	22.3	5.7	6.7	1.8	1.4	1.4
Medical administration	23.6	24.5	30.0	0.9	11.8	4.5	1.8	2.7
Obstetrics and gynaecology	29.3	32.7	24.7	6.7	4.0	0.7	1.3	0.7
Occupational & environmental medicine	27.4	13.1	20.2	6.0	25.0	2.4	2.4	3.6
Ophthalmology	38.5	26.4	14.3	8.8	8.8	8.8	2.2	1.1
Oral and maxillofacial surgery	14.3	31.4	22.9	8.6	11.4	2.9	2.9	5.7
Paediatrics	33.5	25.6	17.9	7.5	12.2	0.9	1.6	0.9
Palliative medicine**	15.4	38.5	25.6	7.7	7.7	5.1	0	0
Pathology	38.5	21.6	17.0	5.3	10.6	3.2	1.1	2.8
Pathology and RACP (jointly)	35.3	28.6	15.6	7.1	8.2	1.5	0.7	3.0
Psychiatry	31.5	27.7	20.1	7.4	8.0	2.0	0.8	2.5
Public health medicine	35.4	20.7	12.2	4.9	6.1	6.1	6.1	8.5
Radiation oncology	43.2	20.0	20.0	7.4	5.3	2.1	0	2.1
Rehabilitation medicine	39.7	20.6	23.6	6.5	3.5	2.5	1.0	2.5
Sexual health medicine	30.8	46.2	7.7	15.4	0	0	0	0
Sport and exercise medicine	33.3	35.7	14.3	2.4	7.1	0	2.4	4.8
Surgery	36.8	26.3	17.7	6.9	7.9	1.7	1.1	1.6
Total	32.2	23.5	21.2	7.7	9.8	2.2	2.2	1.2

* AGPT – Australian General Practice Training; ACCRM – Australian College of Rural and Remote Medicine Independent Pathway; RVTSRemote Vocational Training Scheme
** Counts include both basic and advanced trainees together. All figures were current as of 30 June 2016.
Source: same as previous page

Table 11.2.3 Trends in specialisation training, 2012–16

Medical specialty	2012	2013	2014	2015	2016	Change 2012–16 (%)
Addiction medicine	18	24	22	20	27	50.0
Adult medicine	1468	1513	1699	1822	2001	36.3
Anaesthesia	609	657	664	697	698	14.6
Anaesthesia – pain medicine	59	65	66	27	37	–37.3
Clinical radiology	372	364	410	428	422	13.4
Dermatology	57	49	54	62	55	–3.5
Emergency medicine	1204	1339	1355	1461	1424	18.3
General practice						
– AGPT program	3289	3932	4315	4936	5402	64.2
– ACRRM Independent pathway	156	155	171	179	163	4.5
– RVTS	71	87	103	113	124	74.6
Intensive care	302	281	336	383	282	–6.6
Medical administration	98	107	115	104	110	12.2
Obstetrics and gynaecology	133	159	165	153	150	12.8
Occupational & environmental medicine	84	102	92	89	84	0
Ophthalmology	80	90	90	91	91	13.8
Oral and maxillofacial surgery	38	38	38	39	35	–7.9
Paediatrics	593	556	662	713	798	34.6
Palliative medicine	24	80	28	36	39	62.5
Pathology	314	301	307	307	283	–9.9
Pathology and RACP (jointly)	208	213	236	248	269	29.3
Psychiatry	417	418	418	402	733	75.8
Public health medicine	61	81	81	77	82	34.4
Radiation oncology	141	122	117	108	95	–32.6
Rehabilitation medicine	177	191	202	205	199	12.4
Sexual health medicine	10	20	13	13	13	30.0
Sport and exercise medicine	28	30	41	41	42	50.0
Surgery	1094	983	1094	1056	1065	–2.7
Total	11105	11957	12894	13810	14723	32.6

Source: same as previous page

11.3 TRENDS IN ADVANCED TRAINING

From 2012–16, the total number of trainees in all specialisations increased by an annual average of 6%. The same trend is noted for advanced trainees. Between 2012 and 2016, the number of advanced trainees in all specialisations increased at a rate of 7.3% annually with more female than male trainees. There was a similar trend with part-time trainees. Although part-timers comprised between 11% to 16% of trainees, the numbers increased over time.

