

---

## 3 End-of-life care in Australia

### Key points

- End-of-life care is provided to people who have a medical condition that means they are likely to die within the next 12 months. Care services include physical, spiritual and psychosocial assessment, and care and treatment delivered by health professionals and ancillary staff.
- Most of the 160 000 people who die in Australia each year would benefit from end-of-life care but many do not receive care that fully reflects their choices or meets their needs. Demand for care will grow rapidly in coming years as more people enter the older age groups in which most deaths occur.
- Where it is available, the quality of end-of-life care services in Australia is often excellent. But services are not available everywhere and to everyone who would benefit. Delivery of more effective end-of-life care will require investment and coordinated action across the Australian, State and Territory Governments.
- Hospitals play an important role in the delivery of end-of-life care. Hospital accreditation standards will, from 2019, prescribe a range of best-practice elements for end-of-life care. This should drive the changes that are needed to improve hospital care. However, dying in hospital is not the preferred outcome for most Australians. Too many people who, with appropriate support, could and would choose to die at home or in their aged care residence, die in hospital. Providing end-of-life care for these people where they live would better meet their clinical needs and reflect their choices.
- About 60 000 people die in residential aged care facilities each year. End-of-life care should be core business for residential aged care providers but the quality of end-of-life care in residential aged care is patchy at best. Too often, people are transferred back and forth between hospitals and aged care facilities, as aged care facilities lack palliative care expertise and qualified staff to administer pain relief.
- Many people are unable to communicate their wishes for end-of-life care at the time the care is provided. Yet few people talk about their end-of-life preferences with family and friends, and only about 15 per cent of Australians have prepared for the possibility of being unable to communicate by documenting their end-of-life care preferences in an advance care plan.
- While Governments have recognised community concern about end-of-life care, progress is being hindered by poor stewardship, including conflict over responsibilities and how service provision is coordinated across different settings. Reforms are needed to put users' needs and choices at the heart of end-of-life care services, and to ensure those services have the capacity to meet users' needs.

---

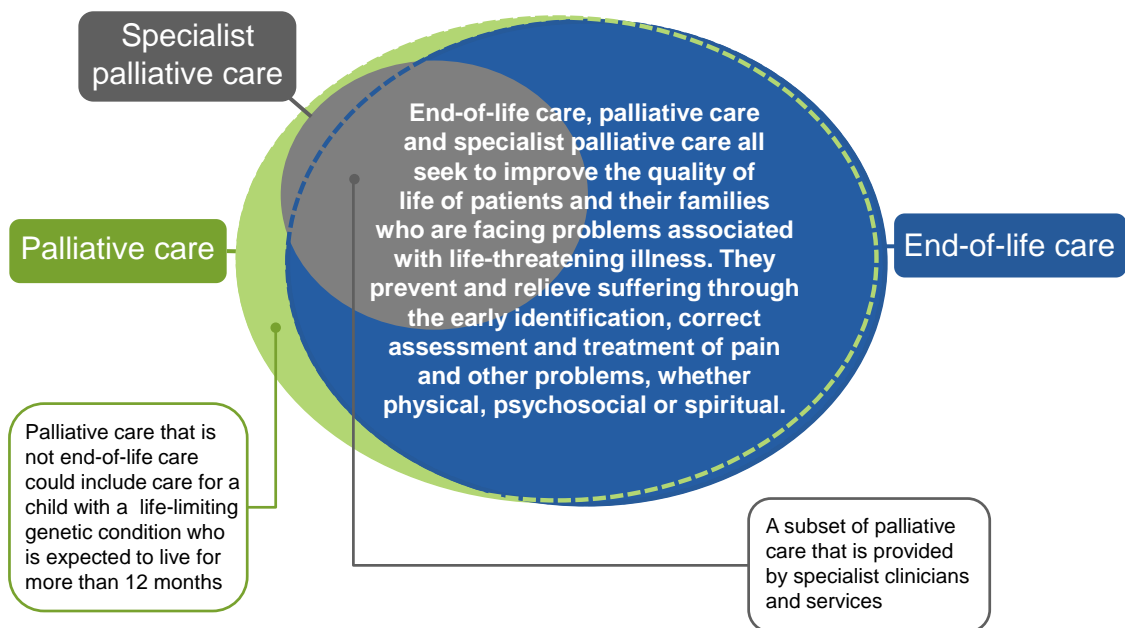
### 3.1 What is end-of-life care?

The Australian Commission on Safety and Quality in Health Care describes end-of-life care services as including ‘physical, spiritual and psychosocial assessment, and care and treatment delivered by health professionals and ancillary staff’ provided to people who are ‘likely to die within the next 12 months’ (ACSQHC 2015a, p. 33).<sup>1</sup>

The terms ‘end-of-life care’ and ‘palliative care’ are used differently throughout Australia, although they largely entail the same approach to care provided to the same users (figure 3.1). Many scholarly articles refer to ‘end-of-life’ and ‘palliative’ care interchangeably (Bloomer, Moss and Cross 2011), and the Commission has taken the same approach in this report.

---

Figure 3.1 **Stylised representation of end-of-life and palliative care**



Sources: Based on PCA (sub. PFR329), SA Health (2009) and WHO (2015).

---

End-of-life care is not a single service provided by a particular profession and is provided in almost all settings where health care is provided, including in people’s homes (AIHW 2014a, p. 291; Department of Health 2017). It typically encompasses a broad range of services, which can include advice and coordination of care, nursing and personal care, 24 hour hotlines, day hospice respite, emotional and practical support, and access to equipment (LSIC 2016). It can also include services for families and carers, such as bereavement support.

---

<sup>1</sup> End-of-life care does not include euthanasia, assisted suicide or voluntary assisted dying.

---

While some end-of-life care is provided by specialist inpatient or community-based palliative care services (including care in people's homes and in hospices), most is provided by generalist services (such as hospitals, community health services and residential aged care facilities). Most end-of-life care is provided by government-funded services, and these services are the sole focus of this report. However, people approaching the end of life can also purchase additional services if they wish.

Compared to many other healthcare disciplines, palliative care is relatively new, having started in the United Kingdom in the 1960s and been fully recognised as a medical speciality in the 1990s (Push for Palliative, sub. DR538).

### Shared stewardship between governments

Reflecting the range of services and settings covered by end-of-life care, stewardship responsibilities are shared between the Australian, State and Territory Governments. In broad terms:

- the Australian Government contributes to the funding of end-of-life care in hospitals (including via payments to State and Territory Governments for public hospitals), residential aged care (including palliative care via the Aged Care Funding Instrument), and community settings (for care provided by general practitioners via Medicare)
- State and Territory Governments are responsible for, and in many cases provide, end-of-life care in public hospitals and community health services, including community-based palliative care services.

The overlapping roles of the two levels of government has led to conflict over responsibilities, and uncertainty and buck passing over how stewardship is shared and service provision is coordinated across different settings. Overlapping responsibilities mean that, in some areas, each level of government has left it to another level to meet resourcing and other stewardship requirements. Weaknesses in current stewardship arrangements are discussed further in section 3.4.

### Mismatch between demand and supply of end-of-life care

There is scope for improvement in the choices available to people approaching the end of life about the setting in which they receive end-of-life care. Up to 70 per cent of Australians would prefer to die at home (PCA, sub. PFR329), but most end up dying in hospital instead (box 3.1). The mismatch between the most commonly preferred place of death (home) and the places where death most commonly occurs (hospital and residential aged care) arises even though preferences for place of care and place of death are not always the same and can change over time.

---

### Box 3.1 **Many people who would prefer to die at home do not**

The Australian literature on end-of-life care (for example, Broad et al. 2013; Swerissen and Duckett 2014) and inquiry participants (including BUPA, sub. PFR380; HammondCare, sub. PFR330; Hobart District Nursing Service, sub. 419) referred to the discrepancy between the proportion of Australians who would prefer to die at home and the proportion who actually do so. Estimates of this discrepancy are uncertain, for two reasons.

First, as Dr Anthony Ireland noted, ‘there are no population-based data describing preferences of Australians for a “place of death”, especially for the relevant population’ (sub. DR527, p. 1). The Centre for Health Economics Research and Evaluation at the University of Technology Sydney pointed out that ‘an important limitation of the general population research to date is that it has focused on preferred place of death without reference to any specific context or to the place of care over the period of functional decline prior to death’ (sub. DR516, p. 3). Little Company of Mary Health Care noted that despite ‘many attempts through research, policy and survey we have no clear universally accepted understanding of what choice [of place of death] people would make or what might influence their choice’ (sub. DR547, p. 5).

Preferences about place of death can also change over time. While the direction of the change can vary, a review of 210 studies across 33 countries found preferences most commonly changed ‘from hospital to home, home to hospice and from home to hospital’ (Gomes et al. 2013, p. 10).

While conscious of these limitations, the same international review found that a majority of respondents preferred to die at home (Gomes et al. 2013). This is consistent with Australian evidence, where the best available estimate suggests that up to 70 per cent of Australians would prefer to die at home (PCA, sub. PFR329).

The second reason for uncertainty about the discrepancy between the proportion of Australians who would prefer to die at home and the proportion who actually do so relates to uncertainty about the proportion of Australians who die at home. This is typically said to be 14 per cent, but in the Commission’s view, that is likely to be an overestimate. The 14 per cent figure is often attributed to Broad et al. (2013), who used ABS and Australian Institute of Health and Welfare data from 2005 to infer the proportion of people over 65 who die in hospital, in residential aged care facilities or ‘other including private home’, with the latter category comprising 14 per cent.

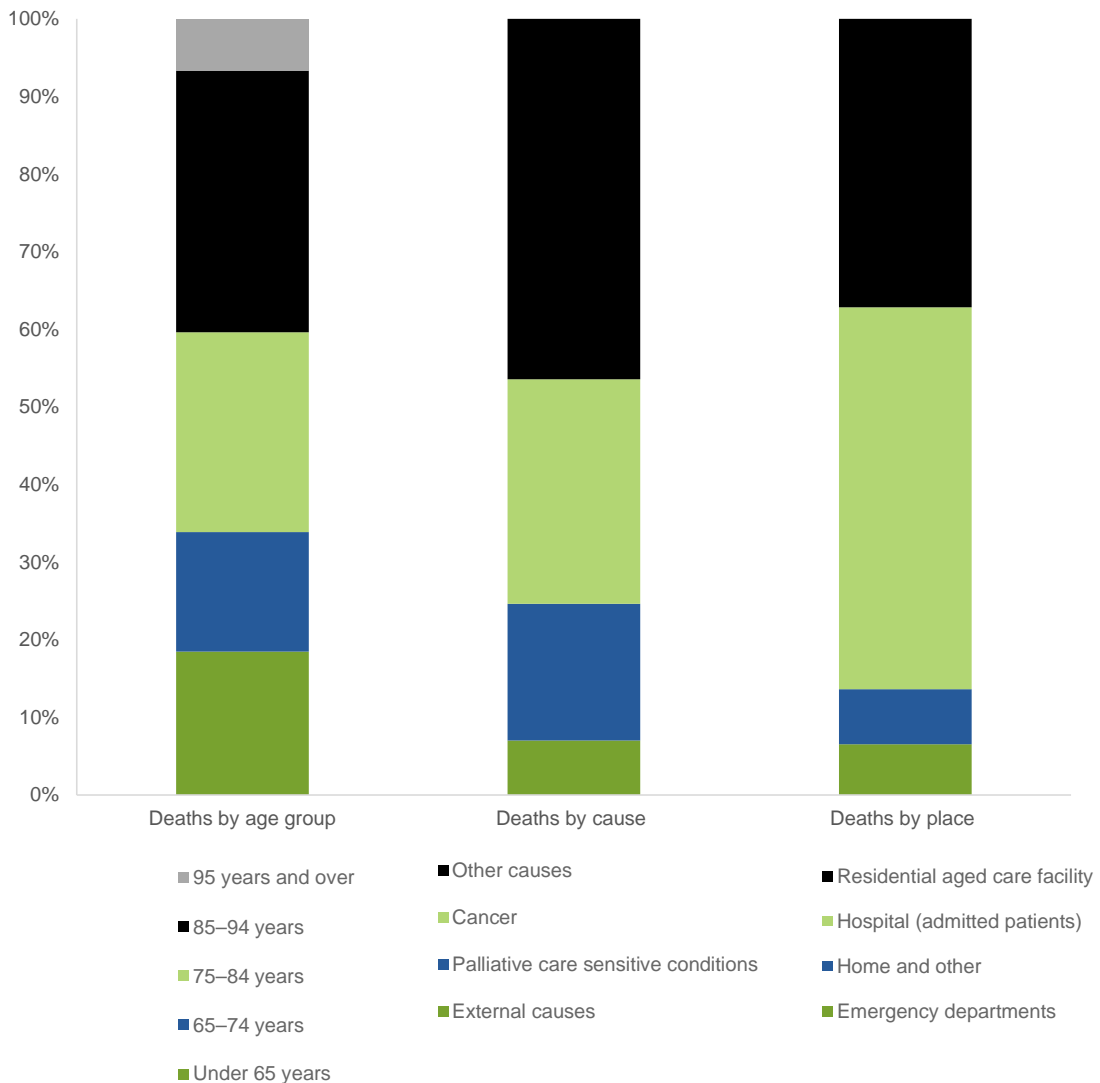
However, these figures do not include those who died in emergency departments. Once deaths in emergency departments are considered, the proportion of people who die at home is smaller than the commonly reported rate, and was likely to have been less than 10 per cent in 2014-15.

Estimates of the proportion of people who could potentially benefit from end-of-life care vary, typically from 50 to 90 per cent of those who die (for example, Murtagh et al. 2013; NHS England 2016; Rosenwax et al. 2005). Given that just under 160 000 people died in Australia in 2015 (ABS 2016a), this suggests that between 80 000 and 140 000 people would benefit from end-of-life care each year.

While there are data on the age, location and cause of deaths in Australia (figure 3.2), these data cannot be put together in such a way as to determine demand for end-of-life care, or the types of care provided in response to that demand. Participants highlighted the poor quality of the available data. For example, Dr Anthony Ireland said the place of death estimates may be inaccurate because the deaths of some residents of aged care facilities who die in hospitals are counted as occurring in both places (sub. DR527). This means that it is not currently

possible to provide an overall picture of the type, amount and quality of end-of-life care Australians receive (AIHW 2016d).

**Figure 3.2 Piecing together end-of-life care needs in Australia**  
Age, location and cause of death, 2015<sup>a</sup>



<sup>a</sup> Palliative care sensitive conditions comprise 11 conditions and diseases used by the Australian Institute of Health and Welfare to identify patients with diseases other than cancer who are likely to require palliative care (AIHW 2012a). Data for place of death are from 2014-15.

Sources: Productivity Commission estimates based on ABS (2016a) and AIHW (2015a, 2016a, 2016l).

What is clear is that demand for end-of-life care is growing, and will increase substantially in coming years. The annual number of deaths will double in Australia in the next 40 years, as a result of the ageing of the population and the progression of the large cohorts born during the post-World War II ‘baby boom’ into the older age groups (ABS 2013b). This will mean

---

that end-of-life care providers will face a ‘tsunami of palliative care admissions ... as our baby boomers move through the system’ (Little Haven Palliative Care, sub. 458, p. 2).

End-of-life care needs are also changing, with a smaller proportion of people dying suddenly and dying from illnesses with a predictable trajectory (such as cancer), and more people experiencing a prolonged period of disability, frailty and illness and then dying ‘with unpredictable timing from a predictably fatal chronic disease’ (such as heart disease, lung disease, frailty and dementia) (ACSQHC 2013, p. 10).

### **3.2 Some end-of-life care is excellent**

Australia’s end-of-life care services, where they are available, are among the best in the world in terms of quality and affordability (EIU 2015). Services are not, however, available everywhere and to everyone who would benefit. This is not unusual internationally and ‘even top-ranked nations currently struggle to provide adequate palliative care services for every citizen’ (EIU 2015, p. 6).

The Australian Commission on Safety and Quality in Health Care provides clear guidance to acute hospitals on end-of-life care through its *National Consensus Statement: Essential Elements for Safe and High-Quality End-of-Life Care* (ACSQHC 2015a). Developed in consultation with health consumers and carers, the consensus statement describes ten elements that are essential for delivering safe and high-quality end-of-life care. When hospitals deliver care that is in line with the consensus statement, that care is typically effective and in line with consumers’ preferences (although this is not always the case, as the actions described by the statement are currently ‘aspirational’ rather than required standards).

In some locations, hospices and community-based palliative care services largely succeed in supporting those who wish to die at home to die at home or in home-like environments. For example, Little Haven Palliative Care said that it supports 60 per cent of its patients to remain at home to die, and a further 24 per cent die with less than five days in hospital (sub. 458, p. 1). Hobart District Nursing Service said that in its hospice@Home service ‘after hours care is available 24/7 through the use of a contact centre, which includes advice, assessment, and possible rapid response deployment of local on-call nursing staff and medical care (via GP Assist) with the aim of avoiding unnecessary admissions to hospital’ (sub. 419, p. 4).

