

2019

# PALLIATIVE CARE IN THE CATHOLIC SECTOR

A report by Catholic Health Australia

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CATHOLIC HEALTH  
Australia

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**“Our care for people who are sick, frail, aged or disabled is founded on love and respect for the inherent dignity of every human being.”**

Code of Ethical Standards for Catholic Health and Aged Care Services in Australia, 2001

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## 1.2 THIS REPORT

Over 80 hospitals, more than 25,000 aged care residential beds and numerous community care services are operated by different bodies of the Catholic Church within Australia. Together, these services employ over 83,000 people.

CHA promotes the ministry of health care as an integral element of the mission of the Catholic Church. It works to fully provide health care in accordance with Christ’s ministry to the sick, the aged and the dying. This ministry is founded on the dignity of the human person, giving preference to the needy, suffering and disadvantaged.

CHA is the peak member organisation of these health and aged care services.  
Further detail on CHA may be obtained at [www.cha.org.au](http://www.cha.org.au)

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## 1.3 ABBREVIATIONS

ABF	activity based funding
ACFI	Aged Care Funding Instrument
ACP	advanced care plan
ACT	Australian Capital Territory
AHSRI	Australian Health Services Research Institute
AIHW	Australian Institute of Health and Welfare
ALOE	average length of episode
ALOS	average length of stay
AN-SNAP	the Australian National Sub-Acute and Non-Acute Patient Classification
APCP	ambulance palliative care plan
BM	benchmark
CALD	culturally and linguistically diverse
CHH	Clare Holland House
CHA	Catholic Health Australia
CMN	Calvary Mater Newcastle
COPD	chronic obstructive pulmonary disease
DVA	Department of Veteran Affairs
EOL	end of life
EOLC	end of life care
FTE	full-time equivalent
GOC	goals of care
GP	general practitioner
ICU	Intensive Care Unit
LGBTI	lesbian, gay, bisexual, transgender or intersex
LHD	local health district
MBP	minimum benefits payable
MBS	Medicare Benefits Schedule
MND	motor neurone disease
MRFF	Medical Research Future Fund
NFR	not for resuscitation
NPA	Northern Peninsula Area
NPCA	National Palliative Care Alliance
NSW	New South Wales
OPCCT	Older Person-Centred Care Team
PaCCSC	Palliative Care Clinical Studies Collaborative
PC	palliative care
PCA	Palliative Care Australia
PCOC	the Australian Palliative Care Outcomes Collaboration
PEPA	Program of Experience in the Palliative Approach
PHI	private health insurance
PHN	primary health network
QLD	Queensland
RACF	residential aged care facility
SA	South Australia
SPC	specialist palliative care
SHHS	Sacred Heart Health Service
SVHA	St Vincent's Health Australia
SVHM	St Vincent's Hospital Melbourne
UK	United Kingdom
VAD	voluntary assisted dying
VMO	visiting medical officer
WA	Western Australia
WHO	World Health Organization

# 1. EXECUTIVE SUMMARY

More Australians will need end of life services including palliative care (PC) in the coming years than ever before. Australia has an ageing population and an increasing burden of chronic disease, which ultimately leads to a larger number of deaths per year. Yet PC rarely rates as a political issue on its own merits with the exception of the relationship as an alternative to voluntary assisted dying (VAD). We, as a nation, need to embrace and resource PC as an integral part of health care that affects everyone in society.

While efforts at all levels of government in Australia are being made to improve end of life care (EOLC), for those delivering service the frustration with systemic barriers inhibiting the care of the dying is palpable. Australia is ranked second in the world for quality and access to PC services, which should be an indicator that our PC system is well resourced and integrated. However, where consistent access to appropriate levels of PC should be given from the time of diagnosis of a life-limiting illness, the reality is that identification of PC needs and referral to PC services is late and treatment is fragmented.

The aim of this report is to contribute to the quality and quantity of information that PC organisations including Catholic Health Australia (CHA), policy makers and decision makers have available. This report uses internally collected and nationally available data and semi-structured interviews from over 30 PC clinicians, PC nursing staff, managers, administrators and researchers from CHA member organisations.

CHA members form a national network of over 80 hospitals, more than 25,000 aged care residential beds and numerous community care organisations. No previous work has been carried out to systematically map and categorise the wide variety of PC activities and programmes in the Catholic sector, to understand the potentially wide-ranging impact of these activities or to explore ways in which further collaboration between CHA members might benefit.

In undertaking this report it is important to recognise the limitations of our ability to capture the scope of PC in the Australian health care system. There is no comprehensive national PC data collection. Also, PC is delivered in many settings, with different funding sources, different reporting requirements and is delivered by a number of different professionals. Capturing the scope of services is difficult to say the least. However, it is crucial that we use the data and expertise available in an attempt to quantify and describe services available to understand where gaps exist, how services can be improved and where potential partnerships may be facilitated.

CHA members provide 13 per cent of all PC-related hospitalisations in Australia. In the private sector, CHA members make up the majority of PC inpatient provision and have more than 52 per cent of private inpatient beds. CHA member tertiary services also outperform other services in many of the measured patient outcomes.

CHA members also provide community-based PC services in both the public and private sectors and are among the first organisations to provide private health insurance funded PC in the community setting. CHA community PC services face similar challenges to non-

CHA services in achieving patient outcomes, constrained heavily by resourcing.

There are many innovative PC programs operating across Australia aimed at meeting local population need, improving equity of access, enabling at home death and improving the knowledge-base of PC service delivery. Systemic barriers to continued improvements in PC including remuneration levels, funding models, fragmentation, workforce shortages and lack of awareness of PC limit the longevity of innovative programs and access to PC in general.

This report provides the following recommendations for consideration by decision and policy makers developed from data analysis and interviews with subject matter experts:

1. **Establish a National Palliative Care Alliance** to act as an expert independent advisory body to the Australian Government on issues relating to PC.
2. **Address systemic funding and access issues.** This includes urgently reviewing explicit or implicit time dependent access requirements, levels of remuneration and barriers to service inbuilt in funding models and public hospital payments.
3. **Strengthen community-based PC to increase at-home death rates and reduce hospitalisations.** This requires increases in resourcing for community services, intensive 24-hour access to telephone support and PC consultancy for all community PC services. Mechanisms to expand the services provided by organisations with existing capabilities should be considered.
4. **Build the capacity of the health and aged care workforce to recognise and respond to PC needs.** The development of capabilities frameworks for aged care and health care staff, ongoing funding for education programs and strategies to address urgent shortage of trained PC nursing staff are needed.
5. **Establish a national minimum data set for PC data collection and continue to work on validated indicators to assess improvement in PC delivery.**
6. **Invest in drivers of innovation including increasing PC research funding** using targeted funding opportunities such as the Medical Research Future Fund (MRFF).
7. **Initiate the conversation to improve PC awareness** through funding for specialist palliative care (SPC) services and other appropriate organisations to improve end-of-life literacy and community education about PC, end-of-life planning, death and dying.

CHA and its members can also contribute to improving the PC sector for all Australians. This can be achieved by:

1. **Continuing to advocate for improvements to PC in Australia.**
2. **Expanding knowledge exchange activities through the establishment of a Catholic Palliative Care Alliance.**
3. **Engaging with members to facilitate a PC and EOLC issues awareness campaign.**
4. **Developing and communicating VAD position statements and disseminating staff educational resources.**

**BOX 1****DEFINING PALLIATIVE CARE AND END OF LIFE CARE**

Palliative care (PC) and end of life care (EOLC) are related but distinct concepts of holistic care of the dying. EOLC generally refers to care of an individual in the last 12-months of life, which is not necessarily provided by specialist staff however, may incorporate elements of PC.

**EOLC**

*The National Consensus Statement: Essential elements for safe high-quality end-of-life care* defines EOLC as (1, 2):

“physical, spiritual and psychosocial assessment, and care and treatment delivered by health professionals and ancillary staff. It also includes support of families and carers, and care of the patient’s body after their death. People are approaching the ‘end of life’ when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:

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

**PC**

PC is an approach for how to live with a life-limiting illness until death, rather than how to die. PC is not limited to the final year of life and has been shown to be more effective when used early in the course of a life-limiting illness (8), (9). The Consensus-Based Definition of Palliative Care defines PC as (11):

“PC is the active holistic care of individuals across all ages with serious health-related suffering<sup>i</sup> due to severe illness<sup>ii</sup>, and especially of those near the end of life. It aims to improve the quality of life of patients, their families and their caregivers. PC:

- Includes, prevention, early identification, comprehensive assessment and management of physical issues, including pain and other distressing symptoms, psychological distress, spiritual distress and social needs. Whenever possible, these interventions must be evidence based.
- Provides support to help patients live as fully as possible until death by facilitating effective communication, helping them and their families determine goals of care.
- Is applicable throughout the course of an illness, according to the patient’s needs.
- Is provided in conjunction with disease modifying therapies whenever needed.
- May positively influence the course of illness.
- Intends neither to hasten nor postpone death, affirms life, and recognizes dying as a natural process.
- Provides support to the family and the caregivers during the patient’s illness, and in their own bereavement.
- Is delivered recognizing and respecting the cultural values and beliefs of the patient and the family.
- Is applicable throughout all health care settings (place of residence and institutions) and in all levels (primary to tertiary).
- Can be provided by professionals with basic palliative care training.
- Requires specialist palliative care with a multiprofessional team for referral of complex cases.”

i Suffering is health-related when it is associated with illness or injury of any kind. Health related suffering is serious when it cannot be relieved without medical intervention and when it compromises physical, social, spiritual and/or emotional functioning. Available at <http://pallipedia.org/serious-health-related-suffering-shs/>

ii Severe illness is understood as any acute or chronic illness and/or condition that causes significant impairment, and may lead to long-term impairment, disability and/or death. Available at <http://pallipedia.org/serious-illness/>

## 2. INTRODUCTION

In recent years, PC has attracted world-wide interest following the realisation of the economic and social value of PC and good EOLC in general (16). Australia's PC services are among the best in terms of integration, quality, affordability and accessibility in the world (17). Australia is ranked as the second-best country in the world (after the United Kingdom (UK)) in which to die, largely due to the existence of subsidised PC services, PC training resources, general public awareness of PC and the availability of analgesics for pain relief (17).

Investment in and recognition of the value of PC have resulted in significant improvements in the number of people receiving PC in hospital and the outcomes of PC in hospital and the community. However, attainable improvements remain, and many consider Australia's health care system underprepared for the estimated demand on PC services that will result from an increasingly ageing population and the introduction of VAD (Box 3-4).

### BOX 2 PC ACTIVITY IN AUSTRALIA

Data collection on PC activities in Australia is not comprehensive and grossly underestimates the level of activity in all settings. The most recent data reported (2015-16 or 2016-17) (6):

- 73,900 PC-related hospitalisations were reported from public acute and private hospitals. This represents a 28 per cent increase in PC hospitalisations between 2011-12 and 2015-16.
- Eighty-five per cent of PC-related hospitalisations were in public hospitals.
- Approximately 50 per cent of people who die in hospital had received PC, an increase of 11 per cent since 2011-12.
- One in 50 aged care facility residents had an Aged Care Funding Instrument (ACFI) appraisal indicating the need for PC.
- Medicare Benefits Schedule (MBS)
  - subsidised palliative medicine specialist services increased by 31 per cent between 2012-13 and 2016-17.
- PC and EOLC within general practice are estimated to account for 1 in every 1,000 GP consultations (12).

While not all people who are dying will benefit from PC, there is a large disparity in the number of people who would likely benefit from PC and those that receive PC. It is estimated that 90 per cent of cancer patients and 50 per cent of non-cancer patients could benefit from PC services, yet only half of them actually receive it (6, 18, 19).

There are also consistently groups of people who fail to access PC. These include, but are not limited to, the elderly, particularly in terms of access to early PC (20), Indigenous Australians (21, 22) and those living in regional and remote Australia (22). The Productivity Commission's report on Human Services acknowledges long standing concerns with equity of access to quality PC as a result of variability in access for those in non urban areas, inadequate access to 24 hour services and under servicing a number of population groups (23).

***"The assumption that everything is fine: no everything is really not fine. Come and do a ward round with me and see, even in a well-resourced hospital, that really cares about these patients, where all the holes are, where all the resource gaps are, all those people that fall through the cracks and where all the opportunities are for us to do that extra bit."***

There are evidence-based societal and economic arguments for improving PC in Australia. PC is effective in relieving symptom burden, improving quality of life for those involved and even prolongs survival in some instances (24, 25). Studies indicate pain, fatigue, impaired appetite, weight loss, constipation, nausea and shortness of breath as the most prevalent or distressing symptoms associated with a life-limiting illness (26). More than 85 per cent of PC patients have no severe symptoms by the time they die (27).

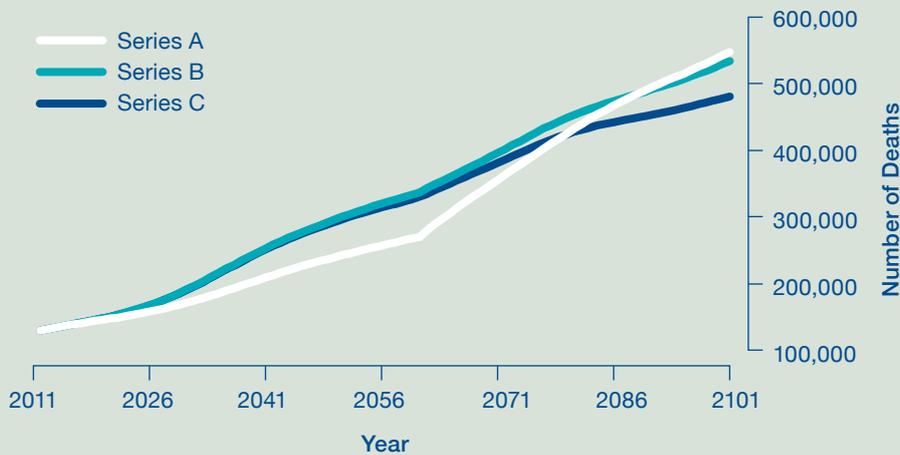
PC can also support people to die in their setting of preference. In Australia, an estimated 54 per cent of people die in hospitals and only 14 per cent die at home (23), when 50 to 70 per cent of people prefer to die at home (28, 29). We know that better is possible; in countries such as the UK, 42 per cent of deaths occur at home or in at-home care. Fundamentally, poor access to quality PC, particularly community-based PC, means many Australians are unable to exercise their preferences at the end of their life (23, 30, 31).

Economic arguments are based on the cost-effectiveness of PC with overall savings attainable different in all settings (32, 33). Studies report that community-based PC is more cost-effective than tertiary care driving calls to expand community-based PC services (32-35). In 2012, the Senate Community Affairs References Committee found that PC costs around \$7,700 per episode in a sub-acute hospital care compared with \$2,500 for community-based care (36). The Silver Chain Group also estimates that each dollar invested in extending home-based PC services in NSW would free up \$1.44 of expenditure on inpatient beds (34).

### BOX 3 DOES AUSTRALIA HAVE CAPACITY TO MEET DEMAND FOR PC SERVICES?

Demand for PC services is predicted to increase dramatically over the coming decades. By 2056, those aged over 65 will increase from 15 per cent to 22 per cent and the proportion of people aged over 85 will double (4). As a result of the ageing population and high rates of chronic disease, the number of deaths is increasing rapidly and is predicted to more than double by 2061 (Fig. 1) (7).

**FIGURE 1  
PREDICTED DEATHS**



Source: ABS 3222.0 – Population Projections, Australia, 2012 (base) to 2101\*

Ninety per cent of participating CHA members held the view that PC services in Australia were inadequate to meet current and future demand. Among those who agreed that Australia had capacity to meet demand was the opinion that achieving this required augmentation of the rigidity of current models, whereby tertiary services are used for complex symptom control and appropriate step-down care is available:

***“the current models are not flexible enough. The community model has been too rigid to allow integration while having active treatment, and to allow people to come on and off the program.”***

\*These three series A B and C are projections that have been selected from a possible 72 combinations of various assumptions with Series B reflecting current trends in fertility, life expectancy at birth, and migration.

## 2.1. POLICY CONTEXT

A focal point of PC policy has become reducing the number of PC-related hospitalisations and a shift towards community-based PC, as outlined in the soon to be superseded National Palliative Care Strategy 2010 – Supporting Australians to Live Well at the End of Life (37), (38). This is both from an economic standpoint and that few people choose hospital as their preferred place to die. There will always be a need for tertiary PC services, which is likely to increase in the coming years, however, hospital should not be a place to die simply because PC in other settings is under-resourced.

