2021

Palliative Care

Needs Assessment

phn GOLD COAST

An Australian Government Initiative

Palliative Care

Local health needs and service issues

- Limited uptake of Advanced Care Plans.
- Limited systems to support care coordination and support to general practice to be the centre of care where possible.
- Current systems not always supportive to ensure planning, commissioning, and delivery of integrated and coordinated service matrix.
- Limited access to integrated palliative care system across the health and social sector
- Limited access to good quality end of life care 24/7.
- Limited access to clear communication, and accessible information for patients, families, and healthcare professionals.
- General practitioners understanding of the clinical triggers for commencing palliative care can vary.
- Over half of general practitioners on the Gold Coast were trained overseas which may affect their understanding of palliative care services.

Key findings

- National research shows that most Australians would prefer to die at home, but many don't, with over half of deaths occurring in a hospital. While the accessibility and use of palliative care services is increasing, the proportion of people who receive palliative care services is still relatively low, particularly for non-cancer related diagnoses.
- At a national level, patient outcomes show that the effectiveness of palliative care services has increased significantly over the last 10 years in relation to symptoms such as pain, fatigue, breathing problems and family or carer problems.
- Data on patient outcomes for palliative care services in the Gold Coast Primary Health Network (GCPHN) region is still emerging. Early indicators would show the effectiveness of inpatient treatment exceeds national benchmarks, however treatment delivered in a community setting did not meet benchmarks due to the limited availability of these services to provide treatment on demand at all times of the day.
- The demand on palliative care and specialist palliative care services is projected to increase in the GCPHN region, with its ageing population and higher proportion of older people in the GCPHN region. Currently, the majority of the specialist palliative care service demand falls to the specialist public inpatient and community facilities at Robina Hospital and Gold Coast University Hospital.
- Consultation highlighted a range of issues that may be impacting the effectiveness of generalist palliative care services to meet the needs of people, which would enable specialist services to focus their limited resources more appropriately on more complex cases.
- These issues include clinical handover and discharge planning to support transitions between the hospital and home (including RACFs). Continued integration and coordination of specialist and generalist palliative care services could lead to more positive patient outcomes. A desire for general practitioners (GPs) to play a central role throughout a person's palliative care journey was reported from multiple perspectives. More broadly, community and sector consultation confirmed issues on the Gold Coast with:

- service access and navigation
- limited health and death literacy
- Workforce capacity and capability for generalist services.
- Service availability and resourcing.
- Professionals feeling supported and able to learn and to care.
- People want to receive care in their homes and local communities as much as possible.
- People want information that supports them to be partners in decisions about their care.
- People need end of life and palliative care that responds to an ageing population.
- People are sicker and require palliative care that can be provided alongside other treatments that respond to their complex care needs.
- Many people with chronic or life-limiting illnesses (including some cancers) are living for much longer, requiring a different response from end of life and healthcare services.
- Some groups in our community do not access services for end-of-life care or get the care they need.
- The healthcare, human services and community workforce needs to adapt with new skills to better identify and support the end of life needs of people, their families, and carers.
- All services need to operate more efficiently to deliver care that is sustainable.
- Community expectations have increased, with growing interest in discussing death and dying and planning for end of life with a method such as advance care planning.

Palliative Care

The Australian Commission on Safety and Quality in Healthcare (ACSQHC) defines palliative care as care specifically tailored to assist with the effects of life-limiting illnesses[1] . It positions palliative care as different from the broader concept of end-of-life care which generally refers to the period of the 12 months prior to death, whereas palliative care may be episodic over an extended period.

Palliative care is an approach to treatment that improves the quality of life for patients and their families facing life-limiting illness, through the prevention and relief of suffering. It involves early identification, impeccable assessment and treatment of pain and other problems (physical, psychosocial, and spiritual).

Palliative care is now provided in almost all settings where healthcare is provided, including neonatal units, paediatric services, general practices, acute hospitals and residential and community aged care services.