The Royal Australasian College of Physicians suggested that the Silver Chain group in Western Australia has been ‘successful in facilitating the integration of end-of-life care across hospital, hospice and home’ settings (sub. 473, p. 9). Another example of integrated end-of-life care is the authorised palliative care plan system implemented by the New South Wales Ambulance Service. When an authorised plan is in place for a palliative care patient, paramedics are permitted to act in accordance with a patient’s palliative wishes by, for example, administering additional pain medication or withholding resuscitation (NSW ACI 2015).

---

Models of care are also emerging that integrate palliative care and residential aged care. For example, HammondCare operates a 9-bed specialist palliative care unit as part of a 124-place mixed low and high-care home. Known as the Lavender Palliative Care Suite, it:

... enables personalised and flexible care routines, and comprehensively provides for residents' individual physical, psychological, social and spiritual needs [and] demonstrates how specialised palliative care can be delivered within an existing residential aged care setting. (HammondCare, sub. 407, pp. 9–10)

Similarly, the Old Colonists' Association of Victoria said that 'few people leave [our] aged care facility to die, a fact that defies the national trend' (sub. DR501, p. 2). Through its Geriatric Rapid Acute Care Evaluation (GRACE) program, the Hornsby Ku-ring-gai Hospital Service in New South Wales helps residents of local aged care facilities to avoid the physical and emotional disruption of hospital admissions, including by providing advice on palliative care treatment options (NSW ACI 2013).

While there are examples of excellent end-of-life care, its supply is limited and only a small proportion of people who die each year receive it.

- In acute hospitals, the overall momentum of care delivery is toward life extension, and many clinicians regard patient death as their 'failure' or a result of their inadequacy (Bloomer, Moss and Cross 2011). This is appropriate. Nevertheless, patients often rely on clinicians to initiate conversations about end-of-life care, but many clinicians are inadequately trained about, and are intimidated by, holding such conversations (Bartel 2016).
- 'There is not enough palliative care' (Swerissen and Duckett 2014, p. 18) in some locations or for patients with illnesses other than cancer. Palliative Care Australia and the Palliative Care Outcomes Collaboration said that 'the greatest current barrier to patients receiving their preferred care is the availability and quality of palliative care services, including in the primary health sector' (sub. 417, p. 2).
- Not all of those who could benefit from end-of-life care know of its existence, or how to access it. For example, Breast Cancer Network Australia said that 'many people with metastatic breast cancer are not aware that palliative care is something that can support them soon after their diagnosis, assist in the management of pain and other aspects of their treatment and the disease, and enable them to plan ahead for end-of-life care' (sub. DR534, p. 3).

There is also a disconnect between the way in which the health system considers, or aims to consider, end-of-life care (the last 12 months of life) and definitions used in the aged care system (where intensive nursing and other end-of-life care services are only funded by the Australian Government in the last week or days of life). Taken together, these factors can severely limit the options that are available when people come to make choices about their end-of-life care.

---

### **3.3 Too many Australians miss out on high-quality end-of-life care**

In light of the constraints on the supply of the types of care that users would prefer, particularly skilled palliative care at home, in hospices and in residential aged care, it is unsurprising that many people who would benefit from end-of-life care do not get the right care, in the right place, and at the right time. As a report published by the Australian Centre for Health Research put it:

... too many people are dying in a way they wouldn't choose, and too many of their loved ones are left feeling bereaved, guilty, and uncertain. The care most Australians receive at the end of life often does not reflect their values, goals, or informed choices. (Bartel 2016, p. 4)

There is scope for improvement in end-of-life care in all settings (including hospitals, community-based palliative care services and residential aged care facilities), and in the integration of care between settings.

#### **Treatment in acute hospitals is not always in line with the preferences of dying patients**

Acute hospitals are, by definition, designed to provide acute care, and the doctors who work in hospitals find it much easier to continue active treatment rather than make a decision to stop (ACSQHC 2013). This has led to hospitals being likened to a 'conveyor belt' (Hillman and Cardona-Morrell 2015, p. 1701) or an 'express train that only goes in one direction ... where a patient once admitted receives a "chain reaction" of interventions' (Willmott et al. 2016, p. 500).

Once they are in hospital, patients approaching the end of life, and their families and carers, can find it hard to understand whether or not hospital is the best place for them and, if they would prefer to forgo certain medical interventions, can find it hard to express those preferences. This inhibits user choice and can lead to poorer care. As Aged & Community Services Australia put it:

With their focus on curative treatment, acute hospitals are often not ideal places for providing appropriate end-of-life care that promotes comfort and quality of life. (sub. 411, p. 4)

Systemic issues in acute care at the end of life include uncertainty of prognosis, delayed recognition of dying by clinicians (especially junior clinicians), poor communication with patients, families and community care providers, and the focus of specialist clinicians on the organ or disease group of their specialty (which can come at the cost of holistic assessment and management of end-of-life care needs) (ACSQHC 2013, pp. 24–25). In addition, the Centre for Health Economics Research and Evaluation (CHERE) at the University of Technology Sydney expressed concern about 'the high number of hospital staff who are not aware of, or properly respect, patients' wishes as expressed in [advance care] directives' (sub. DR516, p. 4).



---

Admission to hospital can be particularly difficult and risky for people with dementia as they ‘face numerous hazards during their stay in hospital and often experience adverse outcomes, including physical and cognitive functional decline, under-nutrition, skin tears and fall-related injuries’ (AIHW 2013a, p. 1). In addition:

People with dementia are frequently not recognised to be dying, and are admitted to acute hospitals in the final few days or weeks of life for the treatment of conditions such as pneumonia or urinary tract infection. This is despite evidence to suggest that acute hospital admission can be detrimental to people with dementia and stressful for their carers (Hennings, Froggatt and Keady 2010, p. 114).

Not all hospitals have formal systems in place to help identify people approaching the end of life. For example, in New South Wales, only 61 per cent of clinical units in local health districts said that they routinely identify patients who are likely to die in the next 6 to 12 months so that end-of-life planning can begin (CEC 2013, p. 7). This leads to a situation where ‘almost two-thirds of terminally ill people for whom home or hospice palliative care would be appropriate die in hospital, often receiving heroic interventions’ (Scott 2014, p. 127). A recent study of Department of Veterans’ Affairs clients aged over 70 years confirms this — only one-third of those who died in hospital received palliative care during the admission in which they died (Ireland 2017).

Even for those who receive palliative care in hospital, such care often comes too late. For example in Victoria, close to two thirds of patients with metastatic lung cancer were engaged with palliative care services at the time of death, but about a quarter of those were referred to those services in the hospital admission during which they died (Philip et al. 2015).

There is also evidence that many of the people who are approaching the end of life in acute hospitals receive non-beneficial treatments (Cardona-Morrell et al. 2016) or undergo tests and scans that do not have a clear effect on care (Clark et al. 2014). While some of these tests and treatments may be sought by patients, this may reflect unrealistic expectations about the likelihood of success of medical interventions such as cardiopulmonary resuscitation (ACSQHC 2013, pp. 12–13).

Indeed, a high degree of medical intervention may have an adverse effect on the quality of care at the end of life. Intensive care physicians are often among those who express concern about the quality of some deaths in hospital. For example, an intensive care consultant told the Australian Commission on Safety and Quality in Health Care that:

To answer your question very directly, you asked ‘Do people die well in this hospital?’ They absolutely do not. People are allowed to linger for far too long, in far too much pain, and causing far too much distress to themselves and their family and the people who care for them ... The current situation, to speak frankly, is completely unacceptable. (ACSQHC 2013, p. 8)

Non-beneficial or unwanted treatments performed near the end of life are often conceptualised as something that occurs in intensive care units (ICUs). Yet only a minority of people are admitted to an ICU at the end of life. In New South Wales, 12 per cent of those who died spent time in an ICU in their last year of life (Goldsbury et al. 2015, p. 7). Similar

---

results were found in South Australia, where the Health Performance Council of South Australia found that 13 per cent of people who died were admitted to an ICU at some stage in the twelve months prior to their deaths, and that a minority (17 per cent of ICU patients, or 2 per cent of total patients) were identified as palliative in the twelve months prior to their death yet spent time in an ICU (HPC 2013).

Many patients would benefit from, and would choose, conservative disease management and support (such as outpatient programs to manage chronic heart or kidney failure) instead of, or in conjunction with, acute care as they approach the end of life. However, those who would benefit are not assured of access to such care. For example, only half of chronic heart failure disease management programs have secured long-term funding (Scott and Jackson 2013). Indeed, the very success of supportive care and disease management approaches in helping people with progressive illnesses to manage their conditions and avoid hospitalisation can be a barrier to obtaining ongoing funding. If such programs are successful in keeping people in relatively good health in the community for longer, they can no longer claim to be treating people who would otherwise be in hospital, and so may lose funding (PC 2017d).

## **End-of-life care is not always available**

Often, people who would benefit from certain types of end-of-life care — such as specialist palliative care or support to die at home — miss out. Many, perhaps tens of thousands of, people cannot access desired support to die in their own home and die in hospital instead. For example, the Victorian Auditor-General found that:

Demand for home-based care is increasing and some metropolitan community palliative care services have struggled to meet this demand, resulting in waiting lists to access services. This can place additional stress on patients and carers, and can mean that some people who have chosen to die at home cannot spend their last days there. (VAGO 2015, p. vii)

Others would prefer to be cared for at home, but are unable to die there, even with support. Dr Anthony Ireland said that:

... mounting needs for symptom control, increasing physical dependency, resultant carer distress or unexpected acute medical events not uncommonly occur in patients who are approaching death. These often overwhelm the capacity of families and community-based care providers. Hospital (or preferably hospice) is often a welcome haven for patient and carers in such situations. (sub. DR527, p. 2)

Yet too often, hospice care is not an option, either because there is no hospice in the area or because there are no available places. For example, Sandra Coburn said, in relation to her father's death, that the support offered by the hospice was 'largely illusory', as the relevant hospice 'had very limited beds (15 at that stage) and could only keep people for a limited period. My father was not yet close enough to death to qualify, despite only having a predicted 4–6 weeks to live' (sub. DR558, p. 2).

---

At the national level, the Institute for Healthcare Transformation at Deakin University said ‘access to care is largely determined by age, diagnosis and geography rather than individual need’ (sub. DR587, p. 4). The Australian Health and Hospitals Association considered that:

Palliative care services have not been broadly embedded into the health system and are fragmented, with varying access and capacity across the country, depending on diagnosis, age, cultural background, geographical location, available resources and clinician knowledge. (AHHA, sub. 427, p. 10)

One indicator of this variation is that family members of those who died under the care of an in-home palliative care service consider themselves among the lucky few (McMillen 2017), while another is concern about poor end-of-life care services in rural areas (box 3.2).

### **Box 3.2 End-of-life care in rural areas**

There is limited evidence about the quality and accessibility of end-of-life care in rural areas, and the way in which this care compares to that available in urban areas. It is clear there is a strongly increased chance of dying in hospital in remote and very remote regions. This could, in part, be due to aged care facilities being located in hospitals in some country areas (HPC 2013).

Several participants told the Commission that Australians living in rural areas have limited access to, and choice about, the end-of-life care services they receive. For example, HammondCare said:

... services are inadequate in many rural and remote areas of Australia and the provision of around-the-clock services is also limited. Rural areas also have poorer access to specialist palliative care services which results in a greater reliance on general practitioners and community nurses, especially after hours, many of whom are not appropriately trained in the provision of palliative care. (sub. 407, p. 3)

Further, ‘those living in rural and remote areas are likely to find it much more difficult to access specialised palliative care services’ (CHA, sub. 440, p. 5), with 85 per cent of specialist palliative medicine physicians working in major cities (AIHW 2016k).

There can also be some advantages to receiving palliative care in a small rural hospital, as it can become an extension of the sense of community fostered in rural areas (Urbis 2016a).

It is also less than ideal that the number of community-based palliative care providers across Australia is not known with certainty. The best measure is the number of community-based palliative care services that contribute data to the Palliative Care Outcomes Collaboration — there are 36 of these throughout Australia (Connolly et al. 2016) (though Palliative Care Australia has a directory that currently lists about 200 community-based palliative care providers (PCA 2017b)).

Another indicator of the room to improve end-of-life care is that many Australians who would prefer to die at home do not have their preference fulfilled (box 3.1). COTA said:

It is really a very poor thing for a country like ours that so many people are unable to die in the place and in the kind of context that they would want to. (trans., p. 325)

---

Australia is not alone in apparently having rates of dying at home that are much lower than people say they want. In 2011, 65 per cent of deaths in Canada occurred in acute care hospitals, even though many Canadians (63 per cent according to an Ontario survey) express a preference to die at home (Costa et al. 2016, p. 2).

Some community-based palliative care providers report that government funding covers a relatively small proportion of their costs. For example, Little Haven Palliative Care said that 35 per cent of its annual budget (\$256 000) is covered by Queensland Government funding (sub. 458, p. 1). (The remainder is covered by fundraising, bequests and donations (Little Haven Palliative Care, sub. 458, att. 2, p. 8)).

Access to both inpatient and outpatient palliative care services is lower among certain groups, including Indigenous Australians (box 3.3), people from culturally and linguistically diverse backgrounds, and people with disabilities (HCSC 2013; LSIC 2016; NSW ACI 2014; SCARC 2012; Urbis 2016a). While people with illnesses other than cancer have many of the same end-of-life care needs as those with cancer (Moens et al. 2014), they are commonly under-represented among those receiving specialist palliative care (Currow et al. 2008; LSIC 2016).

### **Box 3.3 End-of-life care for Indigenous Australians**

Inquiry participants told the Commission that enabling Indigenous Australians to ‘spend their twilight years in their ancestral lands’ (National Congress of Australia’s First People, sub. DR565, p. 7) is a vital, but too often overlooked, element of high-quality end-of-life care. Elaborating on this, the National Congress of Australia’s First People said:

... many of our peoples unfortunately have to pass away in environments alien to them, often associated with the engrained historical trauma, and not sensitive to cultural dignity otherwise received in the lands of their respective peoples ... this perpetuates a vicious cycle of separation from one’s ancestral land, and rootlessness that afflicts a sizable proportion of our peoples. (sub. DR565, p. 8)

Similarly, the Cancer Council NSW (sub. DR537) expressed concern about poor access to end-of-life care for Australians living in remote Indigenous communities. Palliative Care Australia (sub. DR500) noted that place of death is culturally and spiritually significant for many Aboriginal and Torres Strait Islander peoples, and that many feel a need to ‘return to country’ at the end of their lives.

## **Residential aged care services often struggle to meet end-of-life care needs**

Residential aged care is transforming into an end-of-life care service

The aged care system includes a range of different services, many of which are designed to help older Australians live independently in their own home. As people approach the end of

---

life, their care needs increase and many move to a residential aged care facility (RACF).<sup>2</sup> This is usually a permanent move — just over 80 per cent of permanent RACF residents die there (about 60 000 people per year) (AIHW 2017g).

Residential aged care is increasingly provided to people who are older and who have higher care needs. Between 2012 and 2015, the proportion of RACF residents who were assessed as having high care needs across all three care domains (activities of daily living, behaviour and complex health care) rose from 18 per cent to 27 per cent (an increase of just over 15 000 people) (AIHW 2012b, 2015d). Based on current trends, residential aged care is transforming into an end-of-life care service (PC 2015c). BaptistCare Australia and Churches Housing remarked on this, noting that:

The trend for residents to arrive closer to the end of life, with much more complex health and behavioural needs, has been so rapid and marked that there is now discussion about whether residential aged care facilities more closely resemble a ‘hospice’ than a ‘home’. (sub. DR532, p. 4)

### End-of-life care in residential aged care facilities is often inadequate

While the care provided in some RACFs is excellent (section 3.2), participants told the Commission that palliative and end-of-life care are poorly provided in many facilities. This situation is not helped by current policy settings which do not provide the incentives needed to ensure quality care is available to all of those who would benefit from it.

Both Alzheimer’s Australia (2017, p. 11) and Palliative Care Australia (PCA 2016a, p. 3) expressed concern about unmanaged severe pain in RACFs. BaptistCare Australia and Churches Housing (sub. DR532) said that in a rural BaptistCare facility without 24-hour nurse cover, residents who require certain medications after hours must wait while the on-call nurse drives for 30 minutes on country roads to attend to them.

Christy Pirone, Margaret Brown, Dr Chris Moy and Dr Christine Drummond said that:

The number of transfers [from residential aged care] to the acute hospitals because of inadequate staffing and access to appropriate care can be considered to be a failure in our system of care at the end of life. Those who die when old, have equal rights to be cared for with dignity and respect. (sub. DR559, p. 3)

Palliative Care Australia members reported ‘an inability for some [aged care] services to provide palliative care at the end of life, particularly if the person dying has complex symptoms’ (PCA 2016a, p. 6). This can lead to RACFs being ‘reluctant to accept clients who are dying, despite the fact that there is no clinical need for them to remain in an acute setting’ (NSW Ministry of Health 2016a, p. 7).