Table 11.3.1 Vocational trainees: Total, advanced, female participation in advanced training and part-time advanced trainees, 2012–16

	Total college trainees	Advanced trainees	Female advanced trainees	Proportion of advanced trainees (%)	Part-time advanced trainees	Proportion of part-time advanced trainees (%)
2012	16,849	11,105	5536	50.3	1225	11.0
2013	18,013	11,957	6160	52.1	1581	13.2
2014	19,261	12,894	6733	52.2	2083	16.2
2015	20,250	13,810	7399	53.6	2239	16.2
2016	21,224	14,723	7841	53.3	2260	15.4
Change 2012 & 2016 (%)	26.0	32.6	41.6	5.9	84.5	39.2
Annual average (%) change 2012–16	5.9	7.3	10.0	5.9	15.7	10.7

Source: Department of Health 2017b, "Medical Education and Training in Australia:National medical training advisory network", 1st Edition report, viewed 20/7/2019, hwd.health.gov.au/webapi/customer/documents/MET%201st%20edition%202016.pdf.

11.4 MEDICAL STUDENTS IN AUSTRALIAN UNIVERSITIES

In 2018, there were a total of 17,052 medical students in Australia, including undergraduate students, postgraduate students and those undertaking a Doctor of Medicine degree. Eighty-four percent of these students (14,284) were domestic students (Medical Deans Australia New Zealand 2017).

There were 3021 domestic medical graduates in 2017. This number is set to increase by 3.8 per cent from 2017 to 2020, to reach over 3700 in 2020 (Medical Deans Australia and New Zealand 2019).

11.4.1 PREFERRED SPECIALTY OF FUTURE PRACTICE

Adult medicine ranked first as the most preferred specialisation for future practice with 19% of 2,111 graduating students in 2017 preferring this specialty. General practice (17%) and surgery (15%) were ranked second and third respectively. These three specialties have remained the most commonly preferred specialisations since 2013 (Medical Deans Australia and New Zealand 2019). Palliative medicine was one of the least preferred, with less than 1% of graduating students choosing this as a specialisation as shown in Table 11.4.1.

Table 11.4.1 First preference of specialty for future practice, 2017

Specialty	Number	Percent	Rank
Adult medicine/internal medicine	390	18.5	1
General practice	349	16.5	2
Surgery	317	15.0	3
Anaesthesia	226	10.7	4
Paediatrics and child health	189	9.0	5
Emergency medicine	181	8.6	6
Obstetrics and gynaecology	138	6.5	7
Psychiatry	84	4.0	8
Intensive care medicine	54	2.6	9
Ophthalmology	45	2.1	10
Radiology	43	2.0	11
Dermatology	25	1.2	12
Palliative medicine	11	0.5	13
Sport and exercise medicine	11	0.5	14
Non-specialist hospital practice	9	0.4	15
Pathology	9	0.4	16
Public health medicine	9	0.4	17
Radiation oncology	6	0.3	18
Addiction medicine	4	0.2	19
Medical administration	3	0.1	20
Rehabilitation medicine	3	0.1	21
Sexual health medicine	3	0.1	22
Pain medicine	2	0.1	23
Occupational and environmental medicine	0	0.0	24
Total	2111	100.0	

Source: Medical Deans Australia and New Zealand, “National data report: 2013–2017”, viewed 23/04/2019, medicaldeans.org.au/md/2018/09/2018-MSOD-National-Data-Report.pdf.

11.5 PREFERENCE TO WORK IN INDIGENOUS HEALTH

Table 11.5.1 Preference of medical students in their final year to work in Indigenous health, 2014–17

Interest in Indigenous health	2014 (n=2,467)	2015 (n=2,000)	2016 (n=2,252)	2017 (n=2,147)
Yes	38%	37%	39%	43%
No	23%	34%	26%	22%
Undecided	39%	39%	35%	35%

Source: Medical Deans Australia and New Zealand, "National data report: 2013–2017", viewed 23/04/2019, medicaldeans.org.au/md/2018/09/2018-MSOD-National-Data-Report.pdf.