As community PC strengthens, those admitted to hospital will statistically be frailer and more likely to die during a hospital episode. Therefore, it is important that policy includes the difficult and controversial task of identifying and reducing “potentially avoidable” hospital admissions (39).

Broader developments in the landscape likely to impact on PC provision in Australia includes the Voluntary Assisted Dying Act 2017 (Vic) (Box 4). Concerns with the VAD legislation include inadequate resourcing of already strained PC services to deal with an increased workload following the introduction of VAD.

## 2.2. MODELS OF PC

PC is provided in a variety of settings in Australia (Table 1). This includes dedicated PC services delivered in inpatient settings including hospices and hospital consultancy, outpatient settings, primary care settings and in community-based services (40). PC support is delivered by a multidisciplinary team of health care workers including specialist clinicians, general practitioners (GPs), nurses, social workers, allied health professionals and pastoral care staff with the support of administrative staff, volunteers and management staff.

A common aim of all models of PC is to achieve a good life until a good death. This encompasses a holistic approach to care including symptom control and consideration of social, emotional and spiritual wellbeing (41). There is no uniformly accepted model of best-practice to achieve this, particularly with regards to the balance between acute and community-based service integration.

The UK has the most highly regarded PC system in the world, providing the best quality of death and quality of PC (42). System-wide improvements in access to quality PC in the UK were achieved following the development of the End of Life Care Strategy in 2008. Key elements to success of the strategy were improved public awareness through a media campaign and public engagement, as well as workforce development and organisational guidance which improved early identification of people nearing the end of life. This resulted in an increase in the number of expected deaths seen by palliative or hospice services (43). The drive towards EOLC delivered outside of a hospital setting has also been successful with 42.4 per cent of people dying at home or in-home care in the UK in 2012, compared to 14 per cent of Australians (44).

### BOX 4 VAD AND PC

While this report does not focus on VAD, it is written in the context of the introduction of VAD legislation in Victoria. In November 2017, Victoria passed the Voluntary Assisted Dying Act 2017 (Vic) (3), due to be implemented in June 2019. A relatively small number of people are likely to be eligible to access VAD services in Victoria and as such, VAD serves as a distraction from the larger issue of addressing increasing demand for EOLC services in general (5).

CHA has established an End of Life Committee to address issues arising from the introduction of VAD for the Catholic sector. CHA’s response to the introduction of VAD legislation and related enquiries articulate the organisation’s opposition to the introduction of VAD (13, 14). Concerns raised include the lack of current resourcing to ensure the adequacy of alternative EOLC pathways.

There is a great need for information on, and attention to, the resourcing of PC services to cope with the introduction of VAD. Concerns raised during participant interviews for this report include the additional burden placed on PC services without adequate concurrent increases in funding. These concerns have support; internationally, where similar VAD legislation has been approved, services experienced increased workload on PC services generated by referrals, staff training and additional services (15).

***“There are lots of misperceptions of what dying looks like and what can actually be achieved. Unless people have that understanding in place then they will make choice based on what they know.”***

**TABLE 1**  
**MODELS OF PC**

TYPE	SETTING	DESCRIPTION
SPC inpatient units	Inpatient units of public and private hospitals	SPC services are provided by multidisciplinary teams with specialist PC trained teams for patients with complex needs
Non-designated SPC inpatient services	Non-designated SPC areas in public and private hospitals	SPC consultancy teams provide care to patients in other areas of the hospital. Consultancy teams also provide support, education and training to outpatient clinics and to community PC services
Ambulatory PC hospital services	PC provided as an outpatient in a hospital setting or in a community setting	Referral basis from inpatient units or from the community for interdisciplinary assessment, care planning and interventions
Hospice	May be integrated in a hospital, RACF or as a free-standing facility	Designed to be a home-like environment with access to SPC equipment and staff. Day hospices may also be accessed for short-term respite for carers
SPC community services	PC provided "in place". This can be in an RACF or disability service, at home, prison, mental health facilities or in community health services	Multidisciplinary PC competent teams with a focus on care provided by nursing and allied health staff. May be nurse or physician led
Primary care community-based services	GP clinics and other primary care services	Type of health care worker varies and includes GPs, nurses and/or allied health staff

## BOX 5

### AN EXAMPLE OF A SUCCESSFUL COMMUNITY-BASED PC MODEL - THE SILVER CHAIN GROUP

The Silver Chain Group supplies most of community-based PC in Western Australia (WA), as well as some services and partnerships in Queensland (QLD), New South Wales (NSW), South Australia (SA) and Victoria.

Silver Chain WA has successfully achieved an at-home or RACF death rate of 70 per cent. Contributing to this success is the ability of Silver Chain to leverage economies of scale, as 90 per cent of community-based PC in WA is delivered by Silver Chain. The resourcing of the PC community sector in WA has also enabled Silver Chain to innovate in service delivery, with several trials of the use of technology to remotely monitor symptoms and deliver PC underway.

Silver Chain also attributes this success to their clinician-led model of service. St Vincent's Sacred Heart community service in NSW also provides a clinician-led model of community PC achieving admirable at-home death rates. Several other CHA members employ a variation on this model; a nurse practitioner or nurse-led model. These nurse-led models are worthy of consideration as a cost-effective alternative to clinician-led PC (section 6.2).

## 2.3. FUNDING MODELS

PC in Australia is funded by the Commonwealth, state and territory governments, private health insurers and/ or individuals. The source of funding for PC is typically determined by the setting in which it is delivered and the type of health care professionals that are involved (Table 2).

States and territories are the principal source of funds for PC in Australia. In 2015-16, 85 per cent of PC-related hospitalisations were recorded in public hospitals (6). Public patient funding accounted for 75.9 per cent and private health insurance funded 19.8 per cent of these hospitalisations.

**TABLE 2**  
**SOURCE OF PC FUNDING**

SERVICE	FUNDING SOURCE	PAYMENT TYPE
Public hospital services	Mostly state/territory governments but also includes other revenue sources such as private health insurance and the Commonwealth Government	<ul style="list-style-type: none"> <li>State/territory governments fund public hospitals through activity-based funding (ABF) for each episode of care, or block funding. The level of funding is determined by the Australian National Sub-Acute and Non-Acute Patient Classification (AN-SNAP).</li> <li>Private health insurers and the Commonwealth also contribute to public hospital funding when a consumer elects to be treated as a private patient in a public hospital.</li> <li>The Commonwealth contributes indirectly via payments to State/Territory governments and through the private health insurance rebate.</li> </ul>
Private hospital services	Private health insurers, Commonwealth, state/territory, Department of Veterans Affairs (DVA), individuals	<ul style="list-style-type: none"> <li>The Commonwealth pays 75 per cent of the MBS fee for SPC services. For medical services, private health insurers pay 25 per cent of the MBS fee. For hospital costs, insurers are required to pay the minimum benefit payable (MBP), which is a daily rate for a hospital admission.</li> <li>State/territory governments may contract PC services from private hospitals. For example, many private hospitals have a mix of privately and publicly funded PC inpatient beds.</li> </ul>
Community-based PC	Mostly state/territory governments, some private health insurance (and Commonwealth)	<ul style="list-style-type: none"> <li>State/territory governments fund community PC services.</li> <li>Under the Private Health Insurance Act 2007, private health insurers can provide out of hospital coverage for PC as hospital substitute treatment (as above in private hospitals).</li> </ul>
RACF	Commonwealth	<ul style="list-style-type: none"> <li>Via the ACFI.</li> </ul>
Primary health PC services, such as those provided by a GP	Commonwealth	<ul style="list-style-type: none"> <li>The Commonwealth funds PC provided by GPs via Medicare. Commonwealth payments are 100 per cent of the MBS fee for consultations provided by a GP and 85 per cent for all other services provided by a medical practitioner in the community. While, there are no PC specific items for GPs to use on the MBS, many use other items such as chronic disease management consultations to fund PC.</li> </ul>
Other	Commonwealth  Individuals	<ul style="list-style-type: none"> <li>Via Primary Health Networks (PHNs). In the 2017-18 Budget, \$8.3 million over three years (from 2017-18 to 2019-20) was allocated for PC services via selected PHNs was announced.</li> <li>Individuals contribute to the cost of PC through out-of-pocket costs incurred in private hospitals or in primary care. They may also privately fund in-home services.</li> </ul>

## 3. CHA MEMBER PC SERVICES

### 3.1. NEW SOUTH WALES (NSW)

NSW is the largest state by population in Australia and spends an estimated \$210 million annually on PC services (45). The 2017-18 Budget included an additional \$100 million over 4 years for:

- PC training for 300 nurses and allied health staff
- Three hundred scholarships for rural and regional staff
- Nine PC care specialists in rural and regional areas
- Two specialist positions to provide relief to other specialists in rural and regional areas
- An additional 30 PC nurses in hospitals, homes and nursing homes
- Improving medication management for PC patients through community pharmacy initiatives

NSW is the first state to implement a social impact investment to support PC patients in the community. The service will provide community-based PC, delivered by the Silver Chain Group, to approximately 8,300 patients who have a life-limiting illness. The NSW Government is also developing the NSW Health End of Life and Palliative Care Framework.

CHA member services in NSW which operate SPC services include:

#### ***St Vincent's Health Australia, St Vincent's Hospital, Sacred Heart Health Service***

Sacred Heart Health Service (SHHS) in Sydney is Australia's oldest PC service, located in the densely populated eastern suburbs of Sydney, which also hosts a large number of other primary and tertiary health services. SHHS operates a continuum of publicly funded PC services, which include:

- 20 inpatient SPC beds
- PC consultancy across SVHA public and private hospitals
- outpatient services including outreach clinics to Wagga Wagga, Albury and Orange
- community PC services which support approximately 280 people at any given point in their home or RACF. SHHS's multidisciplinary community PC service is led by dedicated registrars and staff PC specialists. An intensive arm of the community service is activated in the last 48-96 hours of life which includes the provision of personal care assistants in the home to avert hospital admissions where possible.

#### ***St Vincent's Health Australia, St Joseph's Hospital***

St Joseph's Hospital is a public sub-acute hospital with 16 inpatient beds. St Joseph's Hospital works in partnership with the Silver Chain Group, who provide community-based PC in western Sydney.

#### ***Mercy Health Services, Mercy Health Service Albury***

Mercy Health Albury is a publicly funded sub-acute hospital providing health services in the Albury–Wodonga region and surrounding areas. Mercy Health Albury has a 10-bed inpatient PC facility and a community PC service that provides support to 100 people at any given time. The community service is staffed with a multidisciplinary team and a visiting medical officer (VMO) model of SPC clinical support. The hospital also has a Creative Living Centre which offers social and emotional support through friendship and activities.

#### ***Mercy Health Services, Mercy Care Centre Young***

Mercy Care Centre Young is a sub-acute health service which provides geriatric evaluation and management, PC and allied health services. Their community PC program offers publicly funded community PC to 50 people at any given time.

#### ***Calvary Health Care, Calvary Health Care Kogarah***

Calvary Health Care Kogarah is a public hospital that delivers three different models of PC:

- an inpatient facility with 32 beds for care of the dying, symptom management and respite. The hospital has a focus on improving equity of access for those suffering from the degenerative neurological disease, motor neurone disease (MND) available by referral from anywhere in the region (section 5.1.3)
- a consultative PC team that operates between Calvary Health Care Kogarah, St George and Southerland hospitals.

#### ***Calvary Health Care, Calvary Mater Newcastle***

Calvary Mater Newcastle (CMN) SPC service is a public service covering both metropolitan Newcastle and the wider Hunter region. CMN supports a range of PC services across the district including:

- an inpatient hospice with 17 beds
- a comprehensive multidisciplinary community PC service for up to 400 people
- GP VMOs that are stewards for primary care in the district
- a specialist outpatient clinic
- district-wide PC telehealth clinic for specialist support of PC teams
- consultative PC service throughout CMN and to other hospitals in the local area.

CMN is part of a strong community of PC providers and supportive groups. CMN together with other local organisations were recently selected by GroundSwell as one of 8 communities, known as GroundBreakers, to be part of the Compassionate Communities Practice Forum. This program provides a grant to investigate the feasibility of a “Compassionate Cities Framework” in Newcastle (section 5.2.3).

Other initiatives at CMN include the ongoing development of a framework for culturally sensitive and appropriate PC for Aboriginal and Torres Strait Islander people in the community. CMN is also working to ensure access for the isolated elderly by working together with aged care services to establish programs and develop frameworks and education for care of people in an RACF with palliative needs.

#### **Calvary Health Care, Calvary Riverina Hospital**

Mary Potter Palliative Care Unit is an 8-bed SPC care unit within the Calvary Riverina Hospital. Calvary Riverina Hospital has established links with hospice and home-based community PC for both public and private patients through the Palliative Care Alliance.

## CHA MEMBER SERVICES IN NSW WHICH OPERATE SPC SERVICES

ORGANISATION	NAME OF SERVICE	LOCATION	TYPE	SERVICES
St Vincent's Health Australia	St Vincent's Hospital, Sacred Heart Health Service	Darlinghurst	Public	Inpatient (20 beds) Outpatient Community and respite Consultative Outreach clinics
St Vincent's Health Australia	St Joseph's Hospital	Auburn	Public	Inpatient (16 beds)
Mercy Health Services	Mercy Care Centre Young	Young	Public	Inpatient (4 beds)
Mercy Health Services	Mercy Health Service	Albury	Public	Inpatient (10 beds) Community
Calvary Health Care	Calvary Health Care Kogarah	Kogarah	Public	Inpatient (32 beds) Community
Calvary Health Care	Calvary Mater Newcastle	Newcastle	Public	Inpatient (17 beds) Out-patient Community Consultative Telehealth clinic
Calvary Health Care	Calvary Riverina Hospital	Wagga Wagga	Public	Inpatient (18 beds)

### 3.2. QUEENSLAND (QLD)

QLD has the highest rate of PC-related hospitalisations in public hospitals that ended with death (56.7 per cent) and second highest rate of death in private hospitals (61.8 per cent) (6). Significant gaps in, and barriers to access have been identified which include service models, services types, geography, workforce and coordination or services (46, 47). In 2013, a report found that specialist services in Queensland are “understaffed, under-resourced, mostly have insufficient beds, and do not have the capacity to provide adequate community care and after-hours cover” (47, 48).

CHA member services in QLD which operate SPC services include:

#### **St Vincent’s Health Australia, St Vincent’s Private Hospital Brisbane**

St Vincent’s Private Hospital Brisbane operates the largest PC inpatient facility in QLD, a 40-bed SPC inpatient unit, with shared public and private beds. The service also operates a consultative model of care across the hospital and to other local health services. St Vincent’s Private Hospital Brisbane is one of the few examples of a private hospital offering private health insurance funded community-based PC. For the past 2 years, BUPA and SVHA have partnered to deliver community PC, enabling more than 45 per cent of people to die at home (section 5.2.2).

#### **Mater Health Services, Mater Hospital Brisbane**

The Mater Hospital Brisbane has a SPC nursing and medical service with daily outpatient clinics in the Mater Cancer Care Centre, as well as inpatient support and admission to the oncology wards in both the public and private hospital, accounting for approximately 20 inpatient beds.

The Mater Hospital Brisbane also delivers support for the transition between the tertiary and primary sectors for RACF residents, their families, carers and GPs through the Older Person-Centred Care Team (OPCCT). OPCCT forms part of the service that provides PC to older people in their homes and 91 nursing homes in Brisbane Metro South, covering 7700 residents. Support includes a 24-hour telephone support and education programs for GPs, nurses and staff in RACF. This initiative has seen a reduction in hospital deaths, ward admissions and length of stay of RACF residents.

### CHA MEMBER SERVICES IN QLD WHICH OPERATE SPC SERVICES

ORGANISATION	NAME OF SERVICE	LOCATION	TYPE	SERVICES
St Vincent’s Health Australia	St Vincent’s Hospital Brisbane	Brisbane	Public Private	Inpatient (20 public beds) Inpatient (20 private beds) Outpatient Consultative Day hospice Community
Mater Health Services	Mater Private Brisbane	Brisbane	Private and public	Inpatient (20 beds shared with oncology)

Other initiatives of CHA members in QLD of note include the SVHA, Northern Peninsula Area (NPA) Family and Community Services and Apunipima Health Council 3-year PC project in Cape York (section 5.1.2).

### 3.3. WESTERN AUSTRALIA (WA)

PC delivery is challenging WA. WA is geographically Australia's largest state, with a high concentration of population in the southwest and sparse population separated by long distances in the rest of the state (49). Underserved populations in WA include those who are widowed, aged over 85, live outside a major city or of Aboriginal or Torres Strait Islander background (24, 50, 51). People with a non-cancer life-limiting illness are also less likely to access SPC. In WA, 70 per cent of people with cancer accessed SPC in the last year of life compared to just 14 per cent of people who died from non-cancer related conditions (50).