---

<sup>2</sup> In this inquiry, the Commission has focused its consideration of aged care on residential aged care. While aged care home care services may occasionally be sole providers of end-of-life care, the Commission was unable to obtain data to suggest that this occurs in anything but a handful of cases.

---

The evaluation of the National Palliative Care Strategy quoted a service manager who said that end-of-life care in aged care is:

... dire with few [registered nurses] being employed in aged care facilities, high turnover of staff, lack of skilled staff and lack of awareness of dying and palliative care needs. People enter aged care facilities now with little time left to live (3–6 months in many cases) and yet the staff are not skilled in palliative care and round the clock pain medication cannot be given as there are no [registered nurses] available. (Urbis 2016a, p. 31)

Alzheimer's Australia (sub. DR521) said that staff working in RACFs need additional training in palliative care, while the Royal Australasian College of Physicians (sub. DR580) considered that palliative care in RACFs may lack input from medical practitioners.

Palliative Care Australia said that in RACFs, the 'structure and staff mix is heavily weighted in the lower paid unregulated staff (PCAs) [personal care assistants] with inadequate levels of qualified healthcare staff especially outside standard business hours' (PCA 2016b, p. 6). People who are approaching the end of life are transferred to acute hospitals for pain management because these staff do not have the skills to lead and coordinate end-of-life care for residents. In 2008-09 about 9600 permanent residents of RACFs died in hospital (AIHW 2013b). More recent data are not available.

Recognition of the particular end-of-life care needs of people with dementia, who comprise about two-thirds of those in residential aged care, was an area of particular concern (Alzheimer's Australia, sub. 431; Davis et al. 2009; SCARC 2012). Likewise, Allied Health Professions Australia expressed concern that the exclusion of residents of aged care facilities from eligibility for Medicare-funded mental health and chronic disease management programs can severely limit residents' access to allied and mental health care (sub. DR496).

Participants also told the Commission that some community members can find it hard to access end-of-life care in aged care, with the Federation of Ethnic Communities' Councils of Australia saying:

... culturally appropriate care under the current home and residential care for older people from CALD [culturally and linguistically diverse] backgrounds is scarce or inadequate ... Many people from CALD communities are not aware of the palliative care supports available to them and do not plan the end of life needs. (FECCA, sub. 433, p. 3)

The Combined Pensioners and Superannuants Association said that 'the information available to clients through the audit reports of the Australian Aged Care Quality Agency does not provide much insight into the way palliative care is actually delivered and what clients can expect' (sub. DR542, p. 3).

Another constraint on access to aged care is the current system of accreditation and approvals of aged care providers and the allocation of bed licences. In some cases, restrictions on the number of aged care places and their locations limit consumers' ability to choose RACFs that best suit their end-of-life care needs. Aged care reforms are moving toward providing users with greater choice over the services they receive, and a move toward a fully demand-driven system of residential aged care has been signalled by the relevant Australian

---

Government committee, but the timeline remains uncertain (Aged Care Sector Committee 2016).

### Assessment and funding systems do not take proper account of palliative care needs

The Australian Government is primarily responsible for regulating, and providing public funding for, aged care services. This includes end-of-life care provided to the approximately 60 000 people who die in RACFs each year.

Many participants told the Commission that the funding arrangements have adverse effects on end-of-life care in RACFs (box 3.4). For example, Leading Age Services Australia said that the current funding system ‘certainly does not encourage nor support end-of-life care and services to the resident, let alone the family and others’ and that there is ‘a disconnect between the funding provided for care and the actual care people receive in residential aged care’ (sub. 463, p. 7). Indeed, only one in six people who died in residential aged care received funding for palliative care (AIHW 2016j).

In light of these concerns, reforms are needed to ensure that people residing in residential aged care receive end-of-life care that aligns with the quality of care available to other Australians.

### **Few Australians make plans for their end-of-life care in advance**

Many people will be unable to communicate their wishes for end-of-life care at the time the care is provided. Consequently, to have a real choice in the care they receive, people must communicate their wishes in advance, ideally by preparing and maintaining a high-quality advance care plan (ACP) (box 3.5).

Governments, hospitals and non-government organisations have made efforts to promote advance care planning, as it has many demonstrated individual and societal benefits, including increased likelihood that patients will receive medical treatment in accordance with their wishes and die in their place of choice, reduced burden on substitute decision makers, and a reduction in the practise of defensive medicine (where doctors engage in costly, active treatment that patients may not want) (Detering et al. 2010; Respecting Patient Choices Program 2012).

Despite these efforts, relatively few people have an ACP. A national telephone survey conducted in 2012 found that only 14 per cent of Australians had an ACP (White et al. 2014). In a separate study of people aged over 65 years presenting to emergency departments, 13 per cent had ACPs (Street et al. 2015).

---

**Box 3.4 Limits on Australian Government funding for end-of-life care in residential aged care**

The Australian Government's Aged Care Funding Instrument (ACFI) is used to assess the care needs of those living in residential aged care. ACFI assessment involves determining whether the resident has low, medium or high care needs across three care domains (activities of daily living, behaviour and complex health care). Funding in each of these domains is categorised as either high, medium, low or nil.

**Time limits on palliative care**

The ACFI specifies that funding specifically for palliative care is only allowable 'in the last week or days' of a resident's life. This limit is strictly adhered to in Australian Government decisions, which has pursued Administrative Appeals Tribunal cases against aged care facilities that sought funding to provide palliative care for too long (for example, Southern Cross Care [2014] AATA 623).

In addition, the ACFI specifies that funding specifically for palliative care requires a directive from a medical practitioner or specialist nurse, as well as completion of a pain assessment. LASA said that 'the required directive is difficult to obtain for providers. As ACFI funding for palliation is provided for a short period only the effort to obtain the directive required exceeds the benefit gained for the resident' (sub. DR512, p. 6).

**The 'high' funding ceiling**

Not only does the ACFI severely restrict the duration of palliative care, ACFI funding for palliative care is not available to all residents — if a resident is already receiving 'high' funding for an ACFI domain, no additional funding is made available if their care needs in that domain increase further. The AIHW reported that in 2014-15 more than 50 per cent of residents of RACFs received 'high' level funding for their health care (AIHW 2016b). This means that no additional funding is available for palliative care (or any other additional health-care needs) for more than half the residents of aged care facilities as they approach the end of life.

The Commission considers that there are several reasons for the continued low uptake of ACPs.

- People are often reluctant to contemplate their own frailty or mortality. Others may simply prefer to live 'one day at a time' and, provided the person has sufficient information and understanding about what an ACP entails, this wish should be respected (Rietjens, Korfage and Heide 2016, p. 421).
- To the extent that people are aware that there is not enough community-based palliative care, this may reduce their motivation to prepare an ACP. As Little Haven Palliative Care said 'in the absence of access to quality end-of-life care in many communities, advanced care wishes, if they include remaining at home to die, may be irrelevant' (sub. DR579, p. 2).
- Advance care planning conversations, particularly those that are necessary to develop high-quality ACPs, take time. Clinicians and patients (and their families) usually require several sessions to discuss all the relevant issues, often over a period of weeks



---

(HammondCare, sub. 407; Scott et al. 2013). Clinicians can struggle to find the time to have these conversations in busy hospital or general practice environments.

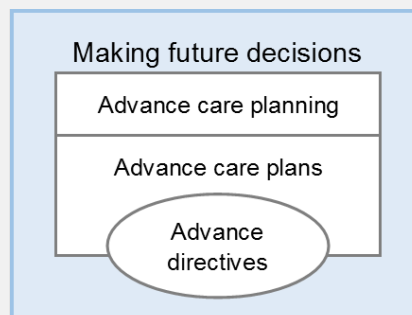
- Many clinicians also feel unprepared to talk about dying, and few have the training or confidence to initiate conversations with their patients about end-of-life care. Even among health professionals working in palliative care services, who would be expected to be best placed to comfortably discuss end-of-life care, about 30 per cent feel unconfident or only somewhat confident in initiating ACP discussions and answering patient and family questions about an ACP (Sellars et al. 2015).

Taken together, these factors suggest that it will never be possible or desirable for everyone to have an ACP. As it stands, however, many people approach the end of life unable to speak for themselves and without a plan in place to guide their care.

### Box 3.5      **Advance care planning: some definitions**

#### **What is an advance care plan?**

An advance care plan (ACP) outlines a person's preferences regarding medical treatment or goals of care in the event they are unable to communicate this themselves at the time that care is provided. ACPs are one component of a wider planning process, as illustrated below.



An ACP often (though not always) includes an advance directive (see below). Other possible components include a letter to the person who will be responsible for this decision making, an entry in the patient medical record, a spoken instruction or other communication which clearly enunciates a patient's view, or any combination of these (Department of Health 2012).

#### **What makes an ACP 'high quality'?**

To be 'high quality', an ACP must fully reflect the patient's wishes and also be useful to clinicians in guiding care decisions. Rather than a stand-alone document, a high-quality ACP reflects a high-quality planning process, including an ongoing conversation between the patient, family or carers and a trained clinician, and regular reviews and updates (Scott et al. 2013). Well-maintained, high-quality ACPs have been shown to increase compliance with patients' end-of-life wishes and to improve family members' perceptions of the quality of their loved one's death (Detering et al. 2010).

#### **What is an advance directive?**

An advance directive (sometimes advance care directive) is an ACP that has been formally recorded, according to its legal status under common law or state legislation (PCA 2012).

*Sources:* ACPA (2017); Brinkman-Stoppelenburg et al. (2014); Street and Ottmann (2006).

---

## Not enough is known about end-of-life care

Several inquiry participants (including COTA Australia, sub. 456; Queensland Nurses' Union, sub. 405) pointed out a need for more rigorous transparency and accountability for both service providers and commissioning bodies working in end-of-life care. CHERE said that:

Data is urgently needed, not only to allow for the appropriate measurement of place of care at the end-of-life and place of death, but also to allow for the accurate measurement of health care costs. (sub. 516, p. 4)

Little Company of Mary Health Care considered that:

The current absence of comprehensive population based data biases policy and funding decisions towards those problems which are visible through the acute hospital lens. (sub. DR547, p. 9)

The Health Performance Council of SA said that:

... more performance information about quality, access, equity and health outcomes of ... end-of-life care services, aged care services and primary care should be transparent and in the public domain. (sub. 437, p. 6)

Such performance data are a fundamental starting point for improving the delivery of those activities to the community (PC 2017a). As Aged Care Crisis said:

Data is essential for managing facilities, for government, local community and provider policy, for consumer and community information, for public discourse, for the market to work, and to anchor regulatory effort to what is happening in the facilities and the sector. (sub. DR525, app. 2, p. 33)

Yet current data and information relating to end-of-life care in Australia are 'fragmented and incomplete' (AIHW, sub. DR508, p. 4), and there are significant gaps in even the most basic administrative data about end-of-life care. In some cases, this is because the information is simply not recorded — for example, the number of days that residents of RACFs spend in hospital (each year, or in their last year of life) is not counted.

Other data are collected but are not linked or made available in an affordable, accessible format. For example, information on the age, location and cause of deaths in Australia is available but the linking of these datasets is not routinely carried out, and the process for obtaining linked datasets is complex, lengthy and expensive (PC 2017a, p. 509). Consequently, these details cannot be put together in such a way as to provide an overall picture of the type, amount and quality of end-of-life care Australians receive (AIHW 2016d).

---

### **3.4 Poor stewardship is hindering better end-of-life care**

While the quality of end-of-life care services in Australia is often excellent, they perform less well on equity considerations, as too many people approaching the end of life end up with little real choice about the care they receive. Similarly, while some services are effective, offering only hospital services to many people who would prefer to be, and could be, well cared for at home, reduces the overall effectiveness of end-of-life care in Australia. It also means that end-of-life care services are not as responsive as they should be to users' needs and choices.

Poor stewardship by governments is a major barrier to the delivery of better end-of-life care in Australia. Inadequate planning, overlapping and uncertain funding and other responsibilities between different levels of government, and limited use of data to monitor and improve services, are all impediments to change.

The significant shortfall in the availability of end-of-life care in settings where people would prefer to receive it — in the community and in RACFs — is the result of poor planning and allocation of resources by governments. This has led to a high proportion of people receiving care (and dying) in hospital, which is often the setting that they least prefer and is the most costly for taxpayers. Investing in end-of-life care in the community and in aged care facilities would avoid this.

To achieve better planning and resource allocation, there will need to be greater collaboration between the Australian, State and Territory Governments. As noted in section 3.1, there is currently overlap in the roles of the different levels of government, which has led to uncertainty and buck passing over how stewardship is shared and service provision is coordinated across different settings.

The problems resulting from the lack of cross-jurisdiction co-operation have been particularly evident for residents of aged care facilities. They may miss out on specialist palliative care because it is unclear whether it is the Australian Government's responsibility as steward of the aged care system, or the role of State and Territory Governments as providers of specialist palliative care.

- The Australian Government rarely acknowledges that providing end-of-life care is (or should be) core business for residential aged care and has, for many years, failed to ensure that residential aged care providers receive sufficient funding for delivering palliative care (box 3.4).
- State and Territory Governments can be reluctant to fund palliative care for people aged over 65 years who, by virtue of their age, could also be eligible for aged care funded by the Australian Government. Some State and Territory Governments have end-of-life and palliative care policies that omit the needs of those in aged care, or focus only on specialist palliative care (ignoring the end-of-life care needs of frail elderly people who do not require specialist care).

---

More generally, there needs to be better coordination of end-of-life care between residential aged care, community-based palliative care, hospitals and primary care. This will require stronger collaboration between governments on identifying and delivering coordinated end-of-life care across all settings.

While there has been some useful cross-jurisdiction co-operation on very specific issues — such as developing guidelines on end-of-life care for adults in acute hospitals (ACSQHC 2015a) — broader attempts at collaboration have lacked substance and been ineffective. For example, since 2000, there has been a National Palliative Care Strategy endorsed by all jurisdictions but a recent evaluation found that its goals were unclear and it has not delivered any improvements in care (box 3.6).

### **Box 3.6      The National Palliative Care Strategy**

Australia has had a National Palliative Care Strategy since 2000, with the current version published in 2010. The strategy is endorsed by the Australian Health Ministers' Advisory Council (the secretaries of the Australian, State and Territory Departments of Health). Its overarching objective is that all Australians with a life-limiting illness live well until the end of life.

A recent evaluation of the 2010 strategy found that it is not clear what it is seeking to achieve and how achievements can be demonstrated, and so it 'has not been effective in aligning state, territory and Commonwealth planning and policies' (Urbis 2016a, p. 43). As Palliative Care Australia put it, 'it was a strategy that sat on a shelf since 2010 with no KPIs, no monitoring, no evaluation' (trans., pp. 118–9).

The evaluation also highlighted the value placed on national governance structures to improve collaboration and accountability, and recommended that 'an action or implementation plan should be developed to guide implementation of the Strategy going forward, with identified objectives, actions, responsibilities, and indicators' (Urbis 2016a, p. 44).

An updated National Palliative Care Strategy is being prepared, a draft of which was released for public consultation in August 2017. Plans for implementing, monitoring and evaluating the updated strategy are still being developed.

*Sources:* Australian Government (2010); Urbis (2016a, 2017).

Poor stewardship is also evident in the failure of governments to address major gaps in the collection and publication of information on end-of-life care. Without such information, the stewardship functions of governments to plan, monitor and improve service provision are significantly constrained. State and Territory Government end-of-life and palliative care policies and plans often contain few tangible measures or goals for ensuring that all of the people who would benefit from palliative care receive it. Among other things, this weakens consumer protection and limits accountability.

---

## 4 Reforms to end-of-life care

### Key points

- The Australian, State and Territory Governments should work together so that Australians can access end-of-life care that better matches their preferences. This will require governments to put greater focus on providing end-of-life care in the place where a person lives.
- A significant increase in the availability of community-based palliative care is required. To achieve this, State and Territory Governments should:
  - assess the need for additional services, select providers (typically using competitive processes) and adequately fund those providers
  - establish standards for community-based palliative care services and fund the delivery of those services for people who wish to and are able to die at home. The standards should include integrated and coordinated nursing, medical and personal care
  - ensure that monitoring frameworks and consumer safeguards are in place so that quality care is provided, and oversight is maintained, as the volume of services provided increases.
- Available evidence indicates that the savings from avoiding a single hospital admission for palliative care (costing about \$11 000) would more than cover the cost of providing community-based care over a period of months (costing between \$6000 to \$10 000).
- People living in residential aged care facilities should receive end-of-life care that aligns with the quality of that available to other Australians. Delivering this will require the Australian Government to:
  - remove current restrictions on the duration and availability of palliative care funding in residential aged care, so that clinical care is available to all residents at the end of life
  - fund this additional care
  - ensure that clinically trained staff hold timely conversations with aged care residents about their future care needs and preferences, and support residents to prepare an advance care plan if they wish to do so.
- General practitioners and practice nurses could play a much larger role in helping people to articulate their preferences for end-of-life care through advance care planning. Changes to Medicare item numbers are needed to enable this.
- The effectiveness of the above reforms will depend on governments implementing broader improvements to their stewardship of end-of-life care. This should involve the Australian, State and Territory Governments, through the COAG Health Council:
  - co-operating to plan, fund, and set standards for end-of-life care so that patients receive high-quality care in each setting and in each jurisdiction
  - developing and implementing an end-of-life care data strategy that establishes a national minimum data set for end-of-life care, and improves the accessibility and use of data
  - commissioning an independent review in 2025 of the effectiveness of end-of-life care across all settings in which it is, or should be, provided.