In 2017, 43% of graduating students expressed preference to work in Indigenous health as part of their career. This has been the highest percentage since 2014, with an increase of 5 percentage points since then. This shows an upward trend implying that Australian medical graduates are becoming more interested in Indigenous health as part of their future practice. These data do not show, however, how many final year students had expressed interest in working in Indigenous palliative care.

12. Policy recommendations

The Institute recognises the importance of bringing in the voices of experts and advocates in an open dialogue to help frame feasible solutions to address the gaps in palliative care provision identified in this report. On 13 May 2019, the Institute brought together a group of palliative care clinicians, ethicists and policy specialists for a roundtable discussion. See Appendix 2 on list of participants.

The following recommendations emanated from the discussion, and are based on the findings of this research.

12.1 DEVELOP INNOVATIVE AND INTEGRATED MODELS OF PALLIATIVE CARE TO MOVE AWAY FROM CURRENT RELIANCE ON HOSPITAL BASED CARE

Palliative care services will continue to increase as Australia's ageing population increases and given that the current burden of palliative care provision rests heavily on the public health system, mainly city-based, there is a need for innovative, integrated models of palliative care provision that move away from the current heavy reliance on hospital-based care to community-based care. The model currently adopted by two Sydney local health district hospitals, Royal Prince Alfred Hospital (RPA) and Concord Repatriation General Hospital (Concord), illustrates how palliative care services can be integrated and delivered in a community-setting. Both hospitals are major hospitals in Sydney, with RPA being a major teaching hospital.

An integrative service model: The RPA-Concord model of palliative care

Launched in January 2018, the RPA-Concord Integrative Model of Palliative Care is a comprehensive approach to ensure that good and timely care is available to individuals in need of palliative care. Prior to the adoption of this model of care, two particular problem areas were identified by RPA (the lead hospital) in their provision of palliative care services. These were:

- Their approach to palliative care provision was not seamless nor was it delivered by primary and specialist providers in the community. The result was heavy reliance on hospital provision of care;
- There were notable gaps in access by some population groups including those from Culturally and Linguistically Diverse (CALD) and Indigenous communities.

This model of care addresses these problem areas by combining the services of the hospitals, community services, locally-based general practitioners, a community-based palliative care team, and a network of volunteers to provide integrated, comprehensive support to individuals who need palliative care in their homes and in residential aged care. It also extends such services to individuals in boarding houses and those with unstable housing. It allows for a more complete, streamlined and integrative approach to ensure that the highest level of care is offered to those in need of palliative care. It draws on the expertise of six cohorts to ensure the successful delivery of palliative care to the community. These include:

1) Hospitals

RPA is the lead hospital with Concord Hospital having a specialised Palliative Care Unit. Both hospitals provide support to symptomatic patients, advance care planning and full palliative care for chronic and end of life patients;

2) Community

The hospitals liaise with the community to help support individuals in their homes, residential aged care, boarding houses, and individuals experiencing homelessness;

3) Community-based/local services.

RPA ensures that linkages with community service providers are strengthened so that palliative care patients in their district have access to the following:

a) Two palliative care nursing practitioners;
b) A clinical nurse consultant;
c) At least one specialist palliative care doctor and where the budget allows, two palliative care doctors and two palliative care trainees or career medical officers;
d) Two social workers; and, two physiotherapists or occupational therapists.

4) General practitioners

General practitioners help patients manage their symptoms and provide support within the community.

5) An Indigenous liaison (palliative care nurse)

An Indigenous palliative care liaison nurse is available to provide care and support to Indigenous people.

6) A network of volunteers

Volunteers are recruited to engage with isolated people and provide access to a range of activities.

This model offers comprehensive care for a more streamlined delivery of palliative care services by integrating various services that are provided by primary caregivers and specialist providers in the community. It also addresses gaps associated with some population groups in the community, such as the Indigenous population, through the provision of an Indigenous palliative care nurse. This model of care also ensures that people spend less time in hospital and more time in their place of residence. This not only provides comfort to the patient and their families, but eases the burden currently faced by public hospitals.