In 2018, the WA Government released the End-of-Life Framework, which aims to improve equitable access to high-quality PC in all settings and increase early recognition of EOLC needs (52). The WA Parliament is also currently undertaking an inquiry into EOL choices, including an examination of the practices utilised to assist a person to exercise their preferences in the management of the end of their life (53).

WA has achieved some success in the delivery of PC. WA has the lowest rate of PC-related public hospitalisations in Australia (14.3 per 10,000 population in WA compared to 39.7 per 100,000 in Tasmania) (6). People who access community SPC in WA have a seven times higher chance of dying in their usual place of residence than those who do not access it (54). Additional benefits include a 9 per cent reduction in average inpatient hospital costs over the last year of life (24).

CHA member services in WA which operate SPC services include a mix of public and private hospitals, as well as a hospice within an aged care facility:

#### **Catholic Homes, Comfort Care Centre**

The Comfort Care Centre (CCC) is a purpose-built 6-bed

hospice facility within a 73-bed RACF, the first of its kind in Australia (section 5.1.4). Between February and June 2018, the CCC received more than 43 admissions, with referrals originating from private and public hospitals as well as Silver Chain community services. Residents have access to PC trained multidisciplinary staff in home-like surroundings including gardens, king sized single beds, ensuites and the capacity for families to share meals or stay overnight should they choose to.

#### **St John of God, Subiaco Hospital**

St John of God Subiaco Hospital has a nurse PC consultant embedded into the service, a clinical nurse specialist and a VMO model of specialist clinician services utilising beds located in the oncology ward. SJOG hospitals form a large network across WA and are well integrated with community services such as Silver Chain.

#### **St John of God, Murdoch Hospital**

St John of God Murdoch Hospital is a 500-bed public hospital which contains a 20-bed SPC inpatient unit, offering approximately 10 public PC beds and 10 private PC beds. The multidisciplinary staff includes 2 PC registrars and 2 PC consultants providing consultancy services throughout the medical wards of the hospital.

#### **St John of God, Geraldton Hospital**

St John of God Geraldton Hospital is a 60-bed private hospital located in regional mid-west WA which includes a 10-bed inpatient SPC unit. The SPC facility is nurse-led, with ongoing support of local GPs and monthly consultancy services from a SPC physician.

#### **St John of God Bunbury Hospital**

St John of God Bunbury Hospital is a 145-bed private hospital providing health care to the southwest of WA. Within the hospital is a dedicated 10-bed SPC inpatient unit which also provides a PC consult service to the rest of the hospital.

### CHA MEMBER SERVICES IN WA WHICH OPERATE SPC SERVICES

ORGANISATION	NAME OF SERVICE	LOCATION	TYPE	SERVICES
Catholic Homes	Comfort Care Centre	Perth	Public	Hospice within an RACF (6 beds)
St John of God	Subiaco Hospital	Subiaco	Private	Consultative
St John of God	Murdoch Hospital, Murdoch Community Hospice	Murdoch	Private Public	Inpatient (10 beds) Inpatient (10 beds)
St John of God	Bunbury Hospital	Bunbury	Private	Inpatient (10 beds) Consultative
St John of God	Geraldton Hospital	Geraldton	Private	Inpatient (10 beds)

### 3.4. SOUTH AUSTRALIA (SA)

SA has the second highest proportion of people over the age of 65 in Australia which will have significant impact on the health system as the population ages (55). SA Health is developing an End of Life Care Strategy aimed at ensuring access to quality and consistency of PC services for all South Australians (56).

CHA member services in SA which operate SPC services include:

#### **Calvary Health Care, Mary Potter Hospice**

The Mary Potter Hospice is a private 15-bed hospice facility located at Calvary Hospital North Adelaide. In addition to multidisciplinary SPC care, the Mary Potter Foundation, a charitable service, supports allied

health and additional services for the Mary Potter Hospice, including complementary therapies and a biography service.

A private health insurance funded PC division of Calvary North Adelaide Hospital, known as Calvary Palliative Home Care, has also been developed. This is an integrated community nursing service led by a team including a nurse practitioner, community clinical manager and registered nurses (section 5.2.2). The PC community service receives referrals from the Mary Potter Hospice, oncology unit of Calvary North Adelaide, and the PC Medical Consultant OPD allowing the team to begin PC needs surveillance and manage transitions between services approximately 6 months from the end of life.

### CHA MEMBER SERVICES IN SA WHICH OPERATE SPC SERVICES

ORGANISATION	NAME OF SERVICE	LOCATION	TYPE	SERVICES
Calvary Health Care	Calvary Hospital North Adelaide, Mary Potter Hospice	North Adelaide	Private	Inpatient (15 beds)

### 3.5. VICTORIA

An estimated 20,000 Victorians received SPC services in 2016-2017, of which 70 per cent was community-based. The shortfall of PC in Victoria is estimated to be more than 65 per cent (57).

In 2017, the Victorian Parliament passed the Voluntary Assisted Dying Act 2017 (Vic) (3). From June 2019, eligible Victorians will be able to request access to VAD. CHA members providing services in Victoria have expressed concern at the inadequacy of the Government's response in ensuring PC services are adequately resourced to meet current and anticipated demand, which includes staff education and public awareness of PC services.

There are several CHA members in Victoria providing hospital, community and aged care services.

CHA member services in Victoria which operate SPC services include:

#### **Mercy Health Services, Werribee Mercy Hospital**

Werribee Mercy Hospital is a public hospital offering a range of health services including SPC. The hospital has 12 inpatient PC beds and is also the base for the community PC service at Sunshine.

#### **Mercy Health Services, Mercy Palliative Care, Sunshine**

Mercy Palliative Care is a community-based PC service offering in-home or RACF support to 650 patients in the north and west metropolitan region of Melbourne. The community service is based on a consultancy multidisciplinary team model. Mercy Palliative Care have recently established a 24-hour telephone support service for those in community care who require symptom management. Demand for the service is high, with over 90 patients requiring support in the first month between the hours of 10.30pm-7am.

#### **St Vincent's Health Australia, St Vincent's Hospital Melbourne (SVHM)**

SVHM operates 2 public inpatient PC facilities in Melbourne, the Caritas Christi Hospice in Kew (26 beds) and at Fitzroy (8 beds). The Kew campus hosts a day hospice, the Centre for Palliative Care, (section 5.3.1) and PC services for prisoners at Port Augusta Jail (section 5.1.1). The SVHM PC consultancy service covers all SVHM campuses, 3 outpatient clinics per month and provides business hours medical consultancy for the Hume Regional Medical Consultancy in Shepparton, Wangaratta and Albury/Wodonga. SVHM also operates a 24-hour telephone PC triage service that provides cover for one third of the state of Victoria.

**Cabrini Health**

Cabrini Health provides an integrated suite of SPC services for privately insured patients across all clinical areas, with the ability to provide step-up and step-down services to meet individual needs. A SPC medical consultant service, which provides service to over 1,000 patients per year, is available at Cabrini Malvern and Cabrini Brighton. For those with acute and intensive SPC needs, Cabrini Prahran has an inpatient unit which provides multidisciplinary care in a 22-bed facility. The inpatient unit operates at 95 per cent occupancy and receives approximately 600 admissions per year.

Cabrini Health is also one of the few health services to offer private health insurance (PHI) funded community PC (section 5.2.2). Cabrini Health provides nurse-led PC assessment and care in the home or RACF. The service provides care to 200-220 people concurrently and achieves a home death rate of approximately 50 per cent. Cabrini also offers a weekly Supportive Care Clinic at the Cabrini Haematology Oncology Centre, which has provided support to 400 patients over 2 years.

**Calvary Health Care, Calvary Health Care Bethlehem**

Calvary Health Care Bethlehem operates a 16-bed dedicated PC facility, a 16-bed neurorehabilitation facility for those living with progressive neurological disease, as well as a community PC service covering the 5 local government areas of Glen Eira, Stonnington, Kingston, Port Melbourne and Bayside, a population of approximately 60,000 people. The multidisciplinary community PC service offers in-reach to 250 people in their homes or RACF at any given point.

People enrolled in the community program can access clinics on site which include individual consultations and group scenarios, such as a group exercise program. The Day Care Centre also operates twice a week providing socialisation and respite for carers. The program is dictated by patients and users of the service and relies heavily on volunteers to run programs which include meditation, cooking, arm chair travel, games and a men’s shed.

**CHA MEMBER SERVICES IN VIC WHICH OPERATE SPC SERVICES**

ORGANISATION	NAME OF SERVICE	LOCATION	TYPE	SERVICES
Mercy Health Services	Werribee Mercy Hospital	Sunshine	Public	Inpatient (12 beds) Consultative
Mercy Health Services	Mercy Palliative Care	Sunshine	Public	Community 24hr phone service
St Vincent’s Health Australia	St Vincent’s Hospital Melbourne, Caritas Christi Hospice	Kew	Public	Inpatient (26 beds) Outpatient Consultative, The Palliative Care Consultation Service (PCCS) Day hospice 24hr phone support
St Vincent’s Health Australia	St Vincent’s Hospital Melbourne	Fitzroy	Public	Inpatient (8 beds)
Cabrini Health	Cabrini Hospital	Prahan	Private	Inpatient (22 beds) Consultancy Community Supportive Care Clinic
Calvary Health Care	Calvary Health Care Bethlehem	Bethlehem	Public	Inpatient (16 beds) Community Day hospice

### 3.6. THE AUSTRALIAN CAPITAL TERRITORY (ACT)

Demand for PC services in the ACT has increased steadily since 2003, with a 36 per cent increase in the number of new patients seen annually and an 85 per cent increase in the number of registered clients (58). SPC services in the ACT are provided by Calvary Health Care and include hospital consultancy at the Canberra Hospital in addition to community, inpatient and outpatient clinics offered by Calvary Clare Holland House (CHH). There has also been significant ACT Government investment in community and volunteer services provided by Palliative Care ACT to provide non-clinical supports to people living with a life-limiting illness.

CHA member services in the ACT which operate SPC services include:

**Calvary Health Care, Clare Holland House (CHH)**

CHH provides community SPC for 250-300 people at any one time, 5-6 weekly consultant-led outpatient clinics and a 19-bed inpatient hospice service. The community PC service is the only service in the ACT offering care in the home or in an RACF setting (section 5.1.4). Uniquely, the model includes 2 nurse practitioners who undertake monthly “needs rounds” (59). Those identified during needs rounds are supported to develop an individually

tailored advanced care plan (ACP) in collaboration with GPs, carers and RACF staff. The model has been acknowledged as a successful innovation and has been adapted to other services across NSW and Victoria and was awarded the ACT Quality and Safety Award.

The community PC service is supplemented by the “Rapid Access Program”, an innovative step-up/step-down program for those with chronic pulmonary obstructive disorder (COPD) or heart failure (section 5.1.3).

To reach underserved populations, CHH pioneered a model of PC case conferencing for Indigenous Australians in collaboration with the local Aboriginal Health Service, Winnunga Nimmityjah Aboriginal Health Service (section 5.1.2). CHH also utilises a supportive care clinic model, in collaboration with the Canberra Hospital, to deliver PC to those attending renal clinics and MND clinics (section 5.1.3).

Further improvements to access for underserved populations are achieved using health care staff education. CHH runs the Program of Experience in the Palliative Approach (PEPA) aimed at educating GPs and other health care workers, such as paramedics, medication education courses for health staff and a staff exchange program with the intensive care unit.

### CHA MEMBER SERVICES IN ACT WHICH OPERATE SPC SERVICES

ORGANISATION	NAME OF SERVICE	LOCATION	TYPE	SERVICES
Calvary Health Care	Clare Holland House	Canberra	Public	Inpatient (19 beds) Community

### 3.7. TASMANIA

The demand for PC services in Tasmania is predicted to increase more rapidly than in other states and territories as a result of size of the ageing population, the highest incidence of cancer in Australia and the second highest burden of chronic disease (27). Publicly funded PC is provided by the Tasmanian Government, through the Department of Health and Human Services and the Tasmanian Health Service. This includes:

- A 10-bed inpatient facility, the JW Whittle Palliative Care Unit, at the Repatriation Centre, Hobart;
- Funding for four public PC beds at Calvary Health care’s St Luke’s Campus in Launceston
- Hospital PC consultation teams
- Community PC services (north, northwest and south)

The Commonwealth also funds the Better Access to Palliative Care program, primarily to increase the capacity of community PC services and improve integration between community, primary and tertiary providers of PC services.

CHA member services in Tasmania which operate SPC services include:

**Calvary St Luke’s Launceston, Palliative Care Melwood Unit**

Calvary St Luke’s private hospital operates a 15-bed inpatient facility, which includes 4 publicly funded beds as well as PC services at home or in residential facilities. An additional bed is available to accommodate emergency admissions for patients whose condition is rapidly deteriorating or for patients who have attempted discharge but have been unable to manage needs. Referrals are received via the Community Palliative Care Team or from the Launceston General Hospital.

**Calvary St John's Calvary, Gibson Unit**

The Gibson unit is a 21-bed private inpatient PC unit, complemented by a 14-chair day oncology unit. The Gibson unit operates a VMO model of SPC physician support and an onsite multidisciplinary PC team.

**CHA MEMBER SERVICES IN TAS WHICH OPERATE SPC SERVICES**

ORGANISATION	NAME OF SERVICE	LOCATION	TYPE	SERVICES
Calvary Health Care	St Luke's	Launceston	Private Public	Inpatient (11 beds) Inpatient (4 beds)
Calvary Health Care	St John's Calvary Hobart, Gibson Unit	Hobart	Private	Inpatient (21 beds)

**2015-2016  
KEY STATISTICS**

**9,401 OR 13%**

of all PC-related hospitalisations occurred in a CHA hospital



**32%**

of all PC-related hospitalisations in a regional/remote CHA private hospital was publicly funded



**1 IN 2**

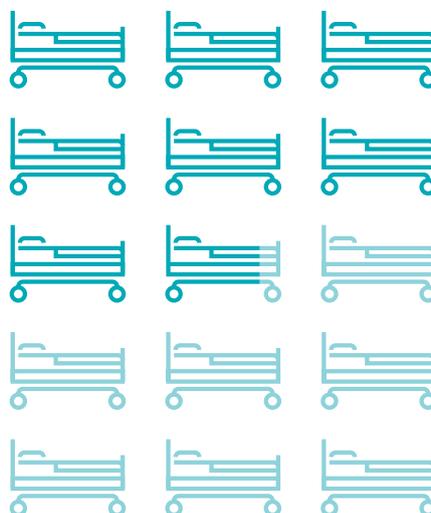
Private PC hospitalisations were in a CHA private hospital

**6%**

of public PC hospitalisations were in a CHA public hospital

CHA members have  
**151 OR 52%**

of private inpatient beds in Australia



**30%**

of CHA private hospital PC was in a regional/remote area

## 4. PC IN THE CATHOLIC SECTOR

CHA members deliver PC in a variety of settings including public and private hospitals, hospices, outpatient settings, RACFs and community-based services. In this section we will examine data collected from hospital and community-based CHA services.

The below analysis of CHA services includes episode-based data collated from CHA public and private hospitals between 2014-2017. These data are compared with latest publicly available data from the Australian Institute of Health and Welfare (AIHW) at the time of writing this report. Aggregate CHA member outcomes data for contributing services was supplied by the Australian Palliative Care Outcomes Collaboration (PCOC) and compared with publicly available national PCOC data. However, it is important to note that contributions to PCOC data are voluntary and does not represent a comprehensive data collection nationally or from CHA members.

The serious deficiencies of national PC data collection have been previously discussed and are a major obstacle for both policy makers and researchers (23, 60). As a result, the data available, although inadequate, differs between jurisdiction and is skewed towards episodic data from tertiary PC services, with little information on community or primary services available. It is acknowledged that there are significant gaps in community and primary-based PC, and improvements to data collection from these services is needed to enable policy makers and organisations to better plan and deliver PC services.

### 4.1. CHA MEMBERS ARE SIGNIFICANT PROVIDERS OF INPATIENT PC SERVICES

In 2015-16, CHA members delivered 13 per cent of all PC-related hospitalisations in public and private hospitals. Fifty-three per cent of PC-hospitalisations in CHA hospitals were in private hospitals. CHA members have 151 private PC inpatient beds, which represents approximately 52 per cent of all private hospital PC beds available in Australia (61).