Specialist palliative care services are comprised of multidisciplinary teams with specialised skills, competencies, experience, and training to deliver care to people where the palliative needs are complex and persistent. Specialist palliative care services operate from a variety of settings, including specialist inpatient consulting services, specialist inpatient settings, hospices, and community-based specialist services[2].

1 Australian Commission on Safety and Quality in Health Care (2015). National Consensus Statement: essential elements for safe and high-quality end-of-life care
2 DoH (Department of Health) 2019. National Palliative Care Strategy 2018. Canberra: Department of Health. Viewed 9 July 2020. This data set is a component of the minimum data set.

The Australian Government established the Royal Commission into Aged Care Quality and Safety in October 2018, which received various submissions on palliative care within the aged care sector. The Commission's final report was released on 26 February 2021. Key recommendations for palliative care included:

- compulsory palliative care training for aged care workers
- comprehensive sector funding specifically including palliative care and end-of-life care
- A review of the Aged Care Quality Standards to regulate high quality palliative care in residential aged care
- access to multidisciplinary outreach service
- A new Aged Care Act that includes the right to access palliative care and end-of-life care

Service demand

On the Gold Coast and more broadly in Australia, the demand for palliative care services is increasing due to the ageing of the population and the increases in the prevalence of cancer and other chronic disease that accompany aging.

There were 3,953 deaths recorded for the GCPHN region during 2017, the most recent year for which data is available. The number of deaths recorded in the GCPHN region has increased from 2,836 in 2006, an increase of almost 40 per cent in the 11-year period.

The ten leading causes of death for the GCPHN region over the period 2013-2017 represented 50 per cent of all deaths, is outlined in Table 1.

Table 1. Ten leading causes of death for Gold Coast PHN region by number and proportion of all-cause mortality, 2013-2017.

Cause of death (ICD classification)	Number of deaths	Proportion of all causes
Coronary heart disease (I20–I25)	2,306	12.9
Dementia and Alzheimer disease (F01, F03, G30)	1,390	7.8
Cerebrovascular disease (I60–I69)	1,228	6.9
Lung cancer (C33, C34)	1,058	5.9
Chronic obstructive pulmonary disease (COPD) (J40–J44)	754	4.2
Colorectal cancer (C18–C20, C26.0)	657	3.7
Prostate cancer (C61)	485	2.7
Suicide (X60–X84)	413	2.3
Diabetes (E10–E14)	406	2.3
Pancreatic cancer (C25)	374	2.1

Given many of the deaths recorded within the GCPHN region are related to a chronic cause many of these deaths are likely to have a different phase where there was an opportunity for the provision of appropriate and effective palliative care.

Service utilisation

Accessibility and appropriate utilisation of high-quality palliative care services can enable a person and their family to receive the care and support they need at the end-of-life, supporting them to die at home with dignity and in comfort and prevent unnecessary hospitalisations. Previous estimates indicate that 70 per cent of Australians wish to die at home[3] , however around half of all deaths occur in hospital.

Palliative care services in Australia are provided in a range of settings including:

- public and private hospital facilities
- residential aged care facilities
- in patient's homes through primary care providers

The availability of data relating to palliative care services is limited, particularly comprehensive data relating to palliative care services delivered in the community by GPs, non- palliative medicine specialists and allied health and ancillary practitioners. The Australian Institute of Health and Welfare (AIHW) has reported it is exploring the development of a mechanism to collect national data on palliative care activity in general practice.

Admitted patient palliative care and other end-of-life care and hospital-based facilities

This section presents information on episodes of admitted patient (patients who undergo a hospital's formal admission process to receive treatment and/or care) palliative care and other end-of-life care occurring in Australian hospitals.

In this section, palliative care-related hospitalisations are separated into two groups:

- **Palliative care hospitalisations**: hospitalisations that involved specialist palliative care. This was evidenced by a code of Palliative care for the 'Care type'.
- **Other end-of-life care hospitalisations**: hospitalisations where a diagnosis of palliative care was provided but the palliative care was not necessarily delivered by a palliative care specialist. This was evidenced by an additional diagnosis of palliative care, but where the 'Care type' was not Palliative care.