---

A comprehensive approach to end-of-life care recognises that the patient and clinicians are both essential participants in discussions and decision making about care needs at the end of life. End-of-life care is provided in the community, residential aged care facilities (RACFs) and hospitals. Stewardship is spread between different levels of government. A stronger focus is needed on care that responds to each patient's choices, values and preferences, given the realities of the patient's clinical condition and treatment options. This requires greater coordination of care between settings. It will also require a coordinated response and ongoing stewardship from health authorities at all levels of government.

The Commission is recommending a number of reforms to put users' needs and choices at the heart of end-of-life care services (table 4.1).

The reforms have been designed to be implemented as a package to increase their effectiveness and to ease the transition. In particular, improving end-of-life care in the community and residential aged care facilities could reduce demand for some hospital services because more people nearing the end of their lives would have an alternative to visiting hospital. Ultimately, though, potential longer-term savings should not be the primary driver of reforms to increase access to high-quality end-of-life care.

As noted in chapter 3, most end-of-life care is provided by government-funded services, and these services are the sole focus of this report. However, people approaching the end of life can also purchase additional services if they wish.

## **4.1 Improving acute care at the end of life**

Most Australians currently die in hospital, and many receive end-of-life diagnoses or referrals to community-based palliative care services while in hospitals or outpatient clinics. Hospitals therefore play a critical role in the delivery of quality end-of-life care. Reform is needed to address the many systemic issues that can make it difficult for hospital staff to deliver good end-of-life care (chapter 3).

### **New standards to improve end-of-life care in acute hospitals**

Efforts to improve the way in which patients approaching the end of life are supported in acute hospitals are already underway as part of ongoing revision of the National Safety and Quality Health Service (NSQHS) Standards. Hospitals must meet the NSQHS Standards in order to obtain and retain accreditation. Version 2 of the NSQHS Standards, which will be implemented in 2019, will require hospitals to meet the elements of the *National Consensus Statement: Essential Elements for Safe and High-Quality End-of-Life Care* (ACSQHC 2017). As noted in chapter 3, the consensus statement describes ten elements that are essential for delivering safe and high-quality end-of-life care, with a focus on patient-centred communication and shared decision making, and the organisational prerequisites necessary for delivering patient-centred care.

**Table 4.1 Overview of proposed reforms to end-of-life care**

<i>Proposed reforms</i>	<i>Timeframe</i>	<i>Potential costs and benefits</i>
<b>Community-based palliative care</b>		
<p><b>Recommendation 4.1</b> State and Territory Governments to increase the availability of community-based palliative care so that people with a preference to die at home can access support to do so.</p>	<p>Assess needs as soon as practicable. Implementation timeframe depends on assessed needs.</p>	<p>Community-based palliative care could cost less than its hospital equivalent. Patients would be able to access community-based palliative care that supports them to die at home if they choose.</p>
<b>End-of-life care in residential aged care</b>		
<p><b>Recommendation 4.2</b> The Australian Government to remove current restrictions on the availability and duration of funding for palliative care in residential aged care, and provide sufficient additional funding so that people living in residential aged care receive end-of-life care that aligns with the quality of that available to other Australians.</p>	<p>As soon as practicable.</p>	<p>Costs would depend on the extent of unmet need, which is currently unknown. Residents of residential aged care facilities would receive end-of-life care that aligns with the quality of that available to other Australians.</p>
<b>Advance care planning</b>		
<p><b>Recommendation 4.3</b> The Australian Government to:</p> <ul style="list-style-type: none"> <li>include initiating an advance care planning conversation as one of the actions that must be undertaken to claim the '75 plus' health check Medicare item numbers</li> <li>introduce a new Medicare item number to enable practice nurses to facilitate advance care planning.</li> </ul>	<p>As soon as practicable.</p>	<p>There would be extra demand on general practitioners' time, but enabling practice nurses to assist would reduce this. More people would prepare advance care plans and receive care that matches their end-of-life care preferences even if they were unable to communicate those preferences.</p>
<p><b>Recommendation 4.4</b> The Australian Government to include the facilitation of ongoing conversations about advance care planning in the aged care Quality of Care Principles.</p>	<p>As soon as practicable.</p>	<p>Residential aged care facilities would spend time ensuring that the choices of residents and their families guide their end-of-life care.</p>
<b>Improving stewardship of end-of-life care</b>		
<p><b>Recommendation 4.5</b> The Australian, State and Territory Governments to co-operate to:</p> <ul style="list-style-type: none"> <li>plan, fund, deliver and set standards for end-of-life care across different settings and jurisdictions</li> <li>develop and implement a strategy for end-of-life care data, including developing a national minimum data set for end-of-life care</li> <li>review the effectiveness of end-of-life care across all settings.</li> </ul>	<p>Enhance cross-jurisdiction co-operation and develop data strategy as soon as practicable. Review in 2025.</p>	<p>Cost of negotiating and implementing cross-jurisdiction arrangements, such as consistent data collection. Improvements to efficiency resulting from better co-operation and better data would contribute to a reduction in costs.</p>

---

## **Implementation of the new end-of-life care standards in hospitals**

One notable element of the consensus statement is a requirement to use triggers to recognise patients approaching the end of life (people who are likely to die within the next 12 months — chapter 3). Many hospitals across Australia are already using triggers to identify these patients, but others are yet to do so.

### **Training clinicians to talk about end-of-life care with patients**

Triggers will only be effective if they prompt clinicians to initiate conversations about the end of life, and thereby enable patients to have timely and ongoing discussions about their end-of-life care with their clinicians, families and carers. Individual clinicians may have to overcome barriers to these discussions. For example, clinicians often fear causing distress or damaging hope. There is, however, evidence that this reluctance can be reduced through targeted training (box 4.1).

### **Focusing on the needs and preferences of individual patients**

It is important that efforts to systematically identify patients who are approaching the end of life, and to equip clinicians to hold conversations about end-of-life care with them, do not become ‘tick and flick’ exercises. The experience in the United Kingdom with the Liverpool Care Pathway (box 4.2) highlights the risk that the approaches used to implement triggers and care pathways may not give sufficient regard to each individual patient and their preferences.

The UK experience also highlights the importance of ensuring that institutional arrangements at the hospital level (including training and clinical governance systems) are designed to support the implementation of standards for high-quality end-of-life care, and that triggers are used to prompt discussions, not to force decisions or transitions in care.



---

## Box 4.1 Training clinicians to talk about end-of-life care with patients

### *Clinicians feel unprepared to talk about dying*

For clinical staff, patient deaths are often expected. Yet the heavy, emotive nature of death, dying and future care needs make them difficult subjects for clinicians to address (Scott et al. 2013).

Triggers may prompt clinicians to have conversations with patients about their future care needs and preferences, and assist clinicians to determine the best timing for those conversations. But clinicians do not always have the skills or understanding necessary to know when and how to hold these difficult conversations (Nedjat-Haiem et al. 2016) or the technical knowledge to facilitate planning (Seal 2007; Street et al. 2015).

### *Training can help*

Several inquiry participants, including HammondCare (sub. 407, DR515), MIGA (sub. 432), Leading Age Services Australia (sub. 463) and the Royal Australasian College of Physicians (sub. 473), suggested that training is needed to give clinicians the confidence necessary to start conversations about end-of-life care. Christy Pirone, Margaret Brown, Dr Chris Moy and Dr Christine Drummond (sub. DR559, p. 4) said the use of triggers to prompt discussion on goals of care was a key step, but this would require 'building capacity of the workforce ... to enable identification of a person at the end-of-life and the skills to partner with consumers to discuss and plan care in respect to a person's wishes'.

There are a number of training programs that have demonstrated their effectiveness in teaching clinicians to engage patients and their families in shared decision making about end-of-life care. For example, the Respecting Patient Choices program is designed to help hospitals establish systems that cater for improved care planning, including staff training programs with a 'person centred' 'complex' advance care planning approach (Brinkman-Stoppelenburg, Rietjens and Heide 2014). Based on a US model and first implemented in Australia at the Austin Hospital, Respecting Patient Choices includes additional practical training (role plays and scenarios) that are specific to the Australian context.

Prior to the introduction of Respecting Patient Choices at the Austin, about 9 per cent of patients had advance directives and only about half of those were active (Lee et al. 2003). After implementing the Respecting Patient Choices training program, 47 per cent of patients were offered advance care planning, of which 70 per cent went on to prepare a written plan. Of the patients who died, about three quarters had some expression of their treatment wishes recorded in their medical record, and one quarter had completed a formal advance care plan document (Lee et al. 2003). The Respecting Patient Choices program has now been adopted by health services and communities across Australia and implemented in at least one lead hospital in every state (CareSearch 2017b).

HammondCare pointed to a range of other educational resources designed to increase clinicians' skills and knowledge about end-of-life conversations and palliative care, including:

- the Palliative Care Curriculum for Undergraduates (PCC4U) program, which targets undergraduate health students
- the online training modules, practical workshops and screening and assessment tools developed as part of the Advance Project, which currently targets practice nurses but could be extended to general practitioners, nurses working in other settings, including aged care, as well as allied health professionals
- the Program of Experience in the Palliative Approach (PEPA), which provides free palliative care workshops and placements in palliative care services. (sub. DR515, pp. 3–4)

---

## Box 4.2      **The rise and demise of the Liverpool Care Pathway**

A new End of Life Care Strategy was adopted in England in 2008. It was developed with the aim of giving people approaching the end of life more choice about where they would like to live and die (UK Department of Health 2008).

The strategy encouraged hospitals to adopt a care pathway originally developed for the care of cancer patients in acute hospital settings — the Liverpool Care Pathway (LCP). In 2008, the LCP had been implemented in hospices and aged care homes, and had been modified to be used for people with other conditions, for example renal disease and heart failure. The LCP was actively promoted by the National Health Service and was adopted as standard practice by more than 1800 health care institutions (Chan et al. 2014).

By 2012, allegations emerged that patients had been placed on the pathway prematurely, or had been poorly managed once they were on the pathway. The UK Government commissioned an independent review of the LCP, which found that although the LCP had clear benefits when used correctly, it had been treated as a ‘tick box exercise’. The review recommended that the LCP name be abandoned, the term ‘pathway’ avoided and that the LCP be replaced by an ‘end of life care plan’ (Neuberger 2013).

Responses to the review pointed out it is ‘as illogical to discredit guidance because of errant clinicians as it is to ban the Highway Code because of bad drivers’ (Regnard 2014, p. 172). After significant media attention, however, the damage was done and the LCP was abandoned.

### Responsibility for end-of-life care in acute hospitals

In hospitals, where many health professionals can be involved in a patient’s care, training clinicians to talk about end-of-life care is only part of the story. It is also important to clarify responsibilities for initiating and conducting end-of-life conversations. Even with appropriate triggers and training for clinicians, this will require concerted effort by hospital leadership. The common refrain that ‘end-of-life care is everyone’s responsibility’, while true, needs to be reinforced by the actions of hospital leadership.

Under the NSQHS Standards, the hospital board, chief executive or senior executive are already required to demonstrate that they monitor the safety and quality of care. This will be extended in version 2 of the NSQHS Standards to include a requirement for a formal governance process to ‘oversee the development, implementation and ongoing review of systems for end-of-life care’ (ACSQHC 2015a, p. 23).

In England, the importance of senior oversight of end-of-life care has been reinforced through public reporting on hospital quality. Hospitals that do not have clear senior oversight of end-of-life care receive poorer ratings for it (box 4.3). Similar measures should be incorporated into Australia’s public reporting on hospital performance (chapter 11).

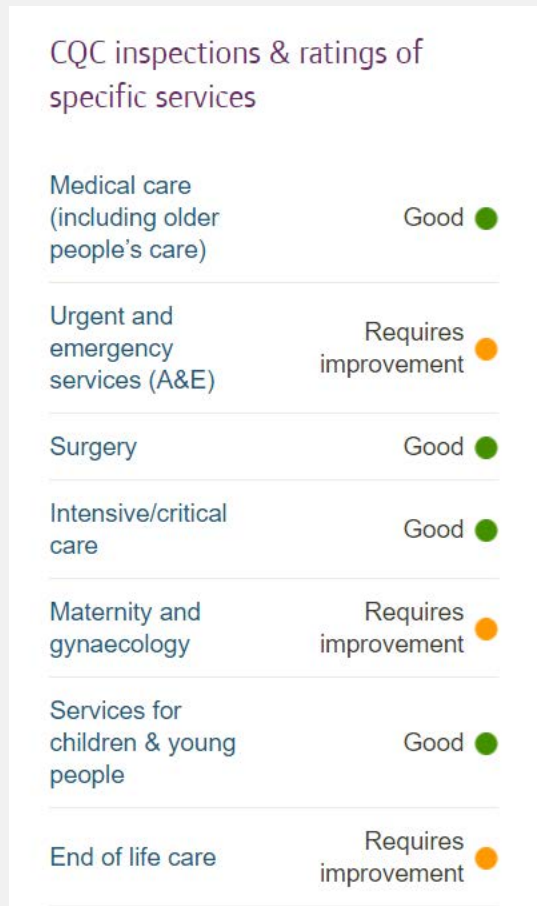
### Box 4.3 Transparency about end-of-life care quality in the United Kingdom

In England, a large amount of consumer-oriented information about healthcare providers has been made available online. Patients can see an overall rating that England’s healthcare regulator — the Care Quality Commission (CQC) — has given to individual hospitals.

The CQC’s assessment of each hospital provides easily accessible information about the quality of each service area, including end-of-life care, using a traffic light system (see example at right). These service ratings can be disaggregated into ratings for five objectives (safety, effectiveness, caring, responsiveness or well-led).

The hospital whose ratings are shown below was rated as inadequate for ‘well-led’ in end-of-life care because:

- there was insufficient time for senior staff to provide leadership and governance
- it was slow to develop end-of-life care services in line with national guidelines
- quality, performance and risks were not effectively managed.



	Safe	Effective	Caring	Responsive	Well-led	Overall
End of life care	Requires improvement	Requires improvement	Good	Good	Inadequate	Requires improvement

Source: CQC (2016).

## 4.2 Enabling more people to be supported to die at home if they wish

Under current arrangements, the supply of quality end-of-life care services to help people to die at home or in a home-like environment is not sufficient to meet demand, with tens of thousands of people missing out on the home-based care they would prefer (chapter 3). As the Grattan Institute pointed out:

... in principle, dying people should be able to choose a community-based palliative care package that supports them to die in place, particularly if they want to die at home. (Swerissen and Duckett 2014, pp. 27–28)

---

In practice, only a small proportion of people who would prefer this type of care have access to it in a way that meets their needs. The Commission considers that addressing the current shortfall in community-based palliative care should start with State and Territory Governments commissioning additional community-based palliative care services. Many inquiry participants agreed (for example, ACSA, sub. DR541; Alzheimer’s Australia, sub. DR521; Benetas, sub. DR543; Breast Cancer Network Australia, sub. DR534; Catholic Health Australia, sub. DR567; City of Whittlesea, sub. DR519; Sandra Coburn, sub. DR558; Community Council for Australia, sub. DR585; MND Australia, sub. DR513; Northern Territory Government, sub. DR593; Palliative Care Australia, sub. DR500; RACP, sub. DR580; Silver Chain, sub. DR509).

Governments should take a systematic approach to commissioning and service delivery by being clearer about what outcomes they are seeking to achieve, for whom and where (chapter 1). This includes ensuring that respective roles of (State- and Territory-Government funded) community-based palliative care services and (Australian Government funded) aged care services are agreed and well-understood by governments, providers and service users (section 4.5).

Enabling people approaching the end of life who wish to die at home to choose between community-based palliative care providers is the long-term objective (recognising that increasing the availability of community-based palliative care is the more immediate priority).

This section considers the issues that will be particularly important to address in order to effectively commission community-based palliative care services. The recommendations relating to commissioning family and community services (chapter 8) and stewardship of human services (chapter 2) are also likely to have broader lessons for commissioning and ongoing oversight of palliative care services.

## **Assessing demand for community-based palliative care services**

Understanding the population’s characteristics, needs and preferences and the role played by existing service providers is critical to good stewardship (chapter 2). In the draft report, the Commission said that the starting point for providing additional community-based palliative care should be a detailed assessment of the current and future demand for such care, and current gaps in service provision.

Little Haven Palliative Care (sub. DR579) suggested that the gaps in community-based palliative care service provision are well documented, and instead of further needs assessment, resources would be better directed towards providing care. However, other participants were supportive of needs assessment (Cancer Council NSW, sub. DR537; Leading Age Services Australia, sub. DR512; Christy Pirone, Margaret Brown, Dr Chris Moy and Dr Christine Drummond, sub. DR559; Victorian Healthcare Association, sub. DR531).