The whole model is premised on the complete wellbeing of the patient, not just the physical symptoms associated with their illness. The success and work-ability of this framework, as evidenced by the real cases (supplied by RPA) that are outlined in the next section, suggests that it could be adapted and used across all districts in Sydney and across all jurisdictions in Australia to ensure the successful whole-of-patient approach in one integrated, comprehensive delivery of palliative care.

CASE STUDIES: COMMUNITY BASED MODEL OF CARE

Mrs D
Colorectal cancer with metastasis
Enduring guardian: Sister
Ambulance Plan, Advance Care Plan
Comprehensive, integrated palliative care in residential aged care facility

> "The integration of care at all levels in which the community-based palliative care nurse practitioner, the general practitioner, the medical staff at the residential aged care facility worked together in consultation with the patient's family resulted in a holistic, seamless, on-going provision of care."

This case illustrates the importance of an integrated model of care in which the GP, residential aged care facility staff, the palliative care nurse practitioner and the patient's family worked in partnership to ensure that symptoms were well controlled, and quality palliative care was given before the patient succumbed to her illness months later.

Mrs D was admitted to RPA with tachycardia and diaphoresis (abnormally rapid heart rate and sweating) via the emergency department. Investigations led to a diagnosis of colorectal cancer. This had spread to her liver with extensive lymphadenopathy (that is, into the lymph nodes), such that no further treatment was rendered suitable. She was then returned to the residential aged care facility where she was seen by the community palliative care nurse practitioner, who then made contact with Mrs D's sister, her enduring guardian, and organised for a conference.

Mrs D had ongoing medical issues with her bowels, persistent abdominal pain and discomfort, reflux and oedema. The care plan was for the community palliative care nurse practitioner to work closely with the GP and the staff of the residential aged care facility to control symptoms and provide quality palliative care within Mrs D's care home. Advance care planning was undertaken with Mrs D's sister and residential care staff, for end of life care within the facility. The palliative care medical specialists were able to advise medication changes needed when required and coordinated by the nurse practitioner through Mrs D's GP.

An ambulance plan was also completed by the palliative care nurse practitioner, in conjunction with the GP, in the event that an ambulance might be called to assist staff with an uncontrolled deterioration or with an event needing rapid assessment. These plans advise the ambulance paramedics what medications can be further given, who to contact for advice and what treatments not to give, in order to avert invasive treatments or unnecessary hospital admission. The integration of palliative care services at the community level allowed Mrs D's symptoms to be managed in place of care, with family and familiar staff around her. She died peacefully a month later, without the need for a hospital readmission as her condition continued to change. This model also facilitated staff and family education and support, whilst caring for Mrs D in her last illness.

The integration of care at all levels in which the community-based palliative care nurse practitioner, the general practitioner, the medical staff at the residential aged care facility worked together in consultation with the patient's family resulted in a holistic, seamless, on-going provision of care. This integrated model of care also resulted in the upskilling of the residential aged care staff. Through the exchange of knowledge provided by the palliative care nurse specialist, the staff at the residential aged care facility became more comfortable with providing end of life care to Mrs D. Quality palliative care was given to Mrs D at her end of life which made her family happy with the care provided at the residential aged care facility. Advanced care planning in an integrated model of care is essential in the care of patients with life-limiting illnesses.

Mrs D
Diagnoses: Alzheimer’s dementia
Metastatic renal cell carcinoma
Parkinson’s disease-like symptoms; behavioural (agitation)
Plans: Advance Care Plan including Palliative Care
Management Plan around her medications

> “Through the support of the palliative care team, the GP and residential care staff, Mrs B remained comfortable as her symptoms were effectively managed. Regular patient reviews were undertaken as well as the ongoing education of the residential aged care staff by the palliative care team.”

This case highlights the complex care that was needed by a patient who was transferred to a residential aged care facility from an acute hospital, and whose symptoms were successfully managed through advanced care planning and an integrative approach to care in the community setting.