In regional and remote Australia, private hospitals are a critical component of PC delivery for both the public and private sector. Approximately 12 per cent of PC-related hospitalisations in regional and remote Australia occurred in private hospitals in 2014-15 (6)<sup>1</sup>. Thirty per cent of CHA member private hospital PC-related hospitalisations were in a regional area.

CHA members also provide 6 per cent of PC services in public hospitals, 18 per cent of which were delivered in a regional hospital. An additional 20 per cent of PC services in CHA private hospitals were publicly funded.

#### 4.1.1. The Sources of Funding in Private Hospitals are Changing

Patients attending CHA private hospitals are funded from a variety of sources including public funding (public in private hospital), private health insurance, the Department of Veteran Affairs (DVA) and other sources, which includes self-insured patients. Sixty-seven per cent of PC-related hospitalisations in CHA private hospitals were paid for by private health insurers compared to 69 per cent on average across Australia (Fig. 2).

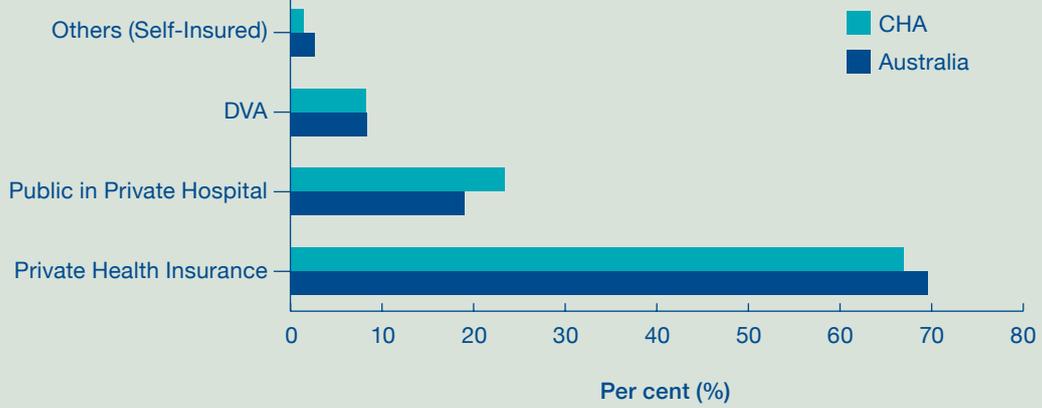
There is a larger proportion of PHI funded PC-related hospitalisations in metropolitan areas compared to regional areas. In 2016-17, privately insured patients accounted for 74 per cent of PC-related hospitalisations in metropolitan areas compared to just 51.9 per cent in regional areas (Fig. 3A). The proportion of privately insured patients in metropolitan areas increased 3.3 per cent between 2014-15 and 2016-17, with a concurrent 7.1 per cent decrease in regional areas.

Decreasing PHI covered PC episodes occurred with a concurrent increase in publicly funded PC-related hospitalisations in regional CHA member hospitals. In 2014-15, 30 per cent of PC-related hospitalisations were publicly funded, which increased 4.6 per cent between 2014 and 2017 (Fig. 3B).

This difference is perhaps unsurprising. It is known that regional Australians have substantially lower levels of private health fund membership. Lower levels of membership are thought to be due to the limited number of private hospitals in regional areas, making PHI less attractive to rural Australians (62). Furthermore, in regional areas where service providers are limited, state and territory governments may choose to purchase (publicly funded) private hospital services to fill a service gap.

1. Comparison between internally collected CHA data and nationally available data on regional PC provision are not comparable. CHA data is collected based on hospital location while AIHW data is published according to remoteness of a person's residence.

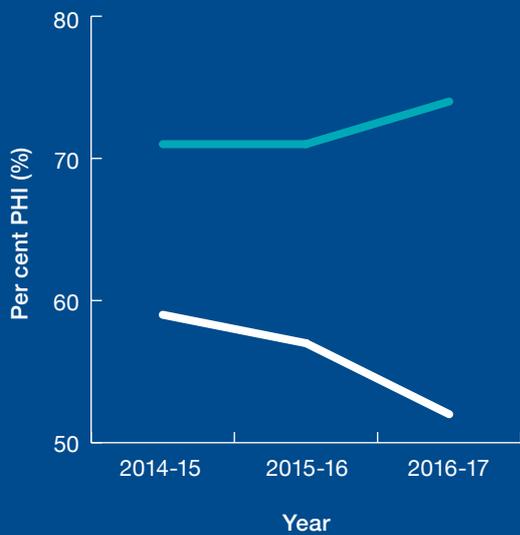
**FIGURE 2**  
SOURCE OF FUNDS PRIVATE HOSPITALS 2015-16



**FIGURE 3**  
SOURCE OF FUNDS PRIVATE HOSPITALS

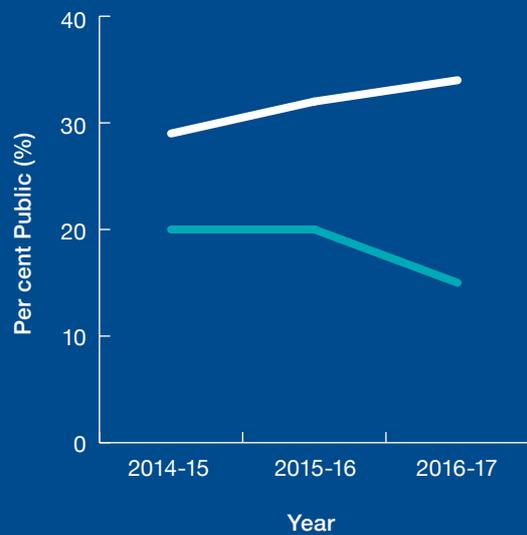
**(A) PHI**

— Metro  
— Regional



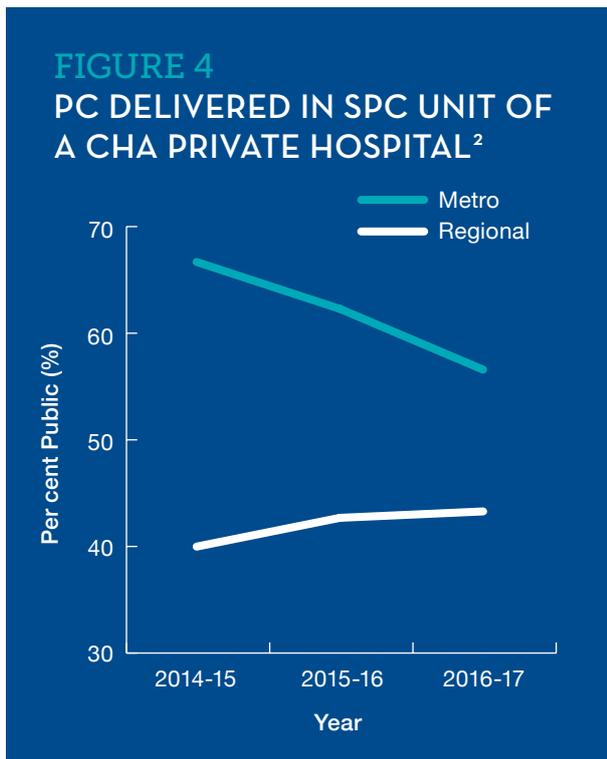
**(B) PUBLIC**

— Metro  
— Regional



### 4.1.2. Half of PC is Delivered Outside of SPC Units in Private Hospitals

PC is delivered under the care of SPC physicians but also as part of treatment delivered by other clinicians, such as PC delivered during an acute care episode. In CHA private hospitals, SPC accounted for more than 51 per cent in 2016-17. In regional areas, patients are significantly less likely to receive SPC as a result of the necessity of PC in other areas of the hospital due to limited SPC staff and dedicated facilities (Fig. 4). Unfortunately, there is no data available to compare patient outcomes between those that receive SPC compared to receiving PC as part of an acute care episode.

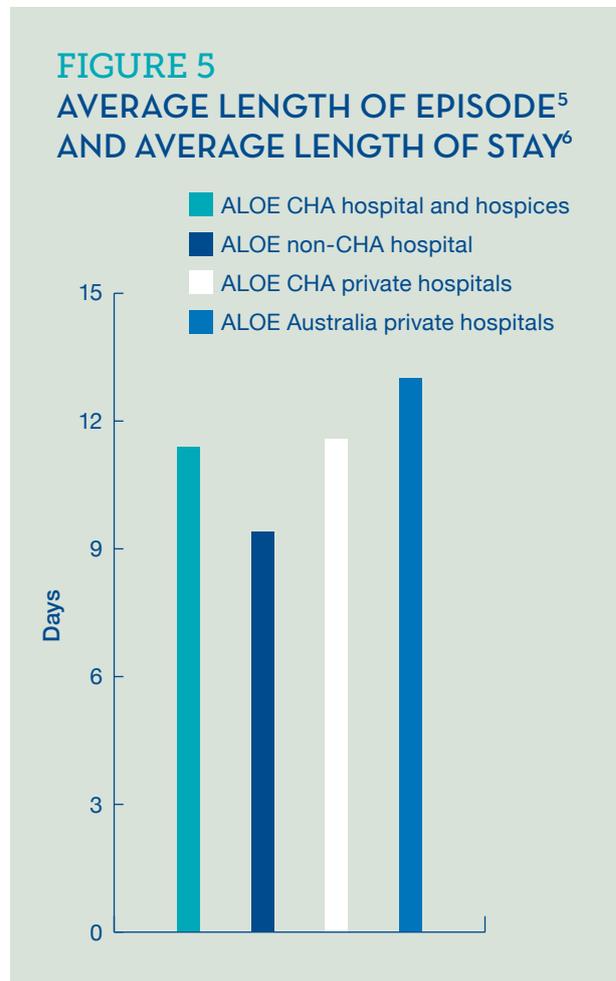


### 4.1.3. The Average Length of Episode or Stay

The average length of episode (ALOE) in CHA hospitals and hospices<sup>3</sup> is on average 2 days (11.4 days) longer than the average of non-CHA hospitals (9.4 days) (Fig. 5). In the private sector, the average length of stay (ALOS)<sup>4</sup> is 2 days shorter for CHA private hospital (11.6 days) when compared to the average of all Australian private hospitals (13 days).

ALOE/ALOS is an important indicator of health system functionality, however, it is important to consider ALOE/ALOS in context. The ALOE/ALOS is heavily dependent on a combination of factors which include the ability of a service to manage symptoms, the existence of adequate step-down services to discharge patients to, the demand for services which creates pressure to discharge patients and patient case-mix.

A shorter ALOE/ALOS is attractive to funders from the point of view of maintaining lower hospital-associated costs. From a public health point of view, interpretation of the driving factors behind ALOE requires consideration of other data, for example, the episode end mode, case-mix of patients, the strength and availability of community PC services and demand-based pressure to discharge patients. There is little information available to draw conclusions from this data however, some aspects such as mode of discharge can be explored.



2. SPC in a private hospital is defined as care delivered under the management of or informed by a clinician with specialised expertise in PC (Caretype Palliative Care). Other PC is defined as PC delivered during the management of an acute inpatient episode. PC intervention is identified as those inpatient episodes with ICD10 clinical code Z515: describing encounter for Palliative Care (Caretype Acute with Palliative Care)

3. PCOC participating organisations.

4. ALOS an equivalent measure to ALOE used in AIHW analysis of admitted PC.

5. PCOC data July-December 2017

6. 2015-16 internal data collection compared to AIHW data 6. (AIHW) Australian Institute of Health and Welfare. Palliative care services in Australia. AIHW; 2018.

### 4.1.4. Mode of Discharge from Hospital or Hospice

Data on the contributing factors to ALOE/ALOS in PC services is not available, with the exception of episode end-mode or discharge data. According to PCOC data, participating CHA hospital and hospice services are more likely to discharge patients to community services compared to non-CHA hospitals and hospices, which are more likely to discharge patients to another hospital (Table 3). Episodes ending in death and the proportion of people discharged to community services are higher in CHA hospitals than non-CHA hospitals, reasons for which will require further analysis.

In contrast, PC patients in CHA private hospitals are 3.8 per cent less likely to die than the average for all private hospitals in Australia. Instead, PC patients in CHA private hospitals are more likely to be discharged to community-based care, other health care accommodation or undergo statistical discharge (Table 4).

### 4.1.5. CHA Hospitals and Hospices are Timely and Responsive

PCOC is a useful data source which provides feedback for organisations to compare to national benchmarks (BM) for several clinician and patient rated PC outcomes. For example, timeliness of care is an indication of the ability of PC services to meet demand (27). The national

**TABLE 3**  
**PCOC EPISODE END MODE HOSPITAL AND HOSPICE SERVICES<sup>7</sup>**

EPISODE END MODE	CHA HOSPITAL (%)	NON-CHA HOSPITAL (%)
Discharged to community	34.2	33.4
Discharged to another hospital	3.2	6.4
Death	57.9	55.1
Change from PC to acute care	0.6	1
Change in sub-acute care type	3.5	0.5
End of consultative episode	0.1	3.3
Other	0.5	0.4
Not stated	0.1	0.1

**TABLE 4**  
**PRIVATE HOSPITAL MODE OF DISCHARGE<sup>8</sup>**

DISCHARGE	CHA	AUSTRALIA
An(other) acute hospital	5.5	5.5
RACF	1.9	2.0
Other health care accommodation	2.0	0.6
Statistical discharge	3.5	1.2
Left against medical advice	0.0	0.0
Died	50.9	54.7
Other – includes community-based services, own residence etc	36.2	35.9

7. PCOC data July-December 2017

8. 2015-16 internal data collection compared to AIHW data 6. (AIHW) Australian Institute of Health and Welfare. Palliative care services in Australia. AIHW; 2018.

BM for timely admission to service is 90 per cent of care commences the day of, or the day after the person is ready for care. CHA hospital and hospice services outperform the national average of timeliness, with 97.2 per cent of people seen on the day of, or the day after the person was ready for care, compared to 96.8 per cent in non-CHA hospitals (Fig. 6A).

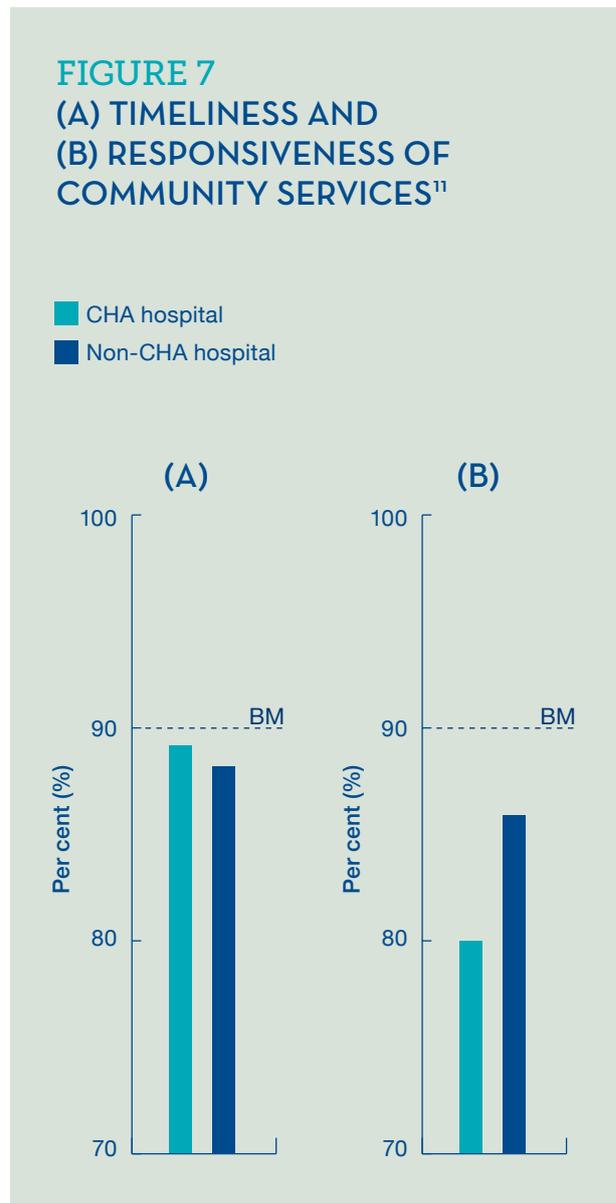
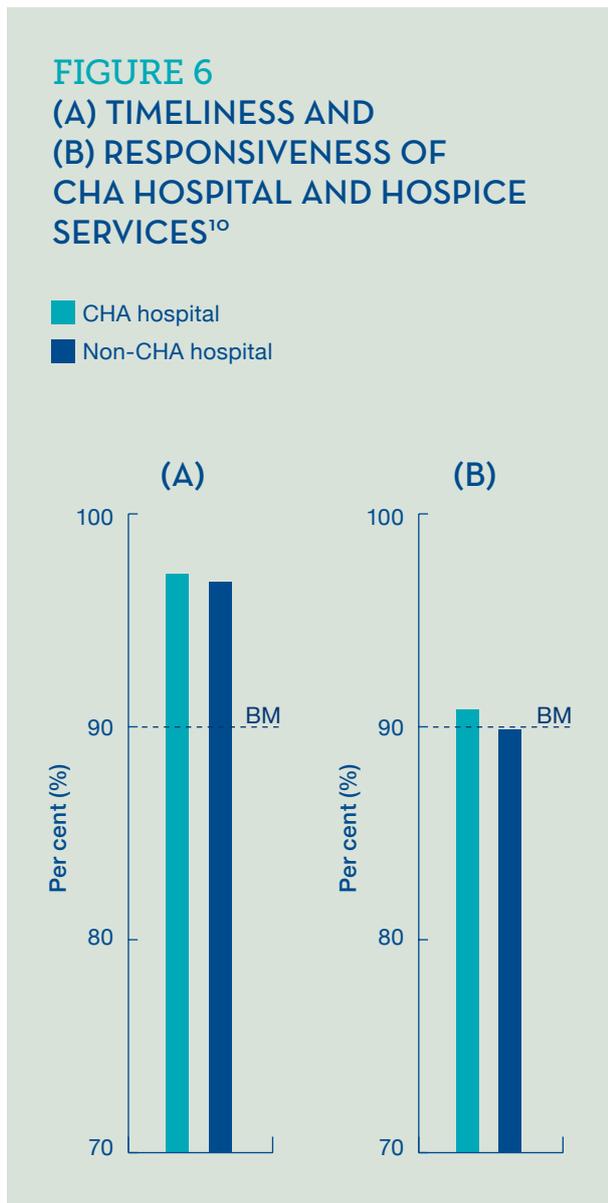
CHA hospital and hospice services are also responsive to urgent needs (Fig. 6B). More than 90 per cent of patients were in an unstable phase for less than 3 days in CHA hospitals. Symptom control for patients in CHA hospitals and hospices was also better than for similar patients in the reference period in non-CHA hospitals and hospices (data not shown)<sup>9</sup>.