---

HammondCare said that it:

... reaffirms that a substantial increase in the availability of community-based palliative care is required, drawing on the experience and expertise of service providers, service users and representative organisations to assess that need. (sub. DR515, p. 1)

Palliative Care Australia (sub. DR500) noted that it is currently reviewing its guidance documents on palliative care service planning and provision, which could help to inform assessments of current and future palliative care needs.

While there is clear need for a major increase in the availability of community-based palliative care, it is highly likely those needs and gaps will differ between regions, as ‘there is huge variability in the delivery of palliative care services across the country’ (Catholic Health Australia, sub. 440, p. 5). Carefully assessing needs and specifying the highest priorities for additional community-based palliative care services would enable governments to target funding to areas where it would have the greatest effect on end-of-life care outcomes.

In addition to assessing the need for more community-based palliative care services in particular locations, State and Territory Governments should consider the diverse needs of different members of the community.

- Leading Age Services Australia (sub. DR512, p. 4) pointed out that ‘any identification of gaps should pay attention to the diversity of Australia’s community to determine whether groups exist in the community whose cultural, religious or way-of-life needs are unlikely to be met by mainstream services’.
- Alzheimer’s Australia (sub. 431, p. 14) noted that ‘all providers of palliative care should be required and supported to ensure that their services are dementia-friendly’. A large proportion of people approaching the end of life have dementia or other cognitive impairments.
- Some participants emphasised the particular needs of Indigenous Australians, many of whom place cultural and spiritual significance on ‘returning to country’ at the end of their lives (Cancer Council NSW, sub. DR537; National Congress of Australia’s First People, sub. DR565; Palliative Care Australia, sub. DR500). The Northern Territory Government anticipates that palliative care ‘on country’ will be an area of service growth as the Aboriginal population in the Northern Territory ages (sub. DR593).
- Christy Pirone, Margaret Brown, Dr Chris Moy and Dr Christine Drummond (sub. DR559, p. 3) drew attention to the needs of people approaching the end of life who have a disability. For example, people with intellectual disability living in community group homes can struggle to obtain end-of-life care in those homes, as staff typically lack the knowledge and skills necessary to care for the dying (Wiese et al. 2012).
- Paediatric palliative care patients have different needs to those of adults, and their parents also need support in their roles as care-givers and proxy decision makers (RACP, sub. 473).

---

Drawing on the experience and expertise of service providers, service users and the organisations that represent them will be an essential component of a comprehensive needs analysis. Bringing this experience and expertise into the process of service design gives stakeholders opportunities to influence program design and the development of outcome measures that will be used to determine success, and to assist governments in assessing the costs of providing effective services. The involvement of local service users and providers is consistent with the experience of commissioning in England, which has shown that ‘fundamental to any commissioning plan for end-of-life care is a local strategy, jointly developed with local people and key partners, clearly setting out your vision for end-of-life care’ (NHS England 2016, p. 12). In this regard, user-focused information on the needs assessment process, such as the *10 Questions to ensure good end of life care in your area* publication available in the United Kingdom (NCPC 2013), could prove useful.

## **Designing services to meet demand**

The objective of the design stage of the commissioning process is to develop and implement systems of service provision that will contribute to meeting the needs identified during the needs assessment. The substantial increase in services likely to be needed across Australia will require careful stewardship, planning and implementation. Workforce and provider availability may limit the speed at which services could be expanded. However, experience suggests that change is possible within a reasonable time frame. For example, a large increase in service availability was recently achieved in Tasmania — the hospice@HOME program cared for over 2000 people between its establishment in December 2014 and June 2016, servicing people for whom community-based end-of-life care was previously unavailable (The District Nurses 2017, p. 9).

Participants highlighted the need to ensure that service delivery models are designed for different geographic areas. In metropolitan areas, this could involve commissioning multiple providers of community-based palliative care services. Were this to be the case, State and Territory Governments would need to determine if people should have choice between providers, and if so, how to enable that choice. The Commission considers that, where feasible, offering service users choice of provider should be the long-term goal of government and increases in service availability should be designed with this in mind. However, initial priority needs to be given to ensuring the wider availability of high-quality end-of-life care services which place users’ interests at the centre of delivery.

The Commission also recognises that choice will not be possible in all areas. For example, in regional areas, options may be more limited if there is not the population base to support more than one service provider. Remote service provision may be possible for some users and for some (but not all) services. For example, the National Rural Health Alliance said:

The need for access to good telehealth and ongoing access to appropriate specialist care is also important to ensure people approaching the end of life are able to remain in their community with the appropriate care and support for themselves and their carers. (sub. 428, p. 12)

---

Remote service delivery models such as telehealth have been demonstrated to help patients ‘to feel supported and remain in their place of residence, hence reducing the pressure for avoidable hospital admissions and use of other services’ (Middleton-Green et al. 2016, p. 1).

### Building on existing person-centred services

People approach the end of their lives with different illnesses, different preferences and different levels of family and community support, which leads to a wide degree of variation in end-of-life care needs. Further, as noted in chapter 3, end-of-life care can encompass a broad range of services delivered by public and private providers, including advice and coordination of care, nursing and personal care, 24 hour hotlines, day hospice respite, emotional and practical support, and access to equipment (LSIC 2016). It also includes services for families and carers, such as bereavement support.

While community-based palliative care providers can, and should, respond to the urgent and diverse needs of their patients in a flexible way, it is also important to ensure that government-funded providers limit their service offerings to those that are clinically necessary or that are essential for peace and wellbeing at the end of life. This would include nursing and medical care and the provision of equipment.

State and Territory Governments should establish standards for community-based palliative care services and fund the provision of those services for people who wish to and are able to die at home. The standards should include integrated and coordinated nursing, medical and personal care.

Other important service specifications for community-based palliative care could include:

- providing access to necessary equipment
- working with patients to smooth transitions between different settings of care (both before their discharge from hospital to community-based care and, should their care needs or preferences change, prior to their admission to hospital or hospice)
- helping patients (and their families and carers) to plan their care needs and preferences, including by providing education about the circumstances a dying person will face and services that they are likely to require
- integrating with other health care services, including specialist palliative care and allied health providers
- services for families and carers, such as bereavement support
- maintaining records and collecting data on the cost, quantity and quality of services provided.

Users should continue to be able to purchase additional services if they wish to do so.

Within these broad parameters, and subject to appropriate consumer safeguards, providers should then be responsible for delivering care that meets the needs of individual clients. This

---

could look very different for different people. Some will require regular assistance to cope with increasing pain and nausea, while others will be in less physical pain but greater distress about their relationships with loved ones. The palliative care provider would be expected to provide more nursing care to the former, and counselling to the latter.

Dozens of community-based palliative care providers across Australia already deliver services that meet this description using a range of different models. At the same time, governments need to ensure that all providers are delivering the specified standard of care as defined by those governments. The details of service agreements between State and Territory Governments and providers are not published, so the Commission has not been able to assess the extent to which those arrangements would provide a good starting point for the expansion of community-based palliative care.

### Determining eligibility for services

Several criteria are already used to determine eligibility for existing community-based palliative care services. Most rely on the judgments made by treating doctors, typically involving an assessment that the person is likely to die within the next 12 months. In 2016, hospitals were the source of about two-thirds of referrals to community-based palliative care, with most of the remaining referrals coming from GPs (PCOC 2016). This reliance on clinical assessment is appropriate as end-of-life trajectories are inherently uncertain, and determining when a person would benefit from end-of-life care requires medical skill and judgment. Doctors also need support and guidance in making those judgments, as well as training in initiating conversations about end-of-life care (box 4.1).

As it currently stands, people who have been judged as needing end-of-life care are sometimes turned away by community-based palliative care providers who lack funding (or, in the case of hospices, beds) to care for everyone who is eligible. These people are then left to seek care elsewhere, typically in a hospital or residential aged care facility. This situation will continue until there are enough community-based palliative care services available to meet demand.

Although rates of death from cancer and from chronic illnesses other than cancer are fairly consistent across jurisdictions, the share of palliative care patients with a non-cancer diagnosis varies a lot between jurisdictions. There appears to be limited rationale for this variation, and so it will be important to ensure that eligibility criteria to access community-based palliative care services are not biased against those who currently miss out on palliative care.

It will also be important to ensure that palliative care services remain focused on meeting the needs of those approaching the end of life. If the duration of care extends beyond the last 12 months of life, it will necessarily cost more to provide. There is therefore a need to monitor that palliative care service providers deliver their services to those with a diagnosis that clearly indicates their need for end-of-life care. Tracking the mean and median duration of care provision, as well as variance around those measures, may be useful in this regard.



---

The Commission considers that community-based palliative care services should be open to any individual with an end-of-life diagnosis where it is both consistent with the individual's preferences and their clinical condition. While governments should plan to meet demand for care, it is unrealistic to expect services to be offered everywhere in the short term. Governments therefore need to plan so that, where services are constrained, provision of community-based palliative care is appropriately managed.

### Designing palliative care services that are well integrated with other services

While good end-of-life care will be different for each individual, a consistently important factor is that it is provided in an integrated manner. From a user's perspective, 'an individual receiving palliative care should experience that care as a single service regardless of how it is administrated' (PCA and PCOC, sub. 417, p. 1), or whether it is provided in hospital, aged care or the community. A range of different models could be used to deliver integrated care (box 4.4).

### **Selecting and funding providers of community-based palliative care**

Once palliative care needs have been assessed and service models designed to meet those needs, State and Territory Governments should consider the most suitable approach to selecting service providers.

In general, the preferred approach should be to run competitive processes, such as tenders, to select providers for the additional community-based palliative care services. In some regional and remote areas, a lack of suitable potential bidders will require governments to provide services directly or nominate an existing supplier. The Mallee Track Health & Community Service (sub. DR499, p. 4) noted that existing multipurpose services (which deliver integrated health and aged care services for some small regional and remote communities) could provide 'a ready platform to achieve a holistic, wrap around, [end-of-life care] service in rural and remote areas'.

---

## Box 4.4      **Toward better integrated care**

Integrated care coordinates the actions of the multiple actors that affect a person's health and care needs. This type of care is particularly important for people at the end of life because:

... regardless of previously expressed choices or preferences people approaching or reaching the end of life will continue to require access to a range of home-based, community and hospital services. (Little Company of Mary Health Care, sub. DR547, p. 6)

Christy Pirone, Margaret Brown, Dr Chris Moy and Dr Christine Drummond said that:

Even where there is access to highly skilled palliative care providers, the plan of care to support a person who wishes to die at home can fail due to a lack of coordination in person-centred planning and resources across health sectors. (sub. DR559, p. 1)

There are many potential ways to improve the integration of end-of-life care across settings.

- Palliative Care Australia suggested that Primary Health Networks could play in role in facilitating integrated care, 'particularly referral between general practice and specialist services' (sub. DR500, p. 1).
- The Royal Australasian College of Physicians considered that 'a designated Navigator to advise and guide the integration of services for particular patients' (sub. 473, p. 9) would be beneficial.
- Hobart District Nursing Service said that it achieved integrated care by commencing the package of care before the recipient leaves an acute care facility (sub. 419, p. 3).
- Case conferences that promote integrated care among medical specialists and GPs have been shown to reduce the cost of hospitalisations for patients receiving end-of-life care (Hollingworth et al. 2016). Case conferencing can also reduce hospitalisations and slow functional decline in patients receiving specialist palliative care (Abernethy et al. 2013).
- The Bushland Health Group employs a nurse practitioner to integrate palliative care into the its residential aged care facilities. This model of care recently won a National Innovation and Excellence in Aged Care award from the Australian Aged Care Quality Agency (AACQA 2017).

Each of these methods could contribute to ensuring that people approaching the end of life can access the services they need as those needs change. The relative merits of different methods of delivering integrated care will depend on the models of care delivered by community-based palliative care providers in different regions.

Improving the integration of care is important not just for those approaching the end-of-life, but also for the health system more broadly. Designing and implementing integrated patient-centred care throughout the health care system will require several changes to structures and funding arrangements to improve coordination of care (PC 2017d).

## Selecting the service provider

Contestability can have a range of potential benefits in human services (chapter 1), and could also have benefits for community-based palliative care services. Indeed, community-based palliative care is ideally suited to this type of contestable approach, as there are no substantial barriers preventing a provider that is not currently supplying services to users from doing so now or in the future. This was recently demonstrated in Tasmania where, until recently, substantial increases in the availability of community-based palliative care had been

---

achieved. Similarly, HammondCare pointed to the Palliative Care Home Support Program in New South Wales, which demonstrates that:

... competitive processes to select providers with expertise in [end-of-life care] — either individually or through consortium arrangements — can produce significantly improved outcomes for patients and their families. (sub. DR515, p. 1)

Approaching the market to provide additional community-based palliative care services would not require State and Territory Governments to make changes to existing service arrangements — Governments could choose to leave current services in place while adding to the service offering. This approach was supported by the Victorian Healthcare Association (sub. DR531) and Cancer Council NSW (sub. DR537, p. 3), which suggested that ‘the focus should be on strengthening what is already on offer, including specialist palliative care services, to meet community needs’.

Existing service providers could:

- tender to increase the availability of services so more people could access care
- tender to provide services in additional locations
- act as a ‘prime provider’ and subcontract to others.

Providers of other related services, such as aged care and community health, could also seek to enter the palliative care market.

The process used to choose providers (or to assess the capacity of a lone applicant to provide the desired services) should focus on whether providers will be able to meet the expected needs of their clients. Several inquiry participants suggested that competitive tendering arrangements do not always lead to the selection of providers who can best meet clients’ needs, instead tending to disadvantage small providers. For example, Little Haven Palliative Care said:

... competitive tender processes advantage larger scale providers with capacity to deliver services on a national basis. Having the administrative support and a greater understanding of the tender process they may present very well on paper. Smaller organisations can be disadvantaged in the process. This happened in Metro North Hospital and Health Service District. Karuna Hospice (a very highly regarded and compassionate service) which had served Queensland Health and the Windsor community so well, was unsuccessful, with the tender awarded to a national provider, who at the time had no presence in Queensland ... (sub. DR579, p. 1)

The Audit Office of New South Wales suggested that the expression of interest process used to allocate funding for palliative care in that State does not result in funding being directed to the areas where needs are greatest, but rather to the health services that have the greatest skill writing expressions of interest (AONSW 2017). This concern is similar to those described by participants in family and community services (chapter 8) and services in remote Indigenous communities (chapter 9).

---

To address this, governments need to design selection criteria that focus on the ability of service providers to improve outcomes for service users and not discriminate on the basis of organisational type or service model, nor should it disadvantage providers who are seeking to enter the market. Governments also need to allow sufficient time for providers to prepare considered responses to tenders, and enter into contracts that reflect the length of the period required to achieve the agreed outcomes (which will mean longer contracts in many cases). Further details on designing tendering arrangements that are less prescriptive and that incorporate more flexibility are provided in chapters 2 and 8.

## Funding

The funding required to provide additional community-based palliative care will depend on the extent of unmet demand, which should be assessed, as noted above.

The available evidence suggests that the cost to governments of providing community-based palliative care can be in the order of \$6000 to \$10 000 per person (box 4.5). This implies that providing additional places for, say, 10 per cent of the people who die each year (16 000 places) would cost governments about \$160 million per year.

Community-based palliative care is currently provided at no cost to the user. The Commission's view is that this should continue for basic services, at least into the medium term, but that this arrangement should be reviewed as part of the 2025 review of end-of-life care services (recommendation 4.5). Complementary services such as 'massage, aromatherapy, relaxation, meditation, acupuncture, or art and music therapy' (CareSearch 2017a) should continue to be funded by the user.

Expanding the availability of services will impose a direct cost on government. These direct costs need to be considered against the potential for avoided hospital costs. The Commission's view is that funding an increase in community-based palliative care is likely to be cost effective for government, as home-based care can cost less (sometimes much less) than its hospital-based alternative. The available evidence suggests that average admission for palliative care in a sub-acute hospital can cost almost \$11 000 (box 4.5). Thus, avoiding one hospital admission could cover the cost of an individual's community-based palliative care over a period of months (assuming it costs about \$10 000), as well as better meeting the preferences of people approaching the end of life. However, the net cost to State and Territory Governments of increasing the availability of community-based palliative care will ultimately depend (among other things) on the extent of unmet demand, which is currently unknown.

While there are potential savings for governments from having fewer hospital admissions, providing more people with access to high-quality community-based palliative care should be the primary driver of reform.

---

**Box 4.5      Community-based palliative care would better meet users' needs and could cost less than its hospital equivalent**

*Community-based palliative care*

The Commission examined the financial and annual reports of 12 not-for-profit providers of community-based palliative care (which were required by the Australian Charities and Not-for-profits Commission to publish information about their finances and activities). Across these organisations, the average total cost of providing community-based palliative care ranged between \$6000 and \$10 000 per person, with a mean of just under \$8000. This provided an average of between 40 and 100 hours of care, delivered over a period of days up to several months. These cost estimates do not include the contribution of volunteers, whose assistance in non-clinical roles is critical to the successful operation of many, if not most, community-based palliative care providers.