Mrs B was 76 years old and diagnosed with Alzheimer’s dementia, metastatic renal cell carcinoma with spinal metastases which were deemed not suitable for chemotherapy. She was sent to a residential aged care facility with complex medications in a syringe driver for symptom management. On the day of the transfer, Mrs B had to be given two medications for the management of pain and agitation. Once returned to the facility, Mrs B developed symptoms similar to Parkinson’s disease.

The community palliative care nurse practitioner visited Mrs B and noted that she had continued to be given Haloperidol for several months for behavioural management by the staff and the GP at the aged care facility. The nurse practitioner asked a palliative medicine physician to assess Mrs B and assist in initiating a discussion with the GP around the use of Haloperidol and the side-effects, especially with prolonged use, and advised that it may be interfering with Mrs B's ability to communicate her needs. Haloperidol was then ceased. Advanced care planning was immediately initiated by the palliative medicine specialist around the management of Mrs B's complex needs including pain and agitation. After several family conferences with the daughters of Mrs B, an Advanced Care Plan was then put in place which included a palliative care management plan around medications.

Through the support of the palliative care team, the GP and the residential aged care staff, Mrs. B remained comfortable as her symptoms were effectively managed. Regular patient care reviews were undertaken as well as the ongoing education of the residential aged care staff by the palliative care team. Mrs B died peacefully at the residential facility six months after admission and without agitation. Her daughters felt supported through their mother's illness and challenging behaviour at the time of her death. The staff of the residential aged care facility also felt supported and gained invaluable knowledge from the community based palliative care team.

12.2 DEVELOP A NATIONAL POLICY FRAMEWORK OR STRATEGY FOR PAEDIATRIC, ADOLESCENT AND YOUNG ADULTS

As noted in this report, the rates of annual increase in paediatric palliative care hospitalisation were in double digits particularly for children aged less than 15 years. While there are national strategies, guidelines and service development standards for palliative care in general, as outlined in section 2 of this report, there is a lack of the same that are specific to palliative care for children and young people who may have chronic or life-limiting illnesses. Although the numbers of paediatric palliative care hospitalisations are still small relative to the older cohorts, the double-digit growth rates point to the importance of adopting a similar national approach to palliative care provision for children and young people.

It is notable that in December 2018, Palliative Care Australia (PCA) issued a “Paediatric Addendum” to its Palliative Care Service Development Guidelines. These guidelines outlined the expectations of PCA for workforce planning and system capability requirements that are essential in the delivery of effective palliative care services to children and young people. This is in recognition of the fact that although there are similarities with adult palliative care provision, there are also differences in working to provide paediatric palliative care. Most notably, the provision of palliative care to children and young people can run for a very short period of time or it can last for many years until these children transition to adult palliative care.

12.3 MAKE ADVANCE CARE PLANNING A FUNDAMENTAL PART OF ROUTINE CLINICAL CARE

Advance care planning involves ongoing, values-directed discussion with health professionals, patients, their family or other designated agents (Caresearch 2017a). It works through choices for care in the context of the patient’s current and anticipated future health. It sets out the overall objective of treatment and the interventions that should and should not be provided or undertaken. An Advance Care Plan guides current and future treatment in the event of a deterioration in a patient’s condition. However, it is more than just a treatment plan. It assists families and loved ones prepare for the future when the patient reaches end of life, and involves them in a process of reflection and information sharing with clinicians in making the best decision for the patient (Palliative Care Australia 2019).

Based on the fundamental principles of self-determination, dignity and avoidance of suffering, advance care planning should begin early in a patient’s illness (RACP 2014). The case studies presented in this report highlight its necessity. Hence, we join the call by Caresearch, Royal Australian College of Physicians, Advance Care Planning Organisation, Catholic Healthcare Australia, and other stakeholders in advocating for the adoption of Advance Care Plans as part of routine patient care.