Key points identified nationally from the admitted patient palliative care and other end-of-life care and hospital-based facilities:

83,430 palliative care-related hospitalisations were reported from public acute and private hospitals in Australia in 2018–19; 57.3 per cent were for palliative care, and 42.7 per cent were for other end-of-life care.

- 53.6 per cent of palliative care hospitalisations and 54.2 per cent of other end-of-life care hospitalisations were for people aged 75 and over.
- 17.7 per cent increase in palliative care hospitalisations and 47.5 per cent increase in other end-of-life care hospitalisations between 2014–15 and 2018–19, compared to a 13.7 per cent increase in hospitalisations for all reasons over the same period.
- 38.4 per cent of all hospitalisations in which the patient died, the patient had received palliative care in 2018–19; 18.6 per cent had received other end-of-life care.

3 Swerissen, H and Duckett, S., (2014). Dying Well. Grattan Institute: Melbourne

- 53.6 per cent of palliative care and 33.9 per cent of other end-of-life care hospitalisations involved cancer as the principal diagnosis in 2018–19.
- 110 public acute hospitals reported that they had a hospice care unit in 2018–19, with just over a quarter located in both New South Wales (27.3 per cent) and Western Australia (27.3 per cent).
- 1 in 6 (16.4 per cent) public acute hospitals (excluding public psychiatric hospitals) in Australia had a hospice care unit in 2018–19.
    - Hospices don't exist in publicly funded hospitals any more in 95 per cent of Australian hospitals

Diagnosis

About half of all palliative care (53.6 per cent) and one third of other end-of-life care (33.9 per cent) hospitalisations recorded a principal diagnosis of cancer in 2018-19. The most frequently reported principal diagnoses other than *cancer* for palliative care hospitalisations were *cerebrovascular disease* and *heart failure and complications* (4.3 per cent and 3.1 per cent, respectively). For other end-of-life care, the most frequently reported principal diagnoses other than *cancer* were *septicaemia* and *other ill-defined causes* (4.9 per cent and 4.8 per cent, respectively).

Table 2 shows the change in Gold Coast Health palliative care-related hospital separations and associated bed days over the period 2014-15 to 2020-21,

Table 2. Number of palliative care-related separations and occupied bed days in Gold Coast Health facilities, 2014-15 to 2020-21,

Age group (years)	Financial year						
	2014-15	2015-16	2016-17	2017-18	2018-19	2019-20	2020-21
Separations							
0-14	0	<5	0	0	<5	0	0
15-44	41	43	57	27	30	34	22
45-69	334	298	299	320	322	352	283
70-84	420	342	336	322	476	506	457
85+	157	160	163	150	231	269	260
Bed days							
0-14	0	6	0	82	65	0	0
15-44	313	395	476	228	269	249	157
45-69	2536	2516	2166	2542	2335	2576	2130
70-84	3184	2627	2406	2544	2868	3068	3101
85+	1060	1086	938	866	912	1322	1308

Source: Gold Coast Hospital and Health Service, Strategy and Health Service Planning Branch

This shows a total of 1,002 palliative care-related separations occurred in 2020-21, which represented a total of 6,696 occupied bed days. The most separations were recorded for the 70-84-year age group. There is a lack of funding for people under 65 years of age as not eligible for palliative care packages. The only option is to self-fund at the moment, Gold Coast Health have been able to fund a small number, but this is reducing their budget for service delivery.

Hospital-based facilities

A specialist palliative care inpatient unit is a specialist unit delivering palliative care services and can include both free-standing facilities and wards within a hospital. In 2018-19, a total of 110 public acute hospitals nationally reported having a hospice care specialist palliative care inpatient unit. In Australia, just over a quarter (27.3 per cent) of hospitals with a specialist palliative care inpatient unit were in each of New South Wales and Western Australia, with 11 in Queensland as of 2018-19

Palliative care delivered in primary care and community settings

GPs plan an important role in palliative care as well as the health-care system more broadly. However, there is not nationally consistent, routinely collected primary healthcare data collection that enables reporting on the provision of palliative care by GPs.