## 4.2. COMMUNITY-BASED PC

The majority of CHA PC services are hospital-based, however, several CHA members also provide community-based PC in both the public and private sectors.

In 2017-18, CHA community PC services provided:

- care for more than 4,800 people
- more than 5,8000 occasions of service
- more than 5,800 occasions of medical service
- more than 35,000 occasions of nursing service
- more than 1,000 occasions of allied health service to people in community PC programs.



9. Casemix adjusted reference patients were in the same phase, started with the same level of symptom have their change in symptom compared to the reference period.

10. PCOC data July-December 2017

11. PCOC data July-December 2017

### 4.2.1. Community-Based Services Struggle to Meet Benchmarks

CHA community services perform well in terms of timeliness (Fig. 7A). Approximately 89.2 per cent of people accessing CHA member community-based PC are seen on the day, or the day after the person is ready for care which is above the average for non-CHA services (non-CHA 83.7 per cent; BM 90 per cent) (Fig. 7A). While CHA services perform well in terms of timeliness, responsiveness of community services to changing needs is an area where improvements can be made (Fig. 7B). Similarly, symptom control was below BM for both CHA and non-CHA services, with CHA outperforming non-CHA services on fatigue management (data not shown).

ALOE in CHA community services is 1 day longer than the average of non-CHA community services (Fig. 8). CHA community services rely more on inpatient services and have lower rates of death in the community than non-CHA services (Table 5).

At-home death rates are frequently used to demonstrate the impact of community PC services. Conversely, the proportion of PC patients who are admitted to hospital for treatment and die is often viewed as a failing of the community system to provide adequate care to die at home. However, PC data must be viewed with some caution. As community services become more proficient at enabling people to die at home, those who require hospital have fundamentally more complex, higher levels of needs and are more likely to die during hospital-based treatment.

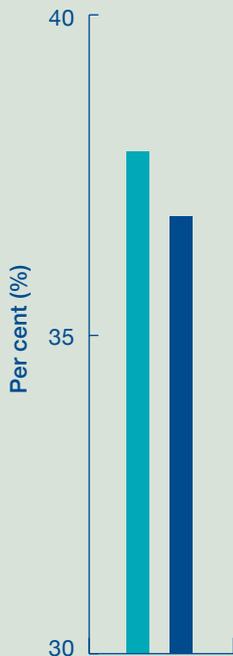
PCOC data indicates that organisations delivering community-based PC have difficulty in achieving BMs compared to hospital and hospice facilities. Those receiving care in a hospital or hospice with dedicated SPC services have better pain and symptom control compared to those receiving PC through community services at home or in an RACF (27, 63).

The Australian Health Services Research Institute (AHSRI) attributes this to (63):

- resources such as equipment and medications are not readily available in the home environment
- variation in the availability of nursing and medical support 24-7
- the ability of the community-based service to respond rapidly to changing needs, in comparison to an inpatient setting where patients receive daily assessment and immediate care is available
- symptoms exceed the level of care that can be provided at home
- choices/preferences for care at home regardless of symptoms and problems
- CHA respondents also identified that under-resourcing also influences the ability of services to meet BM as it leads to under-staffing.

**FIGURE 8**  
**AVERAGE LENGTH OF EPISODE COMMUNITY SERVICE<sup>12</sup>**

■ CHA hospital  
 ■ Non-CHA hospital



12. PCOC data July-December 2017

**TABLE 5**  
**EPISODE END MODE COMMUNITY SERVICES<sup>13</sup>**

EPISODE END MODE	CHA COMMUNITY (%)	NON-CHA COMMUNITY (%)
Admitted for inpatient PC	42.7	28.8
Admitted for inpatient acute care	23.7	32.2
Admitted to another PC service	0.6	0.8
Admitted to primary care	1.1	4
Discharge	6.1	8.1
Death	20.9	25.1
Other	2.6	0.5
Not stated	2.4	0.6

**TABLE 6**  
**COUNTRY OF BIRTH IN PC SERVICES<sup>14</sup>**

COUNTRY OF BIRTH	CHA SERVICES (%)	NON-CHA SERVICES (%)
Australia	65.1	60.6
England	5.1	7.5
Italy	3.6	4.2
Greece	2.8	2.2
New Zealand	1.3	2
China	1.4	1.1
Vietnam	1	0.9
Germany	1	1
Scotland	0.9	1.4
India	0.8	0.8
Malaysia	0.5	0.6
Philippines	0.5	0.4
South Africa	0.4	0.6
Sri Lanka	0.3	0.3
USA	0.1	0.3
Other	13.4	13.6
Not stated	1.8	2.4

13. PCOC data July-December 2017

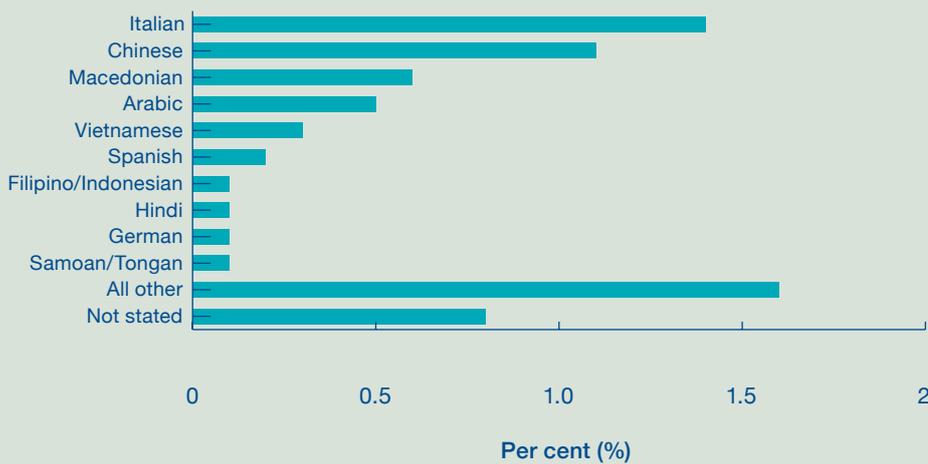
14. PCOC data July-December 2017

### 4.2.2. PC Patient Characteristics

The majority of those who receive PC in Australia have a diagnosis of cancer (6). Although there are a number of other illnesses that can benefit from PC, a smaller proportion of people with non-malignant disease access PC services (64). Factors contributing to this include a lower rate of referrals from other treating specialties, a lack of awareness and identification of PC needs and inadequate resources to meet the complex and long-term needs of this group of people. Nationally and within CHA organisations, non-malignant diagnoses account for approximately one quarter of diagnoses (27).

There is a diversity of patient backgrounds in CHA hospitals, which varies dependent on location and type of service. Most patients receiving PC in CHA organisations are born in Australia and more than 90 per cent are English-speaking (Table 6 and Fig. 9). Approximately 1 per cent of PC patients in CHA hospitals and hospices were of Aboriginal and/or Torres Strait Islander background. Eight per cent of PC patients do not speak English as their preferred language, and a significant portion of people may have cultural needs that require consideration when delivering PC.

**FIGURE 9**  
**PREFERRED SPOKEN LANGUAGE (NON-ENGLISH)<sup>15</sup>**



15. PCOC data July-December 2017

## 5. INNOVATIONS IN CHA PC

### 5.1. IMPROVING EQUITY OF ACCESS

Although PC services in Australia are well regarded in comparison to other countries, PC in Australia is under-resourced and under-developed. It is estimated that only half of those who would benefit from PC receive it (18). Furthermore, there are large disparities in equity of access, with a number of groups remaining underserved. These include, but are not limited to, people who are:

- living outside metropolitan areas
- living with a non-malignant disease
- in RACFs
- living with a physical or psychosocial disability
- lesbian, gay, bisexual, transgender or intersex (LGBTI)
- from culturally and linguistically diverse (CALD) backgrounds
- from an Aboriginal and Torres Strait Islander background
- from a low socioeconomic background including those experiencing homelessness
- veterans
- prisoners
- refugees
- care leavers such as those forcefully removed from a carer or adopted (23, 65-67).

Achieving equity of access to PC will require addressing systemic barriers for these populations. There is significant alignment between CHA members' mission statements and the need to improve equity of access to PC for underserved and vulnerable populations. Some of the work being undertaken by CHA members in this area is discussed below.

#### 5.1.1. Prisoners

##### ***St Vincent's Hospital Melbourne, Centre for Palliative Care – PC for those in correctional facilities***

Prisoners in adult corrective services custody in Australia have increased 38 per cent over the past 5 years. In 2018, there were 42,102 adult prisoners, of which 3 per cent were over the age of 65 (68). In 2015, 1 in 3 prisoner entrants reported having a chronic health condition (69). The high levels of morbidity amongst prisoners contributes to more health service use by prisoners than the general population (70, 71).

Medical services to prisoners are a state and territory responsibility. There are jurisdictional variations in the way health services are provided to prisoners, although most use a combination of services which includes direct service provision, community-based services or through contracted external providers. Both SVHM and St Vincent's Hospital Sydney provide care for prisoners

either within prison hospital facilities or within the public hospital infrastructure itself.

SVHM has provided health services to prisoners at Port Phillip Prison in Melbourne since 1979. This includes a PC consultancy service which attends the prison facility, some out-patient services and inpatient services through St Augustine's secure ward located at St Vincent's Fitzroy campus. St Augustine's is a specially designed ward with 10 beds, able to provide health care for both males and females in prison custody.

Correctional health services aim to provide equivalence of care, where the care prisoners are provided with is of equivalent quality to that provided in the general community. There are a unique set of challenges for those providing PC services to prisoners. This includes advanced disease at diagnosis, limitations on the setting of death and limited options for treatment, such as access to urgent facilities and restrictions on pharmaceutical use (72, 73). There are also profound changes in the nature of SPC services able to be provided; PC typically involves carer and/or family where possible, however, some prisoners have imposed restrictions on family involvement or family estrangement.

Security and procedural requirements also make out-patient follow-up difficult and costly once a prisoner is discharged from St Augustine's ward and returns to Port Phillip Prison. SVHM is working to mitigate barriers to patient follow-up through the use of telehealth, whereby PC nurses and clinicians can provide support and advice over the telephone.

#### 5.1.2. Indigenous Communities

Indigenous Australians are amongst those who are least likely to access PC, despite the need created by a disproportionate burden of chronic disease and higher mortality rates compared with non-Indigenous Australians (66, 74). Some cultural and spiritual aspects of death and dying for Aboriginal people are not well supported by conventional western health care. For example, dying on country or in the community can be a core consideration, however, the remoteness of some communities and a lack of culturally appropriate services act as a barrier to achieving this (75).

##### ***St Vincent's Health Australia, Northern Peninsula Area Family and Community Services and Apunipima Health Council – a pilot model of care through partnerships***

Adoption of a culturally appropriate palliative approach has been slow, particularly in remote and culturally diverse communities, such as those of Cape York. Specialist services can only be accessed via Cairns, resulting in the need for people to travel over 1,000 kilometres to Cairns for treatment. Return to the community following treatment can also be challenging.

In 2016, a tripartite agreement was established between SVHA, Northern Peninsula Area (NPA) Family and Community Services and Apunipima Health Council, to undertake a 3-year PC project. The project, funded by SVHA, aims to develop a model of PC for remote Indigenous communities and to understand the PC needs of local communities and what a patient journey could be that enables a patient to die on Country.

At the project's half-way point, extensive community consultation and action-based research has led to the development of a draft model of care informed by the experiences of 10 clients, a large number for the size of the community. Reported benefits from the project also include improving community PC capacity and building cultural awareness of health care workers who visit the community.

"There are opportunities for other CHA members to learn from this model and assess its applicability in other communities." – Kate Galloway, Chief Executive Officer, NPA.

#### ***Calvary Clare Holland House – delivering community care to Indigenous people in the ACT***

Calvary Public Hospital Bruce CCH and the local Aboriginal Medical Service, Winnunga Nimmityjah Aboriginal Health Service are collaborating to improve PC services for Aboriginal and Torres Strait Islander people living in the ACT. Care is based on a case-management model whereby CHH contributes SPC knowledge and forms action plans for management in partnership with local staff, the individual and their families. This case-management model has received attention for its potential to be implemented in international settings.

### **5.1.3. Non-Malignant Disease**

People with a diagnosis of cancer are more likely to access PC than those with a non-cancer, or non-malignant diagnosis (64). In 2015-16, 48 per cent of those died in tertiary PC services had a diagnosis of cancer and about half of PC episodes of care in hospital were cancer-related (6). However, there are many non-malignant illnesses including COPD, neurodegenerative disorders such as multiple sclerosis, MND, Parkinson's disease, dementia and organ failure that benefit from access to PC. Despite this, less than a third of PC episodes relate to those with a non-malignant disease accessing PC (27).

People with a non-malignant disease encounter barriers to care. There is a general perception that PC is only relevant to a diagnosis of cancer, resulting in poor recognition of PC needs for this group of people amongst health care workers and a lack of resources required to meet long-term complex needs.

#### ***Calvary Health Care Bethlehem – co-location of services for improved access to PC***

Calvary Health Care Bethlehem is an example of a CHA member with a focus on improving access to

PC for those living with a non-malignant disease.

The Bethlehem facility has 16 PC beds as well as a co-located 16 bed facility for neurorehabilitation for progressive neurological diseases, such as MND. Co-location of the services facilitates referral and access to PC for those living with a progressive neurological disease. The site has recently received approval to expand the initiative to include aged care and other general health services to form a health care precinct with improved referral systems.

#### ***Calvary Health Care and St Vincent's Health Australia – Supportive Care Clinics for improved referral processes***

Improving referral processes from a wider range of clinical disciplines is crucial for increasing access to PC for those living with non-malignant diseases. SVHM, Calvary Hospital Kogarah and Calvary CHH have successfully piloted a model of embedding SPC clinicians within supportive care clinics for non-malignant diseases:

- In 2009, a renal supportive care clinic was established at Calvary Hospital Kogarah with an embedded SPC physician. The value of this model was recognised by NSW Health, which initiated state-wide funding for renal supportive care clinics in Kogarah, Penrith and the Hunter New England.
- CHH runs supportive care clinics for the renal and MND units of Canberra Hospital.
- SVHM have piloted a model of embedding a PC supportive care clinic within routine renal and respiratory care clinics. Renal or respiratory physicians with training in PC as well as a SPC physician work together to meet the changing needs of the individuals over time. The supportive care clinics are supplemented with monthly multidisciplinary team meetings to facilitate the shared care of patients.