12.4 UPSKILLING RESIDENTIAL AGED CARE STAFF AND INCREASING THE NUMBER OF PALLIATIVE CARE SPECIALIST STAFF

Concomitant with the recommendation of adopting an integrative model of care as discussed in section 12.1 is the strengthening of skills in residential aged care staff to provide palliative care. As exemplified in the case studies and as noted in the roundtable discussion, residential aged care staff lack the skills in providing palliative care. When situations arise in residential care facilities that call for the patient to be provided with palliation, the usual response is to admit the patient to hospital. The upskilling of staff in residential aged care can avoid this and help ensure that quality palliative care is accessible in a timely manner. It is essential in reducing the heavy dependence on hospitals for acute palliative care. With skilled staff in the residences, hospital admissions that are avoidable are minimised.

There is also a need to increase palliative care specialist staff in residential aged care. It was noted at the roundtable discussion that many staff in residential aged care facilities are junior staff. There is a low staff to patient ratio and high staff turnover. These gaps need to be addressed. This again is linked to the decrease in funding for palliative care in residential care facilities due to the application of stricter measures under the Federal Government's Aged Care Funding Instrument (ACFI).

12.5 UNDERTAKE A REVIEW OF THE AGED CARE FUNDING INSTRUMENT

As discussed in Chapter 8, the Aged Care Funding Instrument evaluates the palliative care needs of residents in aged care facilities. It is the tool for government to allocate subsidies to aged care providers for delivering care. In 2016, the government started to tighten funding to residential aged care providers and envisioned a savings of \$1.2B over 4 years. This was done by applying stricter criteria in assessing residents with complex health care needs. The Australian Institute of Health and Welfare surmised that the decline in the number of residents appraised as needing palliative care was due to the stricter measures in ACFI. Caresearch, Australia's network of resources on palliative care, contends that ACFI is a funding tool and not a comprehensive health planning tool. Hence, using what is essentially funding tool to assess palliative care needs of residents may not be appropriate and results in an underestimation in the number of those really in need of palliation. We recommend a review of ACFI for this reason.

12.6 STRENGTHEN THE ROLE OF GENERAL PRACTITIONERS IN PALLIATIVE CARE PROVISION IN THE COMMUNITY

The low number of GP palliative care encounters (discussed in Section 9.8) means that the role of GPs in providing palliative care in the community must be strengthened. GPs play a crucial role in the provision of community-based palliative care services. The case studies in this report highlight their importance and show how a strengthened collaboration between the GPs, the community-based palliative care specialist team and residential aged care staff in an integrative model of care can result in reducing admissions in acute hospitals for palliation. To ensure that patients are cared for by a quality, integrated service network in their community, more liaison and collaborative partnerships between palliative care specialist teams, aged care teams and general practitioners in the communities is needed.

12.7 PRIORITISE SYSTEMATIC AND COMPREHENSIVE DATA COLLECTION ON PALLIATIVE CARE

In the course of undertaking this report, problems relating to a lack of data were encountered. For example, utilisation of palliative care services in hospitals is measured by episodes of hospitalisation. As such, it is difficult to ascertain unique cases of palliative care access. This hinders estimation of demand or any econometric estimation of palliative care utilisation when viewing it from the perspective of unique, individual cases rather than episodes of admissions for palliation. A person can be hospitalised for palliative care three times in a year, but from a unique case estimation this would have been recorded as one, single case of use or access. As noted elsewhere in this report, there are also problems in accurately estimating the need for palliation in aged care facilities.

As the NSW Ministry of Health (2019) states, the provision of care should be of high quality and should be based on evidence. Evidence requires data. The availability of a comprehensive set of data facilitates innovation and the continuous quality improvement in palliative care provision.

12.8 ACTIVELY ENCOURAGE INCREASED UPTAKE OF PALLIATIVE CARE TRAINING

This report shows the low uptake on palliative care training by physicians and nurses. This was also reflected in the low preference for palliative care as a specialty amongst graduating medical students. Albeit relatively new as a field of specialty when contrasted with ‘traditional’ specialisations like adult medicine, there is a need to generate greater interest in the field. Incentives can take the form of government subsidies for palliative care training, increasing the number of fellowships that are available in the colleges and the availability of university scholarships for students wanting to specialise in the field. These steps can also address the problem of shortfalls in the supply of palliative care specialists and the problems related to an ageing palliative care workforce. Similar incentives are needed in other areas of the palliative care workforce, including nursing.