*Palliative care in hospitals*

The Independent Hospital Pricing Authority (IHPA) reported that the average cost per palliative care separation in sub-acute care was \$10 750 in 2014-15, with some patients visiting hospital multiple times in the weeks and months leading up to death (IHPA 2017). Similar costs were found in a recent database study, using data from the Department of Veterans' Affairs, of 20 000 hospital episodes ending in death. The study found the mean total cost per separation was \$10 800 if the patient was in a designated palliative care bed (about one-third of patients in the study) or \$16 200 for those with no recorded palliative care access (Ireland 2017, p. 549).

*Care at home could cost less*

Participants agreed that community-based palliative care services cost less than their hospital equivalents. For example, Little Haven Palliative Care said that it:

... is caring for 78 palliative patients in the community at an approximate cost to [Queensland Health] of \$700/day (Total – not per patient). Should just one of these patients not have access to community-based palliative support and end up in hospital the cost would be upwards of \$1600/day. (sub. 458, p. 1)

The District Nurses said that the average cost of one of their hospice@HOME packages is \$39-\$78 per day, compared to an acute care admission of \$1500-\$1600 per day (trans., p. 303). Analysis by the Silver Chain Group (sub. 176) found that each dollar invested in extending home-based palliative care services in New South Wales would free up \$1.44 of expenditure on inpatient bed capacity at metropolitan hospitals.

Taken together, all of these sources of information suggest that reducing the proportion of people who die in hospital, and supporting more people to die at home or to stay at home for longer, would not lead to an increase in costs, and may be less expensive. It would also help people to avoid the stress and disruption of hospital admissions, which can be substantial.

This was the view of the Grattan Institute, which found that the costs of supporting individuals to die at home are lower than hospital and residential care, and that overall savings could be achieved if hospital and residential care were replaced by community-based services (Swerissen and Duckett 2014, p. 21).

---

## Monitoring and evaluation of community-based palliative care services

### Consumer safeguards

When governments engage community-based palliative care providers to deliver end-of-life care, they must also put safeguards in place to ensure that those providers deliver high-quality care. Safeguards are particularly important in end-of-life care, given the vulnerability of users, the time-critical nature of their care needs and the stress that an end-of-life diagnosis entails for users, their families and carers. As LASA said:

Peoples' vulnerability and the medications required to be kept in the household make strong safeguards and oversight essential for all community palliative care services ... (sub. DR512, p. 5)

The design of appropriate safeguards depends on the risks that are being guarded against. In community-based palliative care, a critical risk is that the service provider may not respond to urgent care needs in the correct manner (for example, by failing to provide necessary medications, to answer an after-hours phone line or to respond to patient concerns in a timely manner). There is a need to ensure that quality care continues to be provided, and that oversight is maintained, as the volume of services provided increases.

To address risks to the safety and quality of care, many health services are required to meet the NSQHS Standards. Independent accreditation agencies monitor these health services to ensure that they deliver safe and high-quality care in accordance with the NSQHS Standards. The accreditation agencies provide data on the outcomes of their assessments to State and Territory Governments so that Governments can support health service improvement and respond to emerging issues. Community-based palliative care services in several jurisdictions are already accredited under this system. This approach should be considered by other State and Territory Governments. Governments will also be in a better position to directly monitor the quality of care provided by community-based palliative care services as more data on those services become available (section 4.5).

In addition to the safeguards provided through accreditation, there is a health care complaints commissioner or health ombudsman in each State and Territory who is able to respond to concerns about the quality of health care, including complaints about community-based palliative care. To the extent that health care complaints commissioners and ombudsmen are fulfilling this role, there is limited rationale for setting up a dedicated complaints system for community-based palliative care.

More critically, if people who are receiving community-based palliative care have urgent unaddressed care needs, the rest of the health system remains available. People in community care settings can access the broader health system through their general practitioner (GP) (or after hours GP), the ambulance service or through a hospital admission. These alternatives provide an important backstop and an assurance that people who need care will receive it.

---

## How should the outcomes of the new services be assessed?

Governments should develop and apply performance frameworks for the provision of community-based palliative care that are focused on service users and outcomes. A key objective for these services is to allow people who want to die at home to do so. Possible metrics include the number and proportion of deaths that occur at home with the support of community-based palliative care (as opposed to unplanned deaths at home). But these should not be the only measures of success. For example, helping people to stay at home for longer should also be counted as a measure of success for the service. This is true regardless of whether people spend the last few days of life, when pain and care needs can be greatest, being cared for in a setting that better meets those care needs, such as a hospital or hospice. Measuring the number and proportion of people who receive most of their care at home (over, say, the last 100 days of life (AONSW 2017)) would therefore be useful. This was emphasised by the Centre for Health Economics Research and Evaluation at the University of Technology Sydney, which said:

... we have concerns about death at home being perceived as necessarily the most desirable outcome, embedding incentives in program designs for service providers to encourage informal carers to continue providing care at home when this may not be in the interest of either the carer or the patient. (sub. DR516, p. 4)

MND Australia said that:

... for some people the preference is to remain in their residence of choice for as long as possible but to die in hospital. This could be for a variety of reasons such as the needs and preferences of their carer or the availability of specialist support to address complex symptoms. (sub. DR513, p. 3)

Quality of services also matters. Information which provides insights into users' experiences of the service would also be desirable, and better data are needed in order to track progress against outcome measures. Many of these measures will require data to be collected where it currently is not, and would need to be done in a way that does not unreasonably impose on the person being cared for or their loved ones. Strategies for enhancing data on end-of-life care are considered in section 4.5.

---

#### RECOMMENDATION 4.1

State and Territory Governments should increase the availability of community-based palliative care so that people with a preference to die at home can access support to do so. To achieve this, State and Territory Governments should:

- assess the need for additional community-based palliative care services
- design services to address identified gaps in service provision
- establish standards for community-based palliative care services and fund the provision of those services for people who wish to and are able to die at home. The standards should include integrated and coordinated nursing, medical and personal care
- use competitive processes to select providers (or a single provider) to deliver additional community-based palliative care services
- monitor and evaluate the performance of community-based palliative care services against the specified standards
- ensure that consumer safeguards are in place so that quality care is provided, and oversight is maintained, as the volume of services provided increases.

### 4.3 Supporting end-of-life care in residential aged care

About half the people who need end-of-life care each year receive that care, and die, in a RACF. Despite this, governments and aged care service providers rarely acknowledge that end-of-life care is core business for aged care, and many residential aged care services struggle to meet the end-of-life care needs of their residents (chapter 3).

A review of the aged care system was completed on 1 August 2017. Access to palliative or end-of-life care was ‘raised numerous times by consumers, carers and providers’ during the review, but it was not considered by the reviewers as it ‘does not align specifically with the terms of reference’ (Department of Health 2017h). This narrow focus misses the core role residential aged care plays at the end of life for its clients.

Improving the effectiveness of end-of-life care service provision for residents of aged care facilities, irrespective of any other changes that may occur in the broader aged care system, should be a key focus for further reform. In order for older Australians, particularly those residing in RACFs, to receive end-of-life care that aligns with the quality of care available to other Australians, two main reforms are needed. They are:

- providing residents with greater access to services delivered by clinically qualified staff
- helping consumers to select RACFs that deliver high-quality end-of-life care.



---

## Improving end-of-life care in residential aged care

Residents of aged care facilities need to be provided with greater access to services delivered by clinically qualified staff. Achieving this will involve the Australian Government:

- removing funding restrictions that unnecessarily limit the duration of palliative care in RACFs and its availability to residents who have pre-existing high health care needs
- providing sufficient funding for this additional clinical care
- ensuring that residential aged care providers are accountable for the increased funding and that is used to meet or exceed the standard of end-of-life care specified by government.

Many inquiry participants supported this reform direction (AASW, sub. DR557; ACSA, sub. DR541; AHHA, sub. DR561; AHPA, sub. DR496; Benetas, sub. DR543; CHA, sub. DR567; City of Whittlesea, sub. DR519; LASA, sub. DR512; Little Company of Mary Health Care, sub. DR547; OCAV, sub. DR501; Palliative Care Australia, sub. DR500; Queensland Government, sub. DR592; RACP, sub. DR580; Silver Chain, sub. DR509; UnitingCare Australia, sub. DR514; VHA, sub. DR531).

### Delivering adequate resourcing for palliative care in residential aged care

Several participants suggested that the aged care funding instrument (ACFI) (chapter 3) needs to be changed to address the longstanding and widespread concerns about poor quality end-of-life care in RACFs.

The funding arrangements for home care and residential aged care should recognise palliative care as an intensive service provision activity that requires an appropriate level of funding to ensure the provision of quality palliative care services. (ACSA, sub. 411, p. 5)

LASA suggested that a separate payment for palliative care ‘would enable residential care facilities to purchase more and better end-of-life services and expertise for [their] residents’ (sub. DR512, p. 6).

Making intensive nursing and other palliative care services available only in the last week or days of life does not align with users’ needs nor with the way in which the health system considers, or aims to consider, end-of-life care (the last 12 months of life). Nor does it accord with what is known about the trajectories of decline for those with dementia, who comprise more than two thirds of aged care residents.

To address this unwarranted discrepancy, the Commission considers that the Australian Government should properly resource RACFs to provide palliative care to all residents for a longer period of time, including to residents who already have pre-existing high health care needs. Restrictions in the ACFI that unreasonably limit the duration of palliative care in RACFs and its availability to residents who have pre-existing high health care needs should be removed.

---

The Commission reached a very similar conclusion in its 2011 report on *Caring for Older Australians*, finding that palliative care should be funded such that equivalent levels of care can be provided across settings of care, and that the Australian Government should ‘ensure that residential and community care providers receive appropriate payments for delivering palliative and end-of-life care’ (PC 2011a, p. 234). These types of funding are still not available.

While there is a need to remove barriers to accessing specialist palliative care services (box 4.6), the large majority of those who die each year, including those who die in residential aged care, do not require ongoing support from a specialist palliative care service. They simply require skilled care delivered in the RACF that is their home. As such, end-of-life care is core business for the aged care system, and the Australian Government, as steward of the aged care system, is responsible for ensuring that people in the aged care system receive end-of-life care that aligns with the quality of care available to other Australians.

**Box 4.6      Removing barriers to accessing specialist palliative care services**

Participants (including Good Shepherd Australia New Zealand, sub. DR517; HammondCare, sub. 409) suggested that people living in residential aged care facilities may not, in practice, be able to access specialist palliative care services if and when they need to do so. For example, LASA said:

The delivery of specialist palliative care services varies across jurisdictions, where often, especially in residential services, access to specialist palliative care professionals can be very limited. There is often a misunderstanding that people residing in residential services are not eligible to receive state based services such as specialist care. This misconception needs to change. (sub. 463, p. 6)

The limited focus on residents of aged care facilities in most states’ and territories’ end-of-life or palliative care plans reinforces this misconception. Palliative Care Australia said:

Older Australians residing in Residential Aged Care Facilities should be provided equity of access to specialist palliative care if needed, in the same way that those services are available to other Australians. (PCA 2016a, p. 7)

The Commission agrees that people living in a residential aged care facility who require specialist palliative care should have the same access to it as those in the broader community. Where there are misconceptions about eligibility for services, the Australian, State and Territory Governments should work together to address them with hospitals, specialist palliative care services and residential aged care facilities.

Improvements to end-of-life care for close to 60 000 people who die in residential aged care each year (or who would have preferred to die there but are transferred to hospital due to lack of skilled care) can and should occur regardless of any issues that may exist in access to specialist palliative care. In doing this, the Australian Government Department of Health and the AACQA should consult with the Independent Hospital Pricing Authority about appropriate funding benchmarks. These could include, for example, the cost of providing palliative care in sub-acute care services. This will help to ensure that aged care funding is

---

sufficient for people in the residential aged care system to receive end-of-life care that aligns with the quality of care available to other Australians.

### Ensuring that additional funding results in better end-of-life care

Removing the unnecessary limitations on the duration and availability of palliative care in RACFs will only be effective at improving end-of-life care if it is accompanied by sufficient additional funding. The magnitude of funding required will depend on the extent of unmet need, which is currently unknown.

There is a range of ways in which residential aged care providers could use the additional funding to provide end-of-life care for their residents that meets the standard set by government and aligns with the quality of care available to other Australians. Potential strategies could include, for example, purchasing the services of skilled staff from community-based palliative care providers, or employing additional skilled staff themselves. Subject to standards being met, this should be a decision for the individual provider.

#### *Expert service providers or additional skilled staff*

Hospital- and community-based palliative care providers deliver end-of-life care in many parts of Australia. In those places, residential aged care providers could choose to engage their expertise in improving end-of-life care for residents. Many of the considerations discussed in section 4.2 would then be relevant for the aged care provider in engaging such services.

Alternatively, residential aged care providers could employ nurses or nurse practitioners whose role would be to lead and coordinate end-of-life care in the RACF. This could be similar to the system suggested by the RACP, which recommended that the Commission consider ‘the Scandinavian model which assigns on-site practitioners or senior nurses to attend to simple cases to avoid unnecessary hospitalisation’ (sub. 473, p. 9). The nurses or nurse practitioners could coordinate care for residents approaching the end-of-life and facilitate advance care planning (including conducting advance care planning discussions with residents, families and carers). Nurse practitioners could also prescribe certain medications (within the nurse practitioner scope of practice).

Nurses or nurse practitioners could also train and support other staff in the RACF to deliver higher quality end-of-life care. Many RACF staff are untrained in aged care or end-of-life care, and many of those who are trained received training of poor quality (ASQA 2013). There is therefore a role for nurses or nurse practitioners in providing training to their colleagues, with a focus on the immediate needs of particular residents.

---

Inquiry participants agreed that nurses are well placed to lead and coordinate end-of-life care in RACFs. For example, Baptist Care Australia and Churches Housing said:

Ideally, one or two senior nurses in each facility would have responsibility for local expertise in palliative care. At the same time, the other care staff need training to support palliative care, and staffing models need to address the changing needs of larger cohorts entering the end of life stage. (sub. DR532, p. 5)

Push for Palliative described an ‘excellent approach to providing expert care in RACFs’ that ‘reduced transfers to hospital by two thirds in its first year of operation’ (sub. DR538, p. 3). In this model:

... RACFs are visited by a palliative specialist nurse at least once a week. The specialist palliative care nurse spends up to eight hours in each facility, seeing patients, meeting relatives, having discussions, making clinical recommendations, up-skilling staff in capacity and confidence, liaising with GPs and ensuring that the necessary medications are on hand. Advice is available 24/7. (sub. DR538, p. 3)

Transition toward a more widespread presence of nurses and nurse practitioners in RACFs would take time. Several participants — including Aged Care Crisis (sub. DR525), the Combined Pensioners and Superannuants Association (sub. DR542), Little Company of Mary Health Care (sub. DR547), Graham McPherson (sub. DR492) and Push for Palliative (sub. DR538) — considered that increased presence of nurses in RACFs should be hastened through regulation, such as the introduction of nurse–resident ratios or requirement for a registered nurse to be present in a RACF at all times.

However, the Commission’s support for a more widespread presence of nurses and nurse practitioners in RACFs to lead and coordinate end-of-life care is not an endorsement of broader arguments to increase the stringency of requirements for nursing care in RACFs. The Commission remains of the view that mandatory staffing ratios are unlikely to be an efficient way to improve the quality of care in aged care (PC 2011a). The absence of ratios and nurse presence requirements within RACFs allows them to staff flexibly in response to residents’ changing needs, and gives them an incentive to invest in innovative models of care or adopt new technologies that could assist care recipients. Imposing ratios or nurse presence requirements would also be at odds with principles of good stewardship (chapter 2), which require governments to focus on outcomes for users, rather than to prescribe processes or inputs.

### *Coordination with primary care*

While many GPs provide care to residents of RACFs and some RACFs even have onsite GPs, accessing GP care remains a problem for many. After hours care, in particular, can be lacking. This is why the Commission is not recommending relying solely on GPs to deliver improvements in end-of-life care for residents of aged care facilities.

The need to improve primary care in aged care is well known, and aged care is one of the six key priority areas for the Primary Health Networks (PHNs). PHNs are already delivering

---

a range of initiatives in this domain. For example, Sydney North PHN is testing a range of approaches to supporting end-of-life care in RACFs, with a view to reducing unplanned hospitalisations of older people in residential aged care (Sydney North PHN 2016). Broader efforts to improve the integration of care (box 4.4) will also assist in improving primary care for residents of aged care facilities.

### *Consumer safeguards*

The aged care system already has a range of consumer safeguards in place.

- The AACQA accredits Australian Government-subsidised aged care homes and provides compliance monitoring, information and training to providers.
- Since 1 January 2016, the Aged Care Complaints Commissioner has operated as an independent statutory office holder. The office of the Aged Care Complaints Commissioner provides an avenue for anyone to raise their concerns about the quality of care or services being delivered to people receiving aged care services subsidised by the Australian Government.
- The Older Persons Advocacy Network supports consumers and their families to raise concerns about aged care services and systems (OPAN 2017).