Supplementing current models of care with supportive care clinics has the potential to improve the equity of comprehensive PC across all life-limiting diagnoses. The concept of embedding PC within oncology clinics has been successfully trialled (76-78). Supportive care clinics also have the potential to improve the ability of SPC services to support all patients and improve dissemination of expertise and knowledge and collaboration between disciplines. Both Calvary and St Vincent's report that embedding PC within supportive care clinics for non-malignant disease has functioned to improve the quality of care people receive, the acceptability of engaging with PC for patients and the "buy-in" from clinicians from non-PC disciplines.

#### ***Calvary Health Care, Clare Holland House – the Rapid Access Program***

The traditional model of PC is that once active medical treatment is ceased, a patient is referred to PC services even though the benefits of referral before this time are well established. Often PC services enrol a patient in a PC program and care for them from referral until

death. This can be costly and complex for life-limiting illnesses that occur over a long time-frame, such as COPD. A person's PC needs change over time and a key component of good community PC is being able to identify when needs arise. Early referral is crucial for good outcomes, however it is neither viable nor practical to keep all those who could benefit from PC actively on a PC program when their PC needs may not need support.

CHH has successfully implemented a program of monitoring and identification of PC needs for those living in the community. PC trained nurses periodically contact those living in the community on the Rapid Access Program, performing PC needs assessments. Once PC issues arise and are identified, a place in community PC is available immediately to address the support needs of the person.

#### 5.1.4. Residents of RACFs

##### ***Catholic Homes Comfort Care Centre – a hospice within a RACF***

The Comfort Care Centre (CCC) is the first hybrid model of hospice care within a RACF in Australia. The CCC is a purpose-built 6-bed hospice facility within a 73-bed RACF in Perth, WA, with a home-like environment. All residents have access to PC trained staff such as allied health, pastoral care and a GP, and equipment to manage pain and comfort.

***“the philosophy of the comfort centre is to look at a family and say “look, we will take on the burden of care for your loved one”, because it is a really big burden, and anyone who has ever nursed anyone can tell you that. “We will let you as a family write a really great chapter with your loved one.” So their loved one dies well and has an exit that is peaceful and memorable in a good way”.***

Approximately 80 per cent of residents die in the RACF, however, there are concerns about the lack of resources within RACFs to cope with individuals with complex PC needs (6, 23). Between February and June 2018, the CCC received 43 admissions and has been overwhelmed with the previously unmet demand for service. The CCC fulfils a previously unmet function of a step-down service for those leaving hospital but unable to return home or to their RACF. Sixty-eight per cent of patients are referred from local private hospitals, 20 per cent from public hospitals and 11 per cent from community services. Most referrals are from other CHA members such as SJOG Murdoch. Ninety-five per cent of residents have a cancer diagnosis and the ALOS in the CCC is 38 days.

An economic evaluation study of potential savings through a reduction in ED presentations and hospitalisations is underway in collaboration with the University of Western Australia.

##### ***Villa Maria Catholic Homes (VMCH) – improving staff recognition of PC needs***

VMCH operates disability and community services, 13 permanent aged care sites and 21 affordable housing

sites throughout Melbourne. VMCH also provides disability support for school aged children and 12 supported accommodation homes for disability.

To improve staff understanding of PC issues, VMCH received a grant to pilot a staff training and awareness program in PC and EOLC, known as the “Raise the Bar” program. The program aimed to improve recognition of triggers for PC referral. This included training of all non-clinical staff on site to “stop and watch” for changes in residents and communication of changes with nursing staff.

The program achieved significant reductions in hospital transfers; from 22 hospitalisations before the program to 2 hospitalisations in the year after implementation. The clinical training also enabled greater access to medications on site. Several other EOLC initiatives have been established at VMCH. This includes the publication of a book, “What’s Happening?”, which aims to enhance the ability of staff communication with residents, families and carers and the development of PC care toolkits containing a water fountain, candle, hand cream, lip balm and a dignity blanket.

##### ***Cabrini Health Palliative Home Care – linkages with RACF***

In 2015, Cabrini Palliative Home Care and mecwacare RACFs conducted a 12-month project, funded by Decision Assist. The project aimed to establish a resident-centred, evidence-based PC service model across the 391 beds in mecwacare facilities. The project employed strategies to improve communication between staff, families and residents to reduce hospitalisations and improve ACP uptake. This included the establishment of resident and family forums, a residential aged care EOLC pathway, staff education and training and information exchange with primary health providers including 88 local GPs.

These initiatives resulted in a 14 per cent increase in resident ACP, a 23 per cent increase in the number of PC case conferences offered to residents prior to their death and a significant change in practice from project commencement.

##### ***Calvary Clare Holland House – aged care facility “needs rounds”***

Late referral to PC services is one factor contributing to poor PC outcomes for RACF residents. The Calvary Centre for Palliative Care Research and Calvary Public Hospital Bruce established a trial to address this barrier, called INSPIRED (integrating SPC into residential care for older people). “Needs rounds” form the basis of the INSPIRED program, whereby two nurse practitioners, together with GPs, carers and nursing staff, conduct assessment rounds in RACFs twice per month to identify those residents with PC needs. This contrasts with current practice where PC is usually only initiated once residents start experiencing end of life symptoms. The program also contributes to raising RACF staff awareness for PC needs.

## 5.2. COMMUNITY SUPPORT ENABLING AT-HOME OR IN-PLACE DEATH

One of the goals of PC is to enable a person to exercise choice for their care and the setting of their care where possible, which for the majority of people is in their home or RACF (23, 30, 31). This requires strengthening of the continuum of care and improving integration of services, particularly community and primary-based PC.

The Productivity Commission suggests that choice about the timing and setting of care could be achieved by extending access to care in different settings, and introducing greater contestability and competition (23). Concerns about this approach are primarily based upon the likelihood of introducing further fragmentation of care between tertiary PC, community and primary PC services.

Lessons that can be derived from the success of Silver Chain in WA include that organisations funded appropriately to provide a continuum of care are able to overcome fragmentation. Leveraging the significant infrastructure and expertise that exists in tertiary services to provide a continuum of care has the potential to improve integration. This approach also maintains elements of competition and contestability to drive improvements and provide choice to consumers, as multiple providers can provide a continuum of care rather than funding a single provider.

Several CHA members offer a suite of PC services which covers the continuum from tertiary inpatient services, hospices, outpatient services to community-based care, which includes 24-hour 7-days per week telephone support, care in the home and in RACFs. The trend towards offering a more complete range of services is occurring in both the public and private health system.

*“Everything I can do for an inpatient, I should be able to do for them at home”*

### 5.2.1. Publicly Funded Community PC

#### ***St Vincent's Sacred Heart Supportive Care and Palliative Care Clinic – specialist clinician led community PC***

St Vincent's Sacred Heart operates a range of SPC services which includes a publicly funded 24-hour community PC service with a capacity of 250-280 patients. Multidisciplinary teams consisting of registrars, SPC physicians, nurses, occupational therapists, physiotherapists, social workers, pastoral care, dieticians and volunteers provide support services to patients in their homes and RACF. In addition to health worker support, personal care assistants are placed into the homes in the last 48-96 hours of life to enable at home death. St Vincent's Sacred Heart has been able to significantly reduce inpatient beds as a result of offering an integrated community service, particularly with the availability of specialist clinicians to assess and treat people in their own homes.

#### ***Mater Hospital Brisbane – support for transition between tertiary and primary sectors for residents of RACFs***

In addition to inpatient and outpatient services, the Mater Hospital Brisbane also delivers support for the transition between the tertiary and primary sectors for RACF residents, their families, carers and GPs. The Person-Centred Care Team (OPCCT, formerly Mater Aged Care in an Emergency (MACIAE)) forms part of the service that provides PC to older people in their homes and 91 nursing homes in Brisbane metro-south, covering 7700 residents, most within the last 12-18 months of life. Support includes a 24-hour telephone clinical access and support for GPs, nurses and staff in the aged care community as well as educational support for RACF staff.

OPCCT support has reduced hospital deaths by 88 per cent, with most people able to return to their setting of preference to die. Ward admissions of RACF residents was reduced by 40 per cent and ALOS for admissions was reduced by 38 per cent. The reported cost benefit of this program is 10:1.

### 5.2.2. Private Health Insurance and Community PC

There are significant savings for private health insurers to be achieved through a shift from tertiary care to community care where possible. The private health insurance sector has historically been criticised for the rejection of funding outpatient or community PC programs. However, several examples where engagement of private health insurers resulting in funded programs outside of hospital are starting to emerge. St Vincent's Private Hospital Brisbane (SVHB), Cabrini Health and at Calvary Hospital North Adelaide Mary Potter Hospice are health services who have successfully negotiated privately insured patients to be funded for care in the community.

#### ***Cabrini Health – a privately funded SPC service***

Cabrini Health provides nurse-led PC assessment and care in community, at home or a RACF for privately insured patients of any health fund. The program was originally established in 1997 as part of a Pilot Project with private health insurance funds to provide SPC services in the community. The program achieved success, which included improved patient outcomes and significant cost benefits to insurers. This enabled Cabrini to negotiate continuing contracts with private health insurers for the Cabrini Palliative Care homecare program.

The Home Care service provides nurse-led assessment and multidisciplinary care for end of life symptom management in their home or RACF. The service provides care to 200-220 people concurrently and achieves a home death rate of approximately 50 per cent.

### ***St Vincent's Hospital Brisbane – partnerships with private health insurers for community PC***

In 2016, BUPA and St Vincent's Private Hospital Brisbane launched a pilot of community PC for privately insured patients. The pilot is a case management model which allows people to remain at home when approaching the end of their life. Care is delivered by a multidisciplinary team including PC nurses, domiciliary nurses, SPC clinicians and GPs. For those people with high PC needs, intensive assistance through nursing support is provided 4-12 hours per day or night.

The St Vincent's Brisbane and BUPA pilot has approximately 220 patients at any given time and is achieving an at home death rate of 45 per cent, compared to just 26 per cent for those who had received tertiary care, with a median program length of 45 days. Acute bed death rates halved from 21 per cent to 10 per cent.

### ***Calvary Hospital North Adelaide – unanimous acceptance by private health insurers for nurse-led community PC***

Calvary Hospital North Adelaide has launched a private health insurance-funded PC community service as part of new a EOLC service called Calvary Palliative Home Care. The program enables step-up and step-down care between community, tertiary and hospice levels, with the Mary Potter Hospice a cornerstone of the model. The model is nurse practitioner-led, with support from a multidisciplinary team including a community clinical manager, registered and enrolled nurses. The community team provides nursing support and manages transitions between the community service, tertiary and hospice services as well as primary health care providers.

## **5.2.3. PC Networks and Compassionate Communities**

A survey of 200 UK PC services found that community engagement initiatives, including the 'compassionate communities' model, were a priority for 66 per cent of services (79). Compassionate communities is a public health approach to EOLC, originally based on the WHO concept of 'Healthy Cities', whereby community engagement drives the formation of informal networks to fulfil a wide variety of non-clinical functions (80). Compassionate communities form part of the recognition of the importance of social, psychological and spiritual problems associated with EOLC which are complex for health services to address. Supports which compassionate communities offer include personal assistance for shopping, cooking, cleaning and gardening, and emotional support and friendship.

As aforementioned, Newcastle and CMN recently received a Groundswell grant to investigate the viability of the formation of a Compassionate Community in Newcastle. Such initiatives provide an important opportunity to improve supportive networks of care outside of hospital and should be investigated as part of routine practice for hospitals.

## **5.3. IMPROVING THE EVIDENCE-BASE**

Research is a central driver for improving health care performance, patient experience and to assist in meeting future health care challenges. Research also provides economic benefit; for every dollar invested in medical research, the Australian community derives an estimated benefit of between \$2.17 and \$3.39 (81, 82).

Australia is one of the few countries in the world with significant potential to perform research with translational capacity. Embedding research into clinical practice improves translational capacity of research. CHA members are advantageously placed to conduct PC research given the proximity to clinical facilities, the existence of research ethics committees and a commitment to PC as an area of focus.

PC research is embedded in many of the CHA member facilities including hospices, hospitals and aged care facilities. In the past 8 years, researchers at CHA member organisations have published more than 200 peer reviewed articles on PC (Appendix 4). The themes most frequently described in the papers were assessment and methodology, carers and families and physical symptoms. Approximately 8 per cent of papers were published as part of a collaboration between CHA members. CHA members are also active in PC research collaborations including the Palliative Care Clinical Studies Collaborative (PaCCSC).

A unique feature of CHA member PC research is the existence of PC research facilities or institutes, of which there are few in Australia. These include the Centre for Palliative Care Research (SVHA) and the Calvary Palliative and End of Life Care Research Institute, Calvary Centre for Palliative Care Research, the St Vincent's Health Australia Centre for Palliative Care, St Vincent's Health Australia and the Cunningham Centre for Palliative Care.

### **5.3.1. Research Snapshots**

#### ***St Vincent's Health Australia, the Centre for Palliative Care***

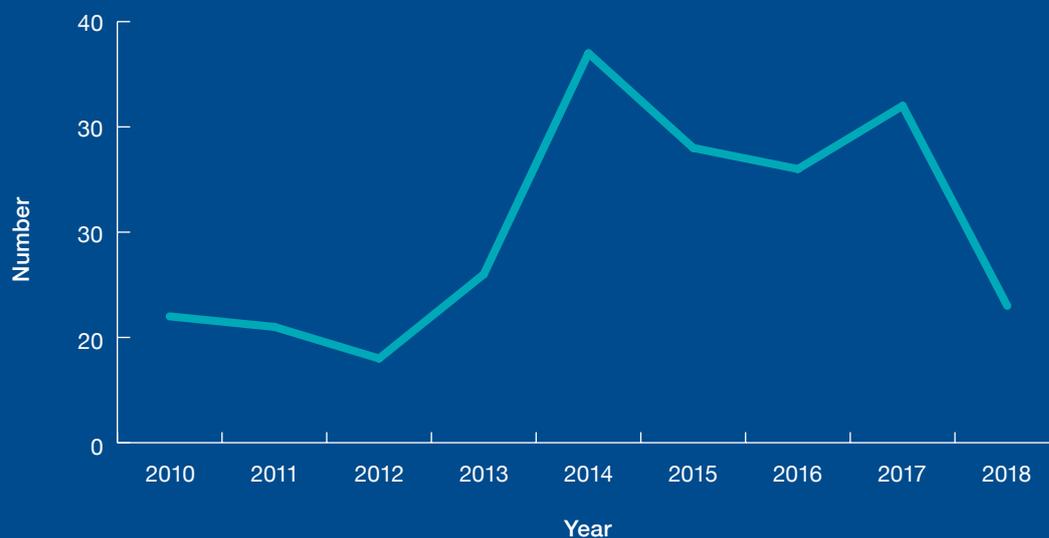
Waiting lists for PC beds combined with the complexity of patient needs is a reality that makes prioritising access to PC beds difficult. There has previously been little information to systematically guide health care workers when triaging patients for PC. Dr Beth Russell, a Palliative Medicine Consultant at SVHA, has developed a PC decision-making triage tool that enables service providers to be transparent, equitable and efficient in prioritising those with the most urgent need to access PC services (83). The tool allows clinicians to assign a score to each patient which enables health care workers to triage patients according to need.

## BOX 5 LITERATURE REVIEW OF CHA MEMBER PC RESEARCH

A systematic review was conducted to capture PC and EOLC research undertaken by CHA members between 2010 and May 2018. The full search strategy and literature review can be found in Appendix 3.

There is a highly productive PC research community amongst CHA members. The 200 papers identified through electronic searches represent a diverse range of PC and EOLC research activity covering a range of services and settings including inpatient, hospice and community-based care (Fig. 10 and Appendix 3). Studies represented multidisciplinary perspectives across medical, nursing, allied health professions and pastoral care, reflecting the multidisciplinary nature of PC and multidimensional needs of patients and their families.

**FIGURE 10**  
**NUMBER OF PC RESEARCH PAPERS PUBLISHED BY CHA MEMBERS BY YEAR**



The themes most frequently described in the papers were assessment and methodology (18 per cent), carers and families (17 per cent), physical symptoms (13 per cent), services and settings including patient experience (12 per cent), decision-making (8 per cent), staff attitudes and experiences (8 per cent), and psychosocial symptoms (6 per cent) (Fig. 11). Other areas with limited publication numbers included education and training, communication, quality of life, bereavement and last days of life. Members also identified pastoral care research as a priority which is not captured by the electronic literature search.