12.9 DEVELOP STRATEGIES TO FOSTER A BETTER UNDERSTANDING OF PALLIATIVE CARE AMONG MEDICAL PROFESSIONALS AND THE PUBLIC

There is a need to address the knowledge gaps in how GPs understand palliative care. This is crucial in strengthening their role in the community. As shown in this report, most GPs have the concept that palliative care is end of life care and they do not distinguish between the two. As a result, they are found to be less comfortable in handling patients needing palliative care in their practices and GP palliative encounters have remained low despite increasing need.

There is also a general misconception about palliative care that is not confined to the medical community alone. If GPs misconstrue palliative care as end of life care and associate it primarily with death, how can the general public be expected to have a better understanding of palliative care? Palliative care is not the last resort for those who are dying. The need to educate and inform is vital to the timely provision of palliative care, both for ensuring that people who need it know that it is available and know how to access it, and for encouraging early access to palliative care in the trajectory of an illness. This is particularly significant for chronic illnesses. Palliative care is not end of life care although end of life care includes palliative care.

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APPENDIX 1: PUBLIC SUPPORT FOR PALLIATIVE CARE FOR THE TERMINALLY ILL

At the end of 2018, the Institute conducted the inaugural PM Glynn Survey on Australian attitudes to hope, trust and belonging. The survey is aimed at investigating the underlying attitudes and concerns that shape responses to current political, social and ethical issues and their implications for Australian society.*

One of the areas the survey explores is attitudes to human rights. Respondents were asked where they stood on ten issues, including access to palliative care in preference to assisted suicide. A full analysis of the data for this question and the others related to it is not yet available, and will be published later in 2020. Given its relevance to this report, however, it was thought that it may be of interest to readers to provide some preliminary indications of the survey findings for the question in this appendix, which are limited at this stage to the response frequencies and cross-tabulations with age and religiosity.

The question asked about palliative care was put as follows:

> Question: Where do you stand on the following human rights issues? . . . Protecting the rights of terminally ill people to receive high quality palliative care and pain control, in preference to legalising assisted suicide or a "right to die"

The formulation of the question was intended to explore attitudes to palliative care when it is proposed as a preferred alternative to legalising assisted suicide or euthanasia. This is a proposal that is often made in public debate by opponents of euthanasia and assisted dying.

It can be reasonably assumed that asking about the right to high level palliative care for the terminally ill simply by itself would receive very high levels of support, as do survey questions asking simply about a right to euthanasia or assisted dying for the terminally ill. Asking about people's attitudes to high quality palliative care in preference to legalising assisted suicide is one way of trying to go a little deeper into the issue than these simpler sorts of questions allow. It comes closer to one form that the public debate sometimes takes.

Fifty-nine percent (59%) of the sample indicated support for this proposal, 17% were opposed, and 24% were neutral or couldn't say. The strength of support and opposition were categorised as follows:

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* The survey was conducted for the Institute in December 2018 by SMR Global Pty. Ltd, a specialist, independent social and market research company. The survey was completed by 3000 respondents aged 16 years and over who were selected at random. The sample was nationally representative for characteristics such as age, gender, city and regional residence and state and territory populations.

	Percentage (%)
I strongly support this	36%
I somewhat support this	23%
I'm neutral on this	21%
I somewhat oppose this	9%
I strongly oppose this	8%
Can't say	3%
Total	100%

As might be expected, support increased with age and with levels of religiosity. Support among those aged 16 to 24 was 53%, compared to 66% for those aged 66 and over. Interestingly, opposition also increased with age, from 12% for 16 to 24 year olds to 19% for those aged 66 and over. Unsurprisingly, reflecting perhaps how remote or immediate this issue may be personally for people of different ages, neutrality was highest among the youngest (35%) and lowest among the oldest (15%).