It is important that governments ensure that these consumer protections are effective. While the standards required of aged care providers are broadly worded (chapter 3), the AACQA conducts both scheduled and unannounced visits to RACFs to ensure that they are complying with them. It can and does issue sanctions and reduce accreditation periods in order to improve the quality of care at facilities that are found to be delivering substandard care. The effectiveness of these quality assurance arrangements was recently examined as part of an independent review of national aged care quality regulatory processes which has not yet been published (Department of Health 2017n).

A range of other measures are underway to provide more detail about the quality of end-of-life care that RACFs are expected to deliver. In particular, the palliAGED website was launched in May 2017, and is a source of online evidence-based guidance and knowledge for palliative care in aged care. Six peak bodies have also endorsed guiding principles on the delivery of palliative and end-of-life care services in residential aged care (PCA 2017a). Together with any related recommendations from the independent review of national aged care quality regulatory processes, and the Commission's recommendation to make palliative care available to all residents who require it, these are likely to drive improvements in end-of-life care in aged care.

---

#### RECOMMENDATION 4.2

End-of-life care should be core business for aged care facilities, and the quality of end-of-life care in residential aged care should align with the quality of that available to other Australians. To achieve this the Australian Government should:

- remove current restrictions on the duration and availability of palliative care funding in residential aged care
- provide sufficient funding for this additional clinical care.

### **Helping consumers to select residential aged care facilities that deliver high-quality end-of-life care**

Information on the quality of aged care remains hard for consumers to access

There are significant challenges in providing effective information for aged care clients. People turn to aged care services when they are experiencing an increase in their frailty and, for many, a reduction in their cognitive capacity. Information about aged care options typically needs to be obtained and understood in stressful circumstances, such as during recovery from an acute health episode or following the loss of support from a spouse or family carer. Decisions can be prompted by crises, and made when the person is vulnerable (PC 2015c). This makes it a particularly difficult time for aged care consumers and their families to consider their end-of-life care needs.

Unless consumers have easy access to information about the quality of care that they can expect to receive in the RACFs they are considering, they cannot select the RACF that best aligns with their care needs and preferences, including those for end-of-life care. This gives aged care providers little incentive to deliver the types of care that consumers value, and to make improvements in that care. In this respect, end-of-life care differs from many of the other services that users receive, and in some cases pay extra for, in residential aged care.










Two main changes are needed to address this gap in information. First, the Australian Government should specify and clearly communicate the standard of end-of-life care that aged care providers are expected to deliver. This standard of care needs to be clear and understandable, not just to aged care providers but also to residents.

Second, consumers need more information about the ways in which RACFs meet or exceed the standard set by the Australian Government for end-of-life care in residential aged care. Despite the recent and ongoing aged care reforms, there has been only limited progress in providing aged care recipients with information on variations in the quality of care, including the quality of end-of-life care.

- The Australian Government provides information on the system, and data for consumers through the MyAgedCare website, including a searchable list of RACFs around Australia.

- The Australian Aged Care Quality Agency (AACQA) publishes detailed accreditation reports that outline the agency’s assessment of the quality of care in each RACF. These include consideration of palliative care, but this information is not nearly as easy to find as it could be and is sometimes presented in a misleading fashion. For example, myagedcare.gov.au does not link to AACQA reports and uses the same ‘big tick’ symbol to denote facilities that are accredited and those that are currently being sanctioned for failing to meet the standards (figure 4.1).

Figure 4.1 **Information shown on *My Aged Care* about a residential aged care facility that does not provide appropriate clinical care or behavioural management**

 Accredited	
Accreditation period	1 Year
Certified	
Commonwealth Government subsidised	
 Current Sanctions	
 Current Notice of non compliance	
Availability	

Source: Australian Government (2017c).

This contrasts with the system operating in the United States, which has a ‘Nursing home compare’ website that includes a user-friendly star rating system — based on health, staffing and quality benchmarks — of registered nursing homes. Research in the Netherlands found that ‘an internet report card can be a useful tool for current and future consumers to assess the quality of nursing home care, and thus support their decision-making process regarding the choice of a nursing home’ (Van Nie, Hollands and Hamers 2010, p. 342). While the extent to which nursing home report cards and other similar rating systems are actually used by consumers to make decisions about care has yet to be definitively established, it is nevertheless in the interests of consumers to publish such information because of its potential to encourage provider self-improvement.

... and people can be reluctant to consider end-of-life care needs

The negative effects of the absence of information about expected standard of care in, and the quality of, residential aged care are compounded by a general reluctance to consider that

---

a move to residential aged care will be the last stage of life. As Palliative Care Australia put it:

... there is an unwillingness in the community to openly acknowledge that most people in residential care will be there until the end of their life. Legislation and policy are also silent on this matter. Consequently, when choosing a service the potential palliative care needs of the resident may not be given sufficient attention. (PCA 2016a, p. 4)

Increased efforts to promote and normalise advance care planning (section 4.4) may help to reduce this reluctance.

When selecting a RACF, consumers are also effectively making a choice about the type and quality of end-of-life care they will receive, although they (and their families) may be reluctant to recognise this. Some resources are available to support choice, such as a guide titled *10 Questions to Ask About Palliative Care in Residential Aged Care* (Combined Pensioners and Superannuants Association, sub. DR542). However, it is notable that government publications designed to guide consumer choice of a RACF do not mention end-of-life care. For example, *Five Steps to Entry into an Aged Care Home* (Department of Health 2016a) suggests eleven questions for consumers to consider when choosing an aged care home, but makes no mention of end-of-life and palliative care (or even that people's care needs will change and increase over time). Similarly, the *Aged Care Roadmap* (Aged Care Sector Committee 2016) is notable for its focus on making dementia care core business throughout the aged care system, without any mention of end-of-life care or palliative care.

A good first step would be for the Australian Government to ensure that all of its aged care publications — both for consumers and policy makers — explicitly acknowledge that one of the roles of residential aged care is to provide end-of-life care.

## 4.4 Advance care planning

Increasing the uptake of high-quality advance care plans (ACPs) — that is, a plan that is developed after conversations with family members, generally with the support of a trained clinician (box 3.5) — is a vital component of putting users' needs and choices at the heart of end-of-life care services.

Having conversations about end-of-life care and preparing an ACP should be routine for people with life-limiting illness. This is true despite ongoing interjurisdictional variation in legal frameworks for advance care planning, particularly those surrounding advance directives (AHMAC 2011). Uncertainty or lack of knowledge about the applicable laws is not sufficient justification to hold back on efforts to promote, and thus to forgo the benefits of, advance care planning.

There was broad agreement among inquiry participants (including Cabrini Palliative Care, sub. PFR343; HammondCare, sub. 407; LASA, sub. 463) and in the research literature (for example, Carter et al. 2016; Detering et al. 2010; Rhee, Zwar and Kemp 2012; Scott et



---

al. 2013) that a high-quality ACP is a key component of effective end-of-life care for people who would otherwise be unable to make their wishes known. Several studies and reports echoed these sentiments, while noting that competent and conversant patients can always speak for themselves, and should be supported to do so wherever possible.

While inquiry participants agreed on the importance of advance care planning, they expressed differing views about when and how to encourage it. Many advocated public awareness campaigns to encourage people to talk about death and dying, despite limited evidence that such campaigns lead to widespread behaviour change (box 4.7).

#### **Box 4.7 Encouraging people to talk about death and dying**

Many inquiry participants supported increased efforts to raise public awareness about death and dying and to encourage people to plan for their end-of-life care needs (for example, AHHA, sub. DR561; HammondCare, sub. 407; Institute for Healthcare Transformation at Deakin University, sub. DR587; LASA, subs. 463 and DR512). Some highlighted current initiatives to encourage talk about death and dying.

- The GroundSwell Project said that its 'Dying to Know Day' initiative is 'a national call to bring to life conversations about dying, death, loss and grief' (sub. DR566, p. 1).
- The Institute for Healthcare Transformation at Deakin University said that its DeathOverDinner campaign 'encourages people to have end-of-life conversations at the dinner table with family and friends rather than the ICU when it's too late' (sub. DR587, p. 18).
- The Palliative Care Outcomes Collaboration and Palliative Care Australia (sub. 417) cited Dying to Talk, Death Cafés and Compassionate Communities as examples of programs that help people to have conversations about their preferences for care at the end of life.

However, HammondCare (sub. 407, p. 4) noted that even advocates of public awareness campaigns acknowledged that 'available [ACP] resources go widely unused and campaigns to normalise its practice have only resulted in minimal uptake'.

While this may in part be due to what LASA (sub. 463, p. 9) described as a 'stigma' against discussing death and dying, it is also due to the complexity of the messages related to advance care planning. In some areas of public communications, such as road safety, people can be motivated to change their behaviour by inducing fear of an adverse outcome (an accident or a fine), and convincing them that behaviour change will reduce the likelihood of that outcome (Delaney et al. 2004). These motivations do not apply to advance care planning. Completing an advance care plan does not reduce the likelihood of death, or of being unable to communicate one's end-of-life care preferences. It merely reduces the consequences of this latter situation. There is also little evidence that passive education alone, without direct counselling, inspires and equips patients or clinicians to have difficult conversations and write plans for a future they are reluctant to imagine (Ramsaroop, Reid and Adelman 2007).

While public awareness campaigns can only ever be a small part of the solution in this space, measures to increase the availability of community-based palliative care (recommendation 4.1) will help to increase the 'death literacy' of family and friends (GroundSwell Project, trans., p. 65). Research also suggests that 'end-of-life caregiving provides a deeply personal connection to death and dying and is a catalyst to developing death literacy' (Noonan et al. 2016, p. 32).

---

Some participants, including Sarah Marlow (sub. DR490) and Palliative Care Western Australia (trans, p. 452) advocated strengthening incentives for completion of ACPs. Other participants considered that promoting the completion of ACPs should be secondary to promoting conversations. For instance, the Institute for Healthcare Transformation at Deakin University said that ‘the output of an advance care plan, directive or document *per se* is not the critical element. What is important is the process of having the opportunity to have numerous discussions with loved ones and suitably skilled professionals’ (sub. DR587, pp. 9–10).

For another group of participants, the timing of conversations about end-of-life care was the most important factor. For example, MND Australia said:

Discussions around end-of-life care need to be instigated as soon as the person with MND is ready, preferably before speech is affected, to ensure optimal interaction and communication to address their more profound concerns. (sub. DR513, p. 4)

On this latter point, the introduction of new standards for end-of-life care in acute hospitals (section 4.1) will be an important step, as the standards will require hospital clinicians to ‘identify opportunities for proactive and pre-emptive end-of-life care discussions’ (ACSQHC 2015a, p. 11). Given those changes, the Commission’s focus is on supporting advance care planning in primary care and residential aged care.

## **Supporting advance care planning in primary care**

When ACPs are prepared in a sensitive, professional way with appropriately trained doctors, nurses or allied health professionals (such as social workers), they are more likely to contain information that is both general enough to be applicable in most situations and specific enough to provide real guidance to the clinicians charged with the patient’s end-of-life care (HammondCare, sub. 407; Scott et al. 2013). Research also suggests there are clear benefits to advance care planning occurring in the primary care setting, before hospitalisation (ANZICS 2014; Scott et al. 2013).

HammondCare (subs. 407, DR515), LASA (sub. DR512) and PCOC and PCA (sub. 417) suggested that GPs and other primary care providers are well placed to facilitate advance care planning. Many other inquiry participants also supported this approach (including AASW, sub. DR557; ACSA, sub. DR541; AHHA, sub. DR561; CHA, sub. DR567; City of Whittlesea, sub. DR519; CHERE, sub. DR516; Silver Chain, sub. DR509; Tasmanian Government, sub. DR590).

## **Encouraging advance care planning in the GP’s office**

The Australian and New Zealand Intensive Care Society recommends incorporating advance care planning into the ‘75 plus’ health check (ANZICS 2014, p. 52). This fits well with the idea of high-quality advance care planning as an ongoing conversation — once someone has

---

an ACP, the annual health check provides a recurring opportunity to continue the conversation and revisit the plan if their circumstances or preferences have changed.

GPs are already required to complete a range of actions in order to claim the item numbers associated with the ‘75 plus’ health check (items 701, 703, 705, 707) (for example taking a detailed medical history, conducting a comprehensive physical examination and providing a preventive healthcare management plan). In addition to the mandatory items, the Australian Government has endorsed the use of the ‘75 plus’ health check for advance care planning (Decision Assist 2015). Currently this is optional and is not explicitly mentioned in the Medicare Benefits Schedule guidance notes for GPs.

The Commission considers that initiating an advance care planning conversation should be an additional requirement for GPs to claim item numbers associated with the ‘75 plus’ health check, where the patient has the cognitive capacity to meaningfully engage in such a conversation. The fact that ‘a patient’s health trajectory is often unknown and will continue to change’ (RACGP, sub. DR524, p. 1) should not preclude GPs from starting a conversation with patients about their future care needs. On the contrary, it is the inherent uncertainty of future care needs that makes early and high-quality advance care planning so important.

Initiating advance care planning may be as simple as providing written information (such as brochures or planning templates) and introducing the purpose and content of ACPs to the patient. This written information could address questions such as the benefits of ACPs, the legalities of advance care planning, the role of the substitute decision maker, and where people can get further advice. An increasing volume of advance care planning information is already available, much of it online, and some of which is targeted to specific users (for example, people with dementia) (HammondCare, sub. 407). Research indicates that written material is most effective if clinicians actively discuss the information provided with patients (Ramsaroop, Reid and Adelman 2007). As noted earlier, training is likely to be required to increase doctors’ confidence and skills in this area (box 4.1).

If a follow-up appointment is required, which will often be the case so that a family member or other substitute decision maker can be present, general Medicare item numbers could be used as they are currently.

### Practice nurses also have a role to play in advance care planning

Trained practice nurses or other allied health professionals are well placed to have advance care planning conversations. Advance care planning by trained nurses and health professionals has been shown to improve patient outcomes and also reduce stress, anxiety and depression in surviving relatives (Detering et al. 2010). A dedicated training package for practice nurses — called ‘Advance’ — is already operational. Supported by the Department of Health, Advance includes screening toolkits and assessment tools designed for use by nurses working in GP clinics (Advance 2017).

---

Despite this, the Australian Nursing and Midwifery Federation considered that nurses are underutilised in advance care planning (ANMF, sub. 474). The Commission agrees, and considers that trained practice nurses could facilitate more advance care planning conversations in primary care settings. As with other activities undertaken by practice nurses, the patient's GP would continue to play a role in overseeing the care provided, including 'the preparation, development and sign-off of plans or directives for their patients' (RACGP, sub. DR524, p. 2).

The involvement of practice nurses in advance care planning will be an important means of increasing the availability of advance care planning to those aged under 75 years who may be approaching the end of life. To enable this, a practice nurse item number for advance care planning should be created, enabling GP clinics to allocate their practice nurses' time to advance care planning facilitation.

#### RECOMMENDATION 4.3

The Australian Government should promote advance care planning in primary care by:

- including the initiation of an advance care planning conversation as one of the actions that must be undertaken to claim the '75 plus' health check Medicare item numbers. At a minimum, this would require a general practitioner to introduce the concept of advance care planning and provide written information on the purpose and content of an advance care plan
- introducing a new Medicare item number to enable practice nurses to facilitate advance care planning.

### **Making advance care planning a normal activity in aged care facilities**

Residential aged care providers should have ongoing conversations with residents about their goals of care or future care needs. Yet few residents of aged care facilities have ACPs, and not all RACFs have trained staff who can facilitate advance care planning in a professional, sensitive way. LASA identified this as a serious concern, noting that 'if a person has not been provided with information about advance care planning or a conversation has not been initiated prior to their admission into residential services then the system has failed them' (sub. 463, p. 6).

More could be done to ensure that people approaching the end of life in residential aged care are given the opportunity to record their preferences for future care (Alzheimer's Australia 2013). The AHHA (sub. DR561, p. 7) said that advance care planning needs to be 'normalised' as part of standard healthcare maintenance and planning. Research supports this view. Abbey said that aged care providers should be required to discuss advance care plans with any new clients entering the community or residential aged care system, describing it as a 'basic requirement for good care' (2013, p. 3).

---

The Draft Aged Care Quality Standards proposed as part of the development of a Single Aged Care Quality Framework include a requirement that assessment and planning ‘includes advance care planning and end-of-life planning if the consumer wishes’ (Department of Health 2017o, p. 19). While the mention of advance care planning in aged care regulations is a welcome development, the proposed standard still places the onus on the resident and the timing of such discussions is ‘guided by working with the older person and taking the lead from them’ (ACSA, sub. DR541, p. 3). Yet people typically wait for doctors or other care providers to broach the subject, while clinicians wait for patients or family members to do so (Scott et al. 2013). An external trigger is needed to break this cycle.