### **Cabrini Health**

PC has evolved greatly since its origins as EOLC within the hospice movement in the UK. PC now encompasses early integration, with evaluation of patient and organisational outcomes. How staff experience and implement these changes from general EOLC to SPC can impact on service delivery. Improvements to the model of care have resulted in better outcomes for patients, such as discharge to home for care and reduced inpatient deaths. However, the staff have had to develop coping strategies to deal with the stress of skill expectations, less certainty about care goals, needing to prioritise care tasks, and reduced shared support rituals.

The Cabrini study of staff experience has implications for services introducing and researching innovative models of PC, particularly with respect to ensuring adequate staff support in adapting to changes (84).

### **Calvary Health Care, Palliative and End of Life Care Research Institute**

NSW Ambulance developed Authorised Care Plans for PC patients, to assist paramedics in understanding preferences for resuscitation, treatment and management. These ambulance palliative care plans (APCPs), recorded and flagged in the ambulance data

**BOX 6**  
**LITERATURE REVIEW OF CHA MEMBER PC RESEARCH CONTINUED**

**FIGURE 11**  
**CHA RESEARCH BY THEME**



**Collaboration**

CHA members are highly collaborative with other research institutions and with other CHA members. Collaboration amongst CHA members, as indicated by co-authorship by more than one CHA-member, occurred in 8 per cent of papers, with the most frequent co-authorship between SVHA and Calvary Health care (44 per cent). The unique position of CHA members in their PC focus and access to clinical facilities, ethics committees and researchers, means that further collaboration between members has the potential to deliver meaningful research outcomes.

system are currently being evaluated by the southern sector of the Local Health District (LHD), involving Calvary Kogarah and two regional teaching hospitals. It will investigate the process of documenting an APCP and the patient, caregiver and clinician experience and the potential for avoiding unwanted admissions to emergency departments.

**Mater Health Services, Mater Research**

The Palliative Care Research Group focuses on the implementation and testing of new drugs and symptom relief methods. One such study aims to understand the economic impact on hospitalisations of the PaCCSC ketamine randomised controlled trial in the management of uncontrolled chronic cancer pain in patients who had not responded to an adequate trial of opioids and co-analgesics (85). Potential cost savings in this setting were estimated from a health system perspective to be approximately \$663,000 in annual hospitalisation costs and 443 inpatient bed-days.

**Mercy Health**

Music therapy has been used in PC to provide comfort to people regardless of age, language, culture and faith. Mercy Health has undertaken a study on the effect of music therapy on paediatric PC patients and their parents, who come from diverse cultural backgrounds. The study aims to understand how paediatric PC patients and their parents use music in their day-to-day lives and their experience of music therapy in home-based PC. Ultimately, the study seeks to identify barriers and improve access to home-based paediatric PC music therapy services for children and families who come from diverse cultural backgrounds.

**St John of God Subiaco**

St John of God is currently comparing the current standard-of-care Not for Resuscitation (NFR) form with the soon to be introduced goals of care (GOC) form. The GOC form aims to address limitations in implementation of NFR and ACP forms and improve patient/family and staff communication regarding appropriate treatment goals during critical events in hospital.

## 6. BARRIERS AND ENABLERS OF CARE

The barriers and enablers to PC have been well described (12, 86), most recently by the Productivity Commission's Report into Human Services (23). Those barriers include:

- remuneration levels or funding models that act as a disincentive to service
- inadequate data and understanding of population need at regional or national level
- fragmentation of services
- weaknesses in current stewardship arrangements between state and territory governments and the Commonwealth
- lack of awareness in health care workers, particularly in the aged care and primary sector
- public awareness and perceptions of PC
- demand that outstrips supply of services
- lack of research investment
- poor uptake in ACP

This report does not undertake to reiterate all the listed barriers that have been previously reported. Instead, this section will describe the barriers and enablers as seen from a CHA member perspective; namely, PC experts from across tertiary health care, aged care and community sectors, most of whom struggle day to day with these barriers to deliver PC to those who need it.

### 6.1. BARRIERS

***“The field knows what we need to do, we just need to be trusted and resourced to do it”***

#### 6.1.1. Policy

##### ***Funding model agility and reimbursement***

Funding was identified as a barrier to access to quality PC by 100 per cent of the participants in this report. Both funding models as well as the level of remuneration were considered to inhibit capacity building and the ability of services to provide good quality care to those who require it.

##### ***Private health insurance (PHI)***

The *National Health Act 1953* requires all hospital cover products to provide a benefit for PC (87). The *Private Health Insurance Act 2007* (the *PHI Act*) subsection 72-1(2) requires that each policy that covers hospital treatment must cover any part of hospital treatment that is PC, if the treatment is provided in a hospital and no Medicare benefit is payable for that part of the treatment (88). Many insurers offer only mandatory PHI cover for PC, the MBP, which is 'equivalent to the benefit paid for treating in a shared ward in a public hospital' and often below the cost of treatment. The

MBP is designed to ensure that vulnerable patients can access private care in the event they need it without complex and often long-term care driving up premiums. The result is that consumers may experience large out-of-pocket costs to cover the difference between the MBP and the cost of treatment.

Reducing costs to private health insurers and premiums for consumers requires expansion of PHI funded services to include community-based care. Under the *PHI Act*, insurers can fund community-based PC as hospital substitute treatment, which is general treatment that substitutes for an episode of hospital treatment (89). Several studies have shown that savings can be achieved by delivering PC in a community setting, yet the uptake of PHI-funded community PC has been slow (32, 33). CHA member services make up some of the few examples of PHI funding community-based PC treatment (section 5.2.2).

So why have private health insurers been so slow to increase the scope of coverage to include PC community-based services? The cost savings argument for community PC is compelling and evidence-based. Difficulties arise in individual organisations negotiating with health insurers to determine the scope of PHI coverage. For example, patients cannot be discharged from hospital under this model without equipment, such as oxygen, and services required to enable a person with PC needs to live at home. The success of these negotiations requires bundled payments for community care, which are complicated by the availability of different provisions for equipment and equipment hire across different jurisdictions.

##### ***Aged Care Funding Instrument***

The Australian Government allocates funding resources via consumers to RACFs through the ACFI. ACFI focuses on the main areas that discriminate core care needs among care recipients, with the most complex and highest care needs receiving the greatest amount of funding. The three domains of funding in the model are activities of daily living, behaviour and complex health care, with each domain divided into low, medium or high funding levels. PC is included in the complex health care domain.

Indication of PC needs in RACFs using the ACFI are skewed and inaccurate. In 2016-17, 1 in 50 aged care residents had an ACFI assessment that included the need for PC despite more than a third of residents dying within a year of admission (6, 90). There are several reasons PC needs in aged care are underestimated by ACFI data and one of these reasons is the ACFI instrument itself. CHA members providing PC in RACF settings identified the ACFI instrument structure and

level of remuneration as a major barrier to PC service provision:

- an ACFI assessment of needs for PC requires a directive by a qualified person, such as a clinical nurse consultant in PC, access to which may be variable particularly in outer regional areas.
- the structure of the funding instrument is based on “points” and a resident may have already reached the maximum points for that domain, meaning that an emerging PC need will not attract any further remuneration.
- the PC claim is encouraged to be within the terminal phase of a resident’s life (the last week or days of life<sup>16</sup>) which does not allow for best-practice PC nor sufficient time to conduct the assessment and lodge the claim.

**“80-90 per cent of the time it’s not worth your time in getting the funding (ACFI).”**

**“There really is no specific funding for PC. The ACFI tool doesn’t allow for it. We need a separate category for PC or EOLC with a different set of rules.”**

**“RACFs are not hospitals, but many of the things we are providing are like a hospital situation, we just don’t get the funding for it.”**

#### **Medicare Benefits Schedule**

The MBS is a list of health services, with an associated item number, that the Australian Government subsidises. There are a number of MBS items that can be used to provide PC services, however, not all are directly related to PC as only PC specialists can claim PC item numbers. For example, GPs cannot claim PC items, but may instead utilise chronic disease management items. Conversely, PC specialists are unable to claim item numbers that other specialists or GPs use.

The inconsistencies in the ability for practitioners to claim MBS items creates a significant barrier to service. A review of the MBS is currently underway and provides an opportunity to address these barriers to care.

There are many specific instances where the MBS rules act as a barrier to service. By way of illustration, access to the 5 MBS rebated referrals to allied health professionals per year that are included in the GP Management Plan or Team Care Arrangements, are currently not able to be used by PC specialists and nurse practitioners. There are also services that do not attract MBS reimbursement and therefore lack incentive to be provided.

**“the MBS has not grown with the discipline”**

The level of remuneration of PC MBS items is also an issue, particularly for those that relate to case conferencing. Case conferencing is vital to maintain continuity of care and integration of services between tertiary and community based PC.

The inadequacies of the MBS for PC was identified as a driver for the lack of PC specialists in Australia and the appetite for PC specialists to be employed as salaried clinicians rather than private consultants.

**“(the MBS) doesn’t acknowledge the amount of time you spend in a consultation doing a holistic assessment of a person, advance care planning or liaising with teams. So by far, a salaried model is better for a specialist.”**

#### **Consultancy services**

PC consultancy is a valuable model that enables non-PC specialists/generalists to seek expert multidisciplinary SPC advice on the prognosis and management of people outside SPC units. Traditionally, this has been a feature of tertiary care provision to maximise access to PC throughout the hospital. Consultancy is an area of tremendous growth and now includes a provision of service to all people in all settings by multidisciplinary teams which include medical specialists and/or clinical nursing consultants. It is an effective and economically rational model of care in a wider PC system.

Funding models for consultant services are complex and differ depending on the jurisdiction and type of service. For example, some public hospitals use packaged sub-acute funding in discretionary amounts to subsidise SPC consultant services. However, the inability of SPC consultant services to access money in a similar way to that provided to inpatient services is restrictive with many services seeking service level agreements or research funding to subsidise service. Difficulty in changing the current status quo lies in that there is no mechanism to collect data to understand how much or what consultancy services are providing and therefore to fund it appropriately.

### **6.1.2. Fragmented Health Care System**

Although Australia is considered to have a well-integrated PC system by international comparison, service fragmentation is acknowledged to be one of the key barriers to improving patient outcomes (17, 36). There are several countries that are moving towards advanced integration of PC services into mainstream service provision. Critically, these countries have diverse models of PC delivery in a variety of settings, multiple PC providers, broad awareness of PC both within health care and in society in general, availability of pharmaceutical

16. The ACFI specifies that funding specifically for palliative care is only allowable ‘in the last week or days’ of a resident’s life (23). Commission Productivity. Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services. Canberra; 2017. Report No.: 85.

agents for symptom relief, integration with education and training providers and strong public health PC policy (91).

Fragmentation of PC occurs at a number of points of the health care system; between primary, community, aged care and tertiary care, between public and private health care and where geographical boundaries are present. In some instances, access to services or funding is based upon estimated time to death, a matter of days to weeks until death for ACFI funding and three-month limits on access to some hospital PC facilities.

The complexities of state and federal funding contribute greatly to fragmentation. For example, the interface between public and private health care is challenging for people in South Australia from transferring from the private hospital system to community-based PC services. People often must exit the private health system before they can enter the public system and access these services.

***“The nexus point between state and federal funding is a really important issue. As soon as you are in a hospital you are in the hands of the states, and as soon as you are in the community you are in the domain of the Commonwealth. We often see cost shifting through pushing people into the community. This is where people fall in the cracks.”***

Although there is ongoing debate regarding health system structure, it is likely that the current model will continue at least in the short-term. Therefore, it is useful to look for examples where innovation within these constraints have resulted in gains. For example, when providers of tertiary care are funded to provide a suite of services which encompasses a continuum of care or those within aged care able to provide PC within the RACF (section 5.1.4).

### 6.1.3. Research Investment

***“with the level of funding we can barely provide the amount of clinical care we need to, let alone research. The funding is just not there.”***

Funding for PC research is a major barrier to improving PC services in Australia. Rather than larger national grants that allow researchers to plan and sustain research projects and staff, PC research relies more on small grants from within organisations, philanthropic donations or from LHDs.

***“funding for PC research is achingly small given that it will eventually affect everyone”***

As a result, research projects are often targeted projects under the directives of the funding bodies rather than projects the researchers themselves had identified as needed. This is a problem of both the research funding system in Australia but also because PC is seen as the “poor relative” in hierarchy of research priorities.

***“First is basic science, because we all want a cure, then psychosocial research and PC comes last.”***

Resources towards embedding research in clinical practice are not readily available. Clinical researchers are limited in the ability to devote time towards research and are therefore unable to build an academic track record, contributing to challenges in attracting funding from traditional resources. Respondents viewed the lack of resources devoted to research as creating a situation where research can only be done as a trade-off with clinical service provision. Increased investment in research would allow organisations to overcome inadequate staff time as well as research proficiency through the engagement of research trained nurses for example.

***“It is a cottage industry, just 5-10 years old, which makes competitive funding difficult.”***

Research in PC is regarded as challenging for several other reasons (92, 93). Respondents of the study also identified the nature of the topic of study and the vulnerability and frailty of the research population as barriers to research.

### 6.1.4. Workforce and Awareness of PC

Widespread perceptions and lack of understanding of PC act as a barrier to access. PC is understood by some in the community to encompass pain relief, pain relief with the meaning to hasten death and PC services to be a place where you go to die (94). This understanding is not limited to health care consumers, but also an understanding held by many health care professionals and represents a significant barrier to accessing PC services (95).

***“Educational demands across the board are astronomical.”***

There remains a significant and persistent stigma associated with death and dying amongst health care professionals and in Australia in general. Low levels of awareness limits quality and access to care through late referral to SPC services, poor symptom control, lack of ACP, distress and loss of time to form acceptance (96). Only 61 per cent of clinical units in NSW routinely identified patients approaching the end of life (23).

***“We live in a very death denying society. It’s not just about educating people or normalising dying, it’s also about building capacity of the community to help themselves better and to advocate for themselves and support each other. Services in that space are very under resourced.”***

***“PC training should be part of every health care worker’s training to some degree.”***

***“They need confidence and competence to recognise literally what is in front of them.”***

While perceptions are slowly changing with the efforts of governments and organisations such as Palliative Care Australia (PCA), health professionals and the community retain a view of PC as terminal care which is appropriate

only after disease-modifying treatment has ceased (97). CHA members, and CHA itself, have engaged in the process of improving awareness of PC and EOLC issues including the use of ACPs. Shifting the culture within health care requires strategic direction from leadership and education of broader health care staff.

Shortages in trained PC staff has been acknowledged in several reports (12, 18, 23, 30). PCA has developed a consensus statement describing the minimum professional staffing to meet PC needs which includes at least 1.5 full-time equivalent (FTE) Palliative Medicine Specialists per 100,000 population (18). However, in 2016, there were just 0.9 FTE (0.7 clinical FTE) specialist palliative medicine physicians per 100,000 population (6).

The lack of PC trained nurses was a concern for most respondents, particularly those services who operate outside of a typical PC facility such as in a community-based PC service or a RACF. In 2016, there were 3,457 PC nurses employed nationally (12.2 FTE per 100,000 population), and only 10 per cent of registered nurses in aged care had PC training (6, 98). Some CHA member organisations employed a “grow your own” strategy to overcome nursing shortfalls through recruitment from related disciplines and in-house PC training and supervision. CHA members also engaged with educational institutions to improve PC training in health care worker courses.

***“It really is a case of grow your own – support people to develop and actively foster them into those kinds of roles rather than expecting there to be people around.”***

Some CHA member services were able to provide personal care assistants as part of community-based care. However, this was not consistent and the lack of funding of PC organisations to provide personal care assistants in the community was seen as a barrier to care.

CHA respondents were also concerned by the lack of PC engaged and trained GPs. GPs knowledge was considered a major barrier to community and aged care PC provision. A 2017 report found that the majority of GPs are interested in delivering PC, however only 3 per cent classified themselves as being expert in PC and 31 per cent felt they had good knowledge. Concerningly, 23 per cent of GPs were reportedly indifferent and 14 per cent actively avoid the use of PC (12). GPs reported system silos, poor discharge practises and a lack of communication between GPs and specialists PC teams as key barriers (12). CHA respondents had mostly positive experiences if the GP was engaged and communicated with by a treating SPC clinician.

***“There is a huge shortage of PC interested GPs... it’s not attractive to them. They are office based as home visits have a bulk billing disincentive. We can’t and don’t rely on primary health care in metropolitan areas.”***

## 6.2. ENABLERS OF CARE

Australia has the potential to deliver efficient and effective PC. Although the barriers discussed above fundamentally contribute to the deficiencies in PC access and quality in Australia, there are some enablers that are worthy of note.