Age (years):	16–24	25–34	35–49	50–64	65+	Total
Support	54%	59%	55%	60%	66%	59%
Neutral	35%	27%	26%	20%	15%	24%
Oppose	12%	14%	19%	21%	19%	17%
Total	100%	100%	100%	100%	100%	100%

Respondents who reported a strong religious commitment recorded the highest level of support for the proposal (74%), compared to those with moderate levels of religious commitment (62%) and those with no religious commitment (49%). Opposition was lowest among the most religious (9%) and highest among the least religious (22%), and neutrality on the question also rose as levels of religiosity declined.

	Actively practice religious faith	A believer but not a fervent follower	Doubter/ Agnostic/ Atheist	Total
Number of respondents	349	1458	1192	3000
Support	74%	62%	49%	59%
Neutral	17%	22%	29%	24%
Oppose	9%	16%	22%	17%
Total	100%	100%	100%	100%

Across age cohorts, “strongly support” ranged from 27% to 46%, and “somewhat support” from 19% to 26%. Across different levels of religious commitment, “strongly support” ranged from 30% to 50% and “somewhat support” from 19% to 26%.

Those who “strongly oppose” range from 6% to 9% across age cohorts, and those who “somewhat oppose” from 5% to 12%. Across the levels of religious commitment, “strongly oppose ranges from 5% to 10% and “somewhat oppose” from 3% to 12%.

In total, a little over one-third of all respondents (36%) strongly support, and a little under a quarter (23%) somewhat support, the right to high quality palliative care for the terminally ill in preference to legalising a right to die. The survey results suggest that as many as 6 out 10 Australians (59%) may support this proposal.

Whatever other conclusions might be drawn from the responses to this question, it is clear that there is majority support for the right of terminally ill people to receive high quality palliative care and pain control, and at the very least a significant degree of openness to this in preference to the legalisation of assisted suicide or a right to die.

As such, this survey finding lends support to the policy proposition set out at the beginning of the report: namely, that before a community decides to take a momentous step such as legalising assisted dying, governments and law makers should ensure that everything possible has been done to address the significant gaps in provision and access in palliative care which this report highlights, to ensure that the right to high quality palliative care is a practical reality for everyone with a terminal or life-limiting illness in Australia.

APPENDIX 2 ROUNDTABLE AND PERSONAL INTERVIEW PARTICIPANTS

Dr. Maria Cigolini
Head of Department,
Palliative Care Medicine
Royal Prince Alfred Hospital, Sydney

Dr. Anthony Herbert
Director, Paediatric Palliative Care Service
Division of Medicine, Children's Health
Queensland Hospital and Health Service

Dr. Annmarie Hosie
Post-Doctorate Research Fellow
Palliative Care Clinical Studies
University of Technology Sydney

Prof. Amanda Johnson
State Head
School of Nursing, Midwifery and
Paramedicine
Australian Catholic University, North
Sydney

Dr. Martin Kennedy
Palliative Care Specialist
Calvary Health Care, Kogarah, NSW

Dr. Natasha Michael
Palliative care physician
Cabrini Health, Victoria

Ms. Jeanette Moody
Chief Executive Officer
Eastern Palliative Care Association Inc.,
Victoria

Ms. Annette Panzera
Director, Health Policy
Catholic Health Australia, Australian
Capital Territory

Prof. Bernadette Tobin
Director, Plunkett Centre for Ethics
St. Vincent's Hospital and Australian
Catholic University, North Sydney

Dr. Amy Waters
Palliative care specialist
St. George Hospital, Kogarah NSW

ABOUT THE PM GLYNN INSTITUTE

The PM Glynn Institute is committed to public policy for the common good. It was established by Australian Catholic University in early 2016 to provide the Catholic community with a standing capacity to analyse public policy issues of concern not only to the Catholic Church and its services, but to the wider Australian community as well.

The Institute's work is shaped by the proposition that understanding the contemporary world also means considering religion and the foundations of faith as important and enduring features of the social and political landscape, both in Australia and globally.

Its role is to generate new approaches and new thinking on public policy issues, and to develop well-supported and practical proposals to address them.

pmglynn.acu.edu.au
pmg@acu.edu.au

pmglynn.acu.edu.au

PM GLYNN INSTITUTE
pmg@acu.edu.au

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