To this end, the Commission considers that the Australian Government should include requirements for ACPs in the aged care Quality of Care Principles, which are the standard against which RACFs are accredited. Many inquiry participants supported this approach (including AHHA, sub. DR561; Alzheimer’s Australia, sub. DR521; Benetas, sub. DR543; CHA, sub. DR567; CHERE, sub. DR516; PCA, sub. DR500; Silver Chain, sub. DR509 and UnitingCare Australia, sub. DR514). However, there were also some participants who expressed reservations.

Aged care providers should be required to ensure that clinically trained staff hold ongoing conversations with aged care residents about their future care needs. This would ideally be part of the role of nurses or nurse practitioners employed in the RACF, but could also be undertaken by GPs or as part of an arrangement with an external palliative care service. The requirement should include helping each resident (or their family or carers) to understand the purpose of ACPs, and to develop or update one. Aged care providers should demonstrate that they have met this requirement by having a current ACP for each resident, or by documenting that the resident does not wish to complete one, within two months of admission to the facility.

The requirement should be designed in a flexible and person-centred manner, so that it encourages conversations rather than ‘being “enforced” through regulatory standards in a manner that encourages “tick-a-box” compliance’ (HammondCare, sub. DR515, p. 3).

... the ongoing communication around goals of care, their clarification and/or amendment should be the focus of any recommendation and mandated requirement — rather than the completion of a document at any single point of time. (Little Company of Mary Health Care, sub. DR547, p. 8)

It should also be inclusive of the role that non-clinically trained staff, such as direct care workers and pastoral care staff, can play in good end-of-life care, as LASA (sub. DR512) and HammondCare (sub. DR515) pointed out.

While non-clinically trained staff should not be excluded from advance care planning conversations, as noted above, people are more likely to prepare ACPs and the advance care planning conversations are more effective, when they are guided by trained clinicians. Introducing a requirement for clinically trained staff to hold ongoing conversations with residents about their future care needs would substantially increase the extent to which a resident’s choices guide their end-of-life care.

---

#### RECOMMENDATION 4.4

The Australian Government should amend the aged care Quality of Care Principles to require that residential aged care facilities ensure that clinically trained staff hold conversations with residents about their future care needs. This should include helping each resident (or their family or carers) to develop or update an advance care plan (or to document that the resident would prefer not to complete an advance care plan) within two months of admission to the facility.

## 4.5 Effective stewardship of end-of-life care

The Commission's recommendations outlined above would go some way toward addressing weaknesses in government stewardship identified in chapter 3. This section considers how to address two other weaknesses in stewardship that were identified in chapter 3. They are:

- buck passing between the Australian, State and Territory Governments, which has hindered access to services and the coordination of care across different settings
- major gaps in the collection and publication of information about end-of-life care, which has constrained the capacity of governments to plan, monitor and improve the provision of end-of-life care services.

The section also considers how improved stewardship could be facilitated in the longer term through an overarching review of end-of-life care.

### Cross-jurisdiction co-operation in end-of-life care

The Commission's recommendations to strengthen the role of State and Territory Governments in community-based palliative care (recommendation 4.1), and the Australian Government in residential aged care (recommendation 4.2), will help to clarify stewardship responsibilities and deliver improvements in care in those settings. However, without improved collaboration between levels of government, there will continue to be gaps, overlap and uncertainty which will hinder access to services and the coordination of care between residential aged care, community-based palliative care, hospitals and primary care.

The Council of Australian Governments (COAG) Health Council should be the lead forum for cross-jurisdiction collaboration on end-of-life care. It is comprised of Government Ministers with responsibility for health matters from the Australian, State, Territory and New Zealand Governments, and was established to enable cross-jurisdiction co-operation on health issues, especially primary and secondary care, and to consider increasing cost pressures. The COAG Health Council has an advisory and support body, the Australian Health Ministers' Advisory Council (AHMAC), which operates as a national forum for planning, information sharing and innovation. Given their clear responsibility for health care and frequent consideration of aged care matters, the COAG Health Council and AHMAC

---

provide a forum for jurisdictions to co-operate in planning, funding and delivering end-of-life care, so that patients receive integrated services across different settings and jurisdictions.

A recent example of collaboration between the Australian, State and Territory Governments to improve end-of-life care is the current discussions to update the National Palliative Care Strategy (chapter 3). It is expected that the revised strategy will be endorsed by AHMAC, as has occurred previously. While past versions of the strategy have lacked substance and had limited effectiveness, there are signs that the next iteration may be more useful. At the time of writing this report, a draft of the strategy had been published which included a national governance structure for end-of-life care which would operate under AHMAC to:

- provide oversight of implementation and monitoring of the National Palliative Care Strategy
- strengthen mechanisms for collaboration and knowledge transfer (Urbis 2017, p. 12).

The creation of an end-of-life care governance structure that reports to AHMAC (and through it to the COAG Health Council) is an essential component of cross-jurisdiction collaboration for end-of-life care.

Governments also need to collaborate in establishing standards for high-quality end-of-life care in each of the settings in which it is provided. They have done so in some areas, such as the updated version of the National Safety and Quality Health Service Standards, which will apply to hospitals in all jurisdictions from 2019 (section 4.1). Cross-jurisdiction co-operation in setting standards for end-of-life care should continue.

## **Data on end-of-life care**

Too often, data on end-of-life care are not collected or are not widely available, making it difficult or impossible to examine usage patterns, costs or outcomes. Several inquiry participants, including the Health Performance Council of SA (sub. 437), PCA and PCOC (sub. 417), the RACP (sub. 473), and the Tasmanian Government (sub. 485) called for a coordinated approach to improving data on end-of-life care.

The Commission agrees that collecting and using better data on end-of-life care is essential for the Australian Government to fulfil its role as steward of end-of-life care in residential aged care, and State and Territory Governments to fulfil their roles as stewards of end-of-life care in hospitals and community-based palliative care.

### **National data strategy for end-of-life care**

Each government could work independently to deliver some of the necessary data improvements. For example, the Australian Government Department of Health recently contracted the AIHW to undertake palliative care data development activities, including

---

improving access to existing data and developing new and improved data sources (AIHW, sub. DR508). But these data development activities cannot be successfully achieved in isolation. A comprehensive and coordinated approach will require the development of a national data strategy for end-of-life care, overseen by the COAG Health Council, that:

- establishes a national minimum data set for end-of-life care
- improves the accessibility of patient-level data so that they are used to deliver high-quality care
- uses system-level data to enable governments to plan, monitor and evaluate how well end-of-life care services are meeting users' needs and to drive improvements in end-of-life care.

Accountability for the national data strategy for end-of-life care should be established via AHMAC, reporting to the COAG Health Council. One potential way forward would be to form a new subcommittee for end-of-life care data, under existing AHMAC information management committees and the proposed new national governance structure for end-of-life care (which also reports through AHMAC to the COAG Health Council). The end-of-life care data subcommittee could perform an equivalent function in end-of-life care to that performed by the National Mental Health Performance Subcommittee in mental health.

Inquiry participants supported the development of a national data strategy for end-of-life care (including AHHA, sub. DR561; Benetas, sub. DR543; Breast Cancer Network Australia, sub. DR534; Cancer Council NSW, sub. DR537; Catholic Health Australia, sub. DR567; CHERE, sub. DR516; City of Whittlesea, sub. DR519; Sandra Coburn, sub. DR558; Little Company of Mary Health Care, sub. DR547; Palliative Care Australia, sub. DR500; RACP, sub. DR580; Silver Chain, sub. DR509).

### Developing a national minimum data set for end-of-life care

One aim of the data strategy should be to establish a national minimum data set for end-of-life care. This would require gathering more data (for example, information about the number of hospital patients who usually reside in a RACF; the availability of community-based palliative care in different regions; or the prevalence of ACPs) or drawing on existing data collections (notably the data on care delivery and outcomes collected by the Palliative Care Outcomes Collaboration).

Collection processes for additional data should be streamlined and rely on existing systems where possible. For example, the AIHW said that existing State and Territory health information systems could be used to address some of the recognised data gaps, including palliative care-related expenditure (sub. DR508).



---

The national minimum data set for end-of-life care should include, in the first instance, linked basic information about a person's end-of-life care, such as:

- place of death. Sufficiently detailed information about location to enable comparison between different locations and settings should be available, along with the name of the institution for hospital, hospice and RACF deaths
- primary and secondary diagnoses. For example, a patient with advanced dementia who died from pneumonia should have both conditions documented
- details of service provision at time of death. This should include details of what, if any, health care or residential care funding they received at the time of death, at what level and for how long, so that the mean and median duration of care provision in both specialist and generalist settings, as well as variance around those measures, can be tracked
- patients' end-of-life care preferences (starting with whether the deceased had an ACP).

Other relevant information might include the number and duration of hospital visits in the last year of life, whether the deceased was receiving active treatment or palliative care at the time of death, whether the ACP (if one existed) was followed and if not, why not, and details of any additional support received. This might include support from a family member, carer or volunteer.

Resulting data should be published, shared between governments and made available to researchers in accordance with the framework for data sharing and release outlined in the Commission's report on *Data Availability and Use* (PC 2017a).

The costs of collecting additional data will depend on the nature and extent of gaps in existing data collections. These may vary between jurisdictions, providers and settings of care, with details determined during development of the end-of-life care data strategy. Improvements to efficiency resulting from better data would contribute to a reduction in costs.

### Using data to improve patient care

In addition to collecting and linking more data, the national end-of-life care data strategy should seek to address problems with data at the patient level. One area of focus should be the accessibility of data within and between care settings.

Effective coordination of documentation for end-of-life care patients transferring between settings is 'critical' especially when patients are near death (Manias et al. 2017, p. 25). This is not always achieved, however, and poor transfer of information at transitions of care has been identified as a key safety and quality issue for patients with complex healthcare needs, such as people approaching the end of life. For example, even when someone has prepared an ACP, it is not uncommon for it to be overlooked or ignored. HammondCare said that ACPs were often not used because they were not available when they were needed,

---

particularly ‘when care moves across settings, or occurs out of hours, or when locums may be used’ (sub. 407, att. 1, p. 26).

One way to improve the transfer of patient information across settings would be through greater use of the My Health Record (MHR) system. The MHR is a secure, online summary of a person’s health information. Inquiry participants, including AHHA (sub. 427), MIGA (sub. 432), HammondCare (sub. 407), and Christy Pirone, Margaret Brown, Dr Chris Moy and Dr Christine Drummond (sub. DR559), supported making greater use of the MHR system, particularly as an access point for ACPs.

Participation in the MHR system is currently voluntary for patients and providers, but an opt-out approach is being adopted over 2017-18 and 2018-19. The Department of Health estimates that 98 per cent of the Australian population will have an MHR by 1 December 2018 (Australian Government 2017b; Department of Health 2017m). There is still work to be done on the clinical usability of the MHR system, however. For example, it is not fully interoperable with existing software used by many health practitioners and does not contain a patient’s full health record, with much information (including hospital data) retained on local systems (PC 2017a). In developing the national end-of-life care data strategy, governments should consider the role of the MHR system, including whether additional incentives are needed to encourage its use in end-of-life care.

### Driving system-level improvements in end-of-life care

Data that allow performance monitoring and evaluation of government activities are a fundamental starting point for improving the delivery of those activities to the community (PC 2017a). Data on end-of-life care are no exception.

As Casarett, Teno and Higginson (2006) pointed out, the stakes are particularly high in end-of-life care, since the ageing population, in which an increasing number (and proportion) of people have a prolonged period of decline and substantial needs for care, magnifies the problems arising from insufficient data, and therefore the benefits associated with improved data availability and use.

In the short run, improvements to service delivery would follow from performance monitoring and comparison of usage patterns, costs and outcomes. This would inform government policy by identifying areas that should be priorities for improvement and describing the effectiveness of existing programs, as well as their cost effectiveness. It would also allow health care providers (and patients) to compare their own performance with that of the sector, and support providers to engage in greater self-improvement activity. For example, Benetas said:

This information could not only inform government policy, it would also provide the sector with invaluable information to help improve service delivery. (sub. DR543, p. 4)

In the long run, better data on end-of-life care would enable governments to accurately plan for future end-of-life care needs at the population level. This is particularly important, given

---

the substantial increase in demand for end-of-life care that is expected over the coming years (chapter 3). Better data would help guide capacity building and funding decisions, such as decisions about training of healthcare professionals in end-of-life care. It would also help policy-makers to anticipate how demographic trends will affect future needs and priorities for care delivery (Casarett, Teno and Higginson 2006; OECD 2017b).

Better data would also help to ensure that government policies reflect public priorities and assist governments to better understand the quality of care provision, including patients' psychosocial experiences and other details about their care. This could be achieved by recording the experiences of family and carers, as is done in the United Kingdom (box 4.8).

#### **Box 4.8      The VOICES survey of bereaved people**

In England, the Office for National Statistics runs an annual National Survey of Bereaved People (known as the VOICES survey), which collects information on people's views on the quality of care provided to a friend or relative in the last 3 months of life.

The survey includes questions about the physical and practical experiences of dying, including perceived pain relief and coordination of care, but also about some of the psychosocial aspects, including the perceived level of deprivation, dignity and respect, and the level of support for relatives, friends or carers at the end of life. The results of the survey are used to inform policy decisions and to enable evaluation of the quality of end-of-life care in different settings, across different ages and different causes of death.

*Source:* Office for National Statistics (2016).

### **Reviewing the end-of-life care system**

The recommendations proposed by the Commission are designed to put users' needs and choices at the heart of end-of-life care services in Australia, and to improve the availability and quality of end-of-life care in each of the settings in which it is currently provided. Several participants called on the Commission to go further, and to recommend the creation of a separate end-of-life care system. For example:

- Hobart District Nursing Service said that 'the time has come for palliative and end-of-life care to be separately funded to reach across age and funding barriers' (sub. DR581, p. 1)
- Sarah Marlow considered that 'funding needs to be available through Medicare to access palliative and [end-of-life] care services at home with no assets testing to ensure that all Australians, irrespective of age and financial circumstances have equal and unbiased access to high-quality health care at home' (sub. DR490, p. 2)
- Benetas suggested that there could be scope for palliative care services to achieve 'synergies and amalgamation with the Commonwealth [aged care] home care program over time' (sub. DR543, p. 2).

---

One-off reviews can be useful in identifying issues and finding solutions for larger systemic issues of this nature (chapter 2).

By 2025, many aspects of end-of-life care in Australia will have changed. First, the demand for end-of-life care will increase significantly — by 2025, the annual number of deaths in Australia is projected to reach 180 000, representing a 15 per cent increase from 2015 (Productivity Commission estimates based on ABS 2013b, 2016c). Not only will there be more people in need of end-of-life care, but each person's care needs are likely to be greater, as a growing proportion of people will die from frailty, dementia and other chronic diseases whose trajectory is uncertain (chapter 3).

In 2025, the services available to people approaching the end of life will also need to be substantially different to those currently available, as current services are not meeting the needs of people approaching the end of life. Ideally, there will be substantially more end-of-life care provided in people's homes. There will also be significant changes in aged care, where ongoing reforms are in progress (Department of Health 2017a) and many reviews have recently been completed or are underway (for example, Department of Health 2017e, 2017h, 2017o; McNamee et al. 2017).

Stewardship arrangements will also be different in 2025, following the planned establishment of a national governance structure for palliative and end-of-life care with a formal link to AHMAC, and through it to the COAG Health Council.

The Australian, State and Territory Governments should undertake a comprehensive review in 2025 to assess whether end-of-life care services are meeting the needs of people approaching the end of life and the costs and benefits of doing so. The review should be conducted by an independent body, so that it can objectively examine the roles and responsibilities of each Government and the mechanisms used for cross-jurisdiction collaboration. It should examine the effectiveness of end-of-life care across all settings in which it is, or should be, provided. It should also consider the extent to which funding and other stewardship arrangements are contributing to the quality, equity, efficiency, accountability and responsiveness of end-of-life care throughout Australia. The review would also provide opportunity to consider the effectiveness of, and possible reforms to, the proposed national governance structure for palliative and end-of-life care.

---

#### RECOMMENDATION 4.5

The Australian, State and Territory Governments should, through the Council of Australian Governments (COAG) Health Council, ensure that there is cross-jurisdiction co-operation to:

- plan, fund and deliver end-of-life care so that patients receive integrated services across different settings and jurisdictions
- set standards for end-of-life care in each of the settings in which it is provided (such as those that will apply to end-of-life care in hospitals in all jurisdictions from 2019)
- monitor and evaluate end-of-life care services.

The COAG Health Council should oversee the development and implementation of a data strategy for end-of-life care that:

- establishes a national minimum data set for end-of-life care (including collecting and publishing linked information on place of death, primary and secondary diagnoses and details of service provision at time of death)
- improves the accessibility of patient-level data (such as advance care plans or hospital discharge summaries) so that they are used to deliver high-quality care
- uses system-level data to enable governments to plan, monitor and evaluate how well end-of-life care services are meeting users' needs across all settings and jurisdictions, and to drive improvements in end-of-life care.

The COAG Health Council should, in 2025, commission an independent review of the effectiveness of end-of-life care across all settings in which it is, or should be, provided.