### 1.3.1.1 Partnerships

CHA member organisations offer PC across public and private hospitals, aged and community care. They have the ability to leverage economies of scale associated with maintaining physical infrastructure of an inpatient unit and the ability to offer service in a continuum of care, including in the community. Maintaining the link of these organisations through CHA itself was viewed as an enabler by participants, particularly for encouraging collaboration in PC research, ACPs, training and education and shared learnings from engagement with funders.

Participants regarded strong PC networks and collaborations as an important facilitator of quality PC service. Similarly, LHDs and PHNs played an important role in service integration.

### 1.3.1.2 Education and Awareness

CHA and its members contribute to the field as advocates for improvements to PC, offering leadership, support and education. Members run programs themselves or support tertiary PC education for multidisciplinary staff. For example, Calvary Riverina Hospital has mandatory online PC training for all staff. Calvary CHH runs a program known as the Program of Experience in the Palliative Approach (PEPA), which aims to engage and educate local health providers including GPs and Paramedics in issues relating to PC. Within the hospital, they have responded to the need to train those in the Intensive Care Unit (ICU) by establishing regular medication education courses for staff.

Strategic leadership includes the development of EOLC plans by members, position statements on EOLC and PC, establishment of internal working groups, internal audits and research of services. SVHA has actively engaged in improving public awareness through the Every Day Dying website ([www.svha.org.au/every-day-dying](http://www.svha.org.au/every-day-dying)). There are also examples of circumventing stigma through a change of name from “palliative care” to include “supportive care” which is perceived as more palatable.

Improving the use of ACPs is seen as a critical component that enables EOLC. An ACPs empowers patient autonomy over preferences for treatment, allows them to express values and priorities and appoint a person who will represent them if they are unable to express their wishes. CHA established resources to support people and CHA organisations in this process available at [www.myfuturecare.org.au](http://www.myfuturecare.org.au). While poor use of ACPs was cited by participants as a barrier, particularly in private hospitals, most CHA respondents identified that their organisation was actively pursuing improving the use of ACPs.

### 1.3.1.3 Research

CHA members lead, participate in and finance PC research in order to improve the experience of those who are dying (section 6.3). Where research is resourced, this was a catalyst for improvements to the quality of service and staff awareness.

### 1.3.1.4 Goodwill, Community Empowerment and Volunteers

There is a striking amount of goodwill in the sector. Goodwill includes the financial donations of private citizens and the examples of unfunded PC programs run by CHA member organisations at a financial loss as part

of their commitment to the mission to help those in need. The contributions of passionate multidisciplinary staff working under frustrating conditions to ensure as many people can access best-practice PC is commendable. Supporting PC organisation and staff efforts is an army of volunteers (Box 6) and actively engaged community members such as through the compassionate communities movement (section 5.2.3).

## BOX 6 VOLUNTEERS

Volunteers form an integral part of the quality of service delivery in CHA organisations. PC volunteers offer support in a variety of roles to those with a life-limiting illness and their families or carers. Support offered by volunteers may be practical, social or emotional in nature and include a range of activities such as relaxation therapies, assistance with transport, journaling and administrative tasks.

It has been shown that PC volunteers have the capacity to positively influence quality of care by adding valuable resources and skills to a resource limited sector, and for individuals by reducing stress, offering practical and emotional support and reducing social isolation (10). The effectiveness of volunteers depends on both their background capabilities and the support and training provided by the organisation. Conversely, support for volunteers can have resource implications for the organisations providing care.

Calvary Health Care Kogarah has been recognised for the quality of their PC volunteering service. In 2018, Calvary Kogarah received the NSW PC award for outstanding professional contributions to the field of volunteer management in PC. The volunteering service also received the Mary Potter Excellence Award, a staff-based recognition of the value of the PC volunteers in the organisation.

Calvary Kogarah has approximately 150 volunteers across the community with more than 40 working in PC community services. Key to their effectiveness is the skill of the volunteer coordinator, Anne Marie Traynor, the calibre of the volunteers that the service attracts and a robust policy and training framework.

Training for all volunteers includes formalised mandatory online training covering topics such as privacy, hygiene, practical skills, fire safety, the code of conduct and some PC training, including bereavement. For those who are volunteering in a PC service, the training requirements are higher and includes 4 full days of face to face training covering issues including issues around dying and self-care. Volunteers are also offered ongoing education and support through 6-weekly debriefings.

## 1.4 RECOMMENDATIONS

### 1. Establish a National Palliative Care Alliance (NPCA) to act as an expert independent advisory group to the Australian Government on issues relating to PC.

The NPCA should support the Government by providing strategic, evidence-based advice on priorities of national importance, policy and practice implementation and evaluation strategies. The NPCA should report to the Australian Government through the Minister for Health, providing annual reports to the Minister.

### 2. Address systemic funding and access issues

- 2.1. Urgently review all explicit or implicit time-dependent access requirements to funding (e.g. ACFI) and admittance to inpatient PC facilities.
- 2.2. Review the Medicare rebate for medical services provided for PC activity. This includes a review of flexibility to provide multidisciplinary holistic care, advanced care planning and remuneration for items such as case conferencing and home visits.
- 2.3. Ensure ACFI provides adequate funding that aligns with the level of care and skill required to care for those needing PC that goes beyond terminal care. This also involves improving ACFI agility to respond to episodic needs with supplementary payment.
- 2.4. Develop recommendations for funders to guide provisions for equipment, medication and services for community-based care.
- 2.5. Review payment models for consultancy services.

### 3. Strengthen community-based PC to increase at-home death rates and reduce hospitalisations.

- 3.1. Support intensive 24-hour access to PC support, and not just in hospitals. This includes implementation of 24-hour telephone support, innovative telehealth options for remote monitoring of symptoms and expansion of PC consultancy services.
- 3.2. Enabling at home death requires improvements to the resourcing of community PC and integration of services. Organisations with existing capabilities to provide a continuum of care, such as hospitals, should be funded to do so.

### 4. Build the capacity of the health and aged care workforce to recognise and respond to PC needs.

- 4.1. Fund ongoing education programs for the wider health workforce to improve PC literacy.
- 4.2. Develop capabilities frameworks for PC competencies for aged care staff and health care staff.
- 4.3. Establish a strategy to address the urgent shortage of trained PC nursing staff together with tertiary education institutions.
- 4.4. Establish a national minimum data set for PC data collection and continue to work on validated indicators to assess improvement in PC delivery locally and nationally.

### 5. Invest in drivers of innovation.

- 5.1. Increase investment in PC research to improve the evidence base using targeted funding opportunities such as the Medical Research Future Fund. Areas of focus should be advised by the NPCA.

### 6. Initiate the conversation to improve PC awareness.

- 6.1. Provide funding to allow SPC services and other appropriate organisations to improve end of life literacy about PC, end of life planning, death and dying.
- 6.2. Develop formalised outcomes, methods of measurement, and training to ensure excellence in the performance of ACP conversation procedures.

## **CHA and its members should:**

- 1. Continue to advocate for improvements to the PC sector.**
- 2. Expand knowledge exchange activities by establishing a Catholic Palliative Care Alliance through which to:**
  - Share non-commercial-in-confidence learnings from successful private health insurance funded community-based PC pilots.
  - Develop online PC volunteer support and training.
  - Collaboratively fund PC research seed grants with tertiary education institutions. Areas of need include, but are not limited to, developing an online tool for services to review patient deaths and research into the feasibility of telehealth initiatives for PC patient cohorts.
  - Promote PC research collaboration between members. The strategic placement of CHA members to collaborate on PC research could be further exploited through leveraging clinical trial platforms, research ethics committees and expertise amongst members.
  - Review strategies to disseminate ACP and VAD resources.
- 3. Engage with sector to facilitate an awareness campaign to patients and members of the public on issues surrounding death, dying, and PC.**
- 4. Develop VAD position statements and educational resources for staff which include clear and concise language with regards to VAD.**

## APPENDIX 1 LIST OF CHA MEMBER PC SERVICES

ORGANISATION	NAME OF SERVICE	STATE/ TERRITORY	SUBURB	TYPE	SERVICES
Catholic Homes	Comfort Care Centre	WA	Perth	Public	Hospice within an RACF (6 beds)
St John of God	Subiaco Hospital	WA	Subiaco	Private	Consultative
St John of God	Murdoch Hospital, Murdoch Community Hospice	WA	Murdoch	Private Public	Inpatient (10 beds) Inpatient (10 beds)
St John of God	Bunbury Hospital	WA	Bunbury	Private	Inpatient (10 beds) Consultative
St John of God	Geraldton Hospital	WA	Geraldton	Private	Inpatient (10 beds)
Mercy Health Services	Werribee Mercy Hospital	Victoria	Sunshine	Public	Inpatient (12 beds) Consultative
Mercy Health Services	Mercy Palliative Care	Victoria	Sunshine	Public	Community 24hr phone service
St Vincent's Health Australia	St Vincent's Hospital Melbourne, Caritas Christi Hospice	Victoria	Kew	Public	Inpatient (26 beds) Outpatient Consultative, The Palliative Care Consultation Service (PCCS) Day hospice 24hr phone support
St Vincent's Health Australia	St Vincent's Hospital Melbourne	Victoria	Fitzroy	Public	Inpatient (8 beds)
Cabrini Health	Cabrini Hospital	Victoria	Prahan	Private	Inpatient (22 beds) Consultancy Community Supportive Care Clinic
Calvary Health Care	Calvary Health Care Bethlehem	Victoria	Bethlehem	Public	Inpatient (16 beds) Community Day hospice
Calvary Health Care	St Luke's	Tasmania	Launceston	Private Public	Inpatient (11 beds) Inpatient (4 beds)
Calvary Health Care	St John's Calvary Hobart, Gibson Unit	Tasmania	Hobart	Private	Inpatient (21 beds)

ORGANISATION	NAME OF SERVICE	STATE/ TERRITORY	SUBURB	TYPE	SERVICES
St Vincent's Health Australia	St Vincent's Hospital Brisbane	QLD	Brisbane	Private Public	Inpatient (≈20 beds) Inpatient (≈20 beds) Outpatient Consultative Day hospice Community
Mater Health Services	Mater Private Brisbane	QLD	Brisbane	Private and public	Inpatient (20 beds shared with oncology)
St Vincent's Health Australia	St Vincent's Hospital, Sacred Heart Health Service	NSW	Darlinghurst	Public	Inpatient (20 beds) Outpatient Community and respite Consultative Outreach clinics
St Vincent's Health Australia	St Joseph's Hospital	NSW	Auburn	Public	Inpatient (16 beds)
Mercy Health Services	Mercy Care Centre Young	NSW	Young	Public	Inpatient (4 beds)
Mercy Health Services	Mercy Health Service	NSW	Albury	Public	Inpatient (10 beds) Community
Calvary Health Care	Calvary Health Care Kogarah	NSW	Kogarah	Public	Inpatient (32 beds) Community
Calvary Health Care	Calvary Mater Newcastle	NSW	Newcastle	Public	Inpatient (17 beds) Out-patient Community Consultative Telehealth clinic
Calvary Health Care	Calvary Riverina Hospital	NSW	Wagga Wagga	Private	Inpatient (18 beds)
Calvary Health Care	Clare Holland House	ACT	Canberra	Public	Inpatient (19 beds) Community
Calvary Health Care	Calvary Hospital North Adelaide, Mary Potter Hospice	SA	North Adelaide	Private	Inpatient (15 beds)

## APPENDIX 2 TECHNICAL NOTES

### ***Inpatient data private hospitals***

Activity reported is based on hospitalisations for inpatients discharged in fiscal years 14/15, 15/16 and 16/17. Activity is divided into metropolitan or regional (including inner regional, outer regional, remote and very remote<sup>17</sup>) or both.

SPC in a private hospital is defined as care delivered under the management of or informed by a clinician with specialised expertise in PC<sup>18</sup>.

Other PC is defined as PC delivered during the management of an acute inpatient episode. PC intervention is identified as those inpatient episodes with ICD10 clinical code Z515: describing encounter for Palliative Care<sup>19</sup>.

Figures are compared to national inpatient data provided by the AIHW for the fiscal years 2014-15 and 2015-16.

### ***PCOC data***

PCOC data was provided by PCOC for the reporting period July-December 2017 for participating CHA members. This includes 26 services comprised of 20 inpatient and 6 community services.

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17. Aligns with Australian Bureau of Statistics (ABS) Australian Statistical Geographical Standard (ASGS) for Remoteness Areas inner regional, outer regional, remote and very remote.

18. Caretype Palliative Care. Source: Queensland Hospital Admitted Patient Data Collection (QHAPDC) Manual 2017 – 2018 Collection Year v1.0

19. Caretype Acute with Palliative Care

# APPENDIX 3 LITERATURE REVIEW

## METHODS

Briefly, PubMed database was searched between April and June 2016. The search consisted of a combination of search terms relevant to palliative care. Terms to retrieve research relevant to palliative care included 'palliative care', 'palliation', 'end of life care', 'advance care planning', 'advance directive' and 'advanced care plan'. To identify research conducted by CHA members, search terms included 'Australia' and contained the name or part-name of a CHA member in the 'Affiliation' field. The search was limited to papers published between 2010-2018 in English.

1. "Calvary"[Affiliation]) OR "Cabrini"[Affiliation]) OR "St Vincent's"[Affiliation]) OR "St John of God"[Affiliation]) OR "Mater"[Affiliation]) OR "Mercy"[Affiliation]) AND Australia)
2. "English" [Language]
3. "2010"[Date – Publication]: "2018"[Date – Publication]
4. "palliative care" [MeSH Major Topic]
5. "palliation" [Text Word]
6. "end of life care"[Text Word]
7. "advance care planning"[MeSH Major Topic]
8. "advanced care plan" [Text Word]
9. "advance directive" [Text Word]
10. 1 AND 2 AND 3 AND 4 OR 5
11. 1 AND 2 AND 3 AND 6
12. 1 AND 2 AND 3 AND 7 OR 8 OR 9

For inclusion papers needed at least one author based at a CHA member organisation. As EOLC and PC are often used interchangeably and can refer to related concepts, papers were screened for direct relevance to PC. EOLC research was included as papers were frequently published in an EOLC context. Papers reporting on active treatment or EOLC/ACP in the context an unexpected death were excluded. Citations were exported to Endnote and duplicates were removed. Quality appraisal was not conducted in this review as the focus is on comprehensively mapping the area of interest.

A recent review of PC research reported difficulties identifying PC literature using electronic database searches, with 91 per cent not obtained from easily accessible sources such as PubMed (99). Therefore, CHA member websites were also used to identify additional papers, books and reports of interest not identified by the PubMed search.

Research was categorised into key themes including symptoms (physical, psychosocial or spiritual), methodology or assessment, carers and families, services and settings (including patient experience), decision-making, staff attitudes and experience, setting of care or death, bereavement, education and training, communication, aged care, quality of life and last days of life.

## RESULTS

The themes most frequently described in the papers were assessment and methodology (18 per cent), carers and families (17 per cent), physical symptoms (13 per cent), services and settings including patient experience (12 per cent), decision-making (8 per cent), staff attitudes and experiences (8 per cent), and psychosocial symptoms (6 per cent). Other areas with limited publication numbers included education and training, communication, quality of life, bereavement and last days of life. Members also identified pastoral care research as a priority which was not captured by the electronic literature search.

SVHA identified a research focus on carer experience, models of care, family and carer support, advanced cancer and presentation at the emergency department and epidemiology. SVHA is also undertaking studies to map points of contact of patients with hospitals to be more predictive of when PC could become involved.

CHA members are highly collaborative with other research institutions. Collaboration amongst CHA members, as indicated by co-authorship by more than one CHA-member, occurred in 8 per cent of papers, with the most frequent co-authorship between SVHA and Calvary Health Care (44 per cent). The unique position of CHA members in their PC focus and access to clinical facilities, ethics committees and researchers, further collaboration between members has the potential to deliver meaningful research outcomes.

## APPENDIX 4 LIST OF CHA MEMBER PUBLICATIONS BETWEEN 2010-2018

Agar M, Ko DN, Sheehan C, Chapman M, et al. Informed consent in palliative care clinical trials: challenging but possible. *Journal of palliative medicine*. 2013;16(5):485-91.

Agar MR, Lawlor PG, Quinn S, Draper B, et al. Efficacy of Oral Risperidone, Haloperidol, or Placebo for Symptoms of Delirium Among Patients in Palliative Care: A Randomized Clinical Trial. *JAMA internal medicine*. 2017;177(1):34-42.

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Cahill PJ, Sanderson CR, Lobb EA, Phillips JL. The VOICE Study: Valuing Opinions, Individual Communication and Experience: building the evidence base for undertaking Patient-Centred Family Meetings in palliative care - a mixed methods study. *Pilot and feasibility studies*. 2018;4:51.

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