Additionally, while the Medicare Benefits Schedule includes specific items for palliative medicine specialist services (delivered by palliative medicine specialists) for which it will reimburse a proportion of the MBS fee there are no palliative care-specific item that can be used by GPs or other medical specialist who may be providing palliative care. It is likely that GPs use other MBS items, for example, those for chronic disease management and home visit items, when providing patients with palliative care. Therefore, the number of palliative care-related services delivered by GPs cannot be established from existing Medicare data.

BEACH survey data

Palliative care related encounters provided by GPs using data from the Bettering the Evaluation and care of health (BEACH) survey of general practice activity which was conducted for the last time in 2015-16. The national findings included:

- In 2015–16, about 1 in 1,000 GP encounters reported for the BEACH collection was palliative care-related.
- About 9 in 10 palliative care encounters were with people aged 65 and over, and 4.8 per cent were with those aged under 55.
- Females accounted for a greater proportion of GP palliative care-related encounters (53 per cent) than males (47 per cent), but there was no difference between the sexes in palliative care encounter rates (about 1 per 1,000 of GP encounters for both males and females).
- In 2015–16, 1.3 per cent of palliative care-related encounters were recorded as being with Indigenous Australians[4].

Medicare subsidised palliative medicine services

This section discusses the number and type of Medicare Benefits Schedule (MBS) subsidies for palliative care-related services provided by palliative medicine specialists. The Royal Australian College of Physicians (RACP) describes palliative medicine as *'the specialist care of people with terminal illnesses and chronic health conditions in community, hospital, and hospice settings. Palliative Medicine Physicians work collaboratively with a multidisciplinary team of health professionals to provide end of life care, provide relief from pain and symptoms of illness, and optimise the quality of life for a patient. Palliative medicine treats the physical aspects of illness, but also integrates psychological and spiritual facets of patient care'*[5].

4 Britt H, Miller GC, Henderson J, Bayram C, Harrison C, Valenti L et al. 2016. General practice activity in Australia 2015–16. General practice series no. 40. Sydney: Sydney University Press.

5 RACP (Royal Australian College of Physicians) 2020. Australasian Chapter of Palliative Medicine. Sydney: RACP. Viewed 18 March 2021

A palliative medicine specialist is a medical specialist who is a Fellow of the RACP and has completed the College's training program in palliative medicine, a Fellow of the Australian Chapter of Palliative Medicine or both[6].

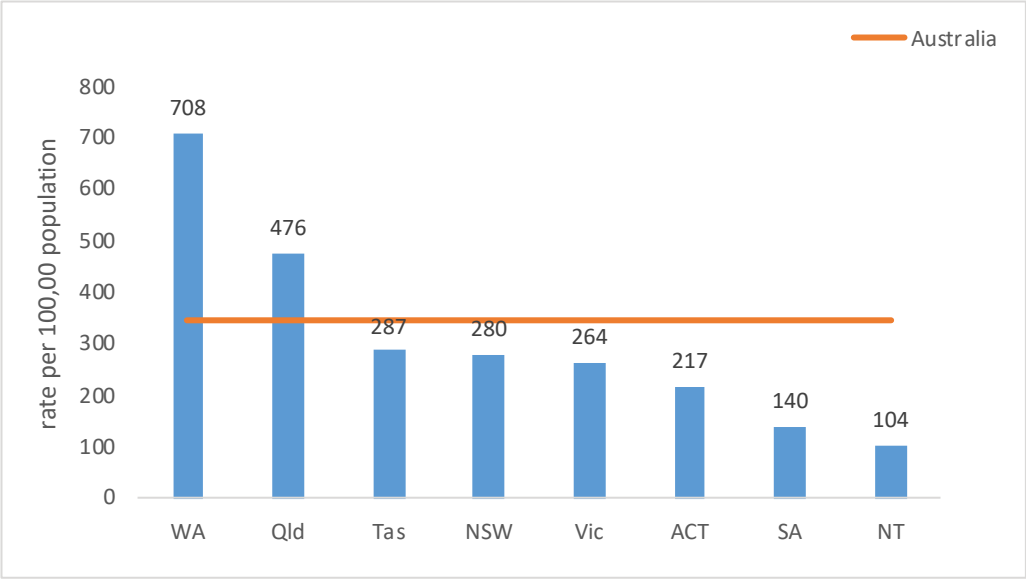
Broadly, the MBS-subsidised palliative medicine specialist services can be categorised as follows:

- palliative medicine attendances (specialist consultation with patient)
  - attendances at hospital or surgery
  - home visits
- palliative medicine case conferences (multidisciplinary team meetings)
  - community case conference—organisation and coordination
  - community case conference—participation
  - discharge case conference—organisation and coordination
  - discharge case conference—participation

In 2019–20 there were 88,605 MBS-subsidised services provided by palliative medicine specialists. This is an increase of 4.4 per cent per year over the last five years, from 74,555 in 2016-17. Palliative medicine attendances in hospital or surgery made up the majority 80.2 per cent (71,077 services) of all MBS-subsidised palliative medicine specialist services in 2019–20 with a further 9.4 per cent (8,369) of all services being consultations in the patient's home.

The rate of MBS-subsidised palliative medicine specialist services in 2019-20 varied among states and territories. Western Australia recorded the highest rate (707.7 per 100,000 population with Queensland having the second highest rate (475.6) or 24,397 services which was the highest total number of services claimed among all Australian states.

Figure 1. MBS-subsidised palliative medicine specialist services, by states and territories, rate per 100,000 population, 2019-20



Source: Medicare Benefits Schedule data (AIHW analyses)

6 ANZSPM (Australian and New Zealand Society of Palliative Medicine) 2008. Defining the meaning of the terms: Consultant Physician in Palliative Medicine and Palliative Medicine.

General practice palliative care-related attitudes and awareness

A study commissioned by the Australian Government Department of Health researching the awareness, attitudes and provision of best practice advance care planning, palliative care, and end of life care within general practice. The study identified that GPs' understanding of what constitutes palliative care and end of life care varies widely and that differing palliative care settings have very different requirements in terms of best practice.

The study also provided a variety of recommendations including:

- better defining the role of GPs in palliative care
- promoting a better understanding of the clinical triggers for commencing palliative care
- the development of local directories to enable GPs to access palliative care resources and better communication
- integration with other parts of the health system including encouraging referrals to specialist palliative care teams or GP experts[7]

Palliative care for people living in residential aged care

The Australian Government subsidies residential aged care services for older Australians whose care needs are such that they can no longer remain living in their own homes. Providing palliative care in residential aged care is complex. In 2019-20, there were 244,327 people living in residential aged care in Australia—of whom 3,178 (1.3 per cent) had an Aged Care Funding Instrument (ACFI) appraisal indicating the need for palliative care.

7 DOH (Department of Health) 2017. Final report: research into awareness, attitudes and provision of best practice advance care planning, palliative care, and end of life care within general practice. Canberra: Department of Health.

Workforce

The palliative care workforce is made up of a number of health professional groups including specialist palliative medicine physicians, nurses, GPs, pharmacists, other medical specialists (such as oncologists and geriatricians), as well as other health workers, support staff and volunteers. Reliable data relating to the size and breakdown of the palliative care workforce is not currently available for the GCPHN region.

There were 271 palliative medicine physicians employed in Australia in 2018, 0.8 per cent or about 1 in 130 of all employed medical specialists. On the Gold Coast in 2019 there was a total of six medical practitioners with a primary speciality of palliative medicine employed in the Gold Coast working in registered profession.

Table 3 below highlights the employed palliative medicine physicians for each state.

Table 3. Employed palliative medicine physicians, average total hours worked per week, FTE, and FTE per 100,000 population, states, and territories, 2018

	Number of palliative medicine physicians	Average total hours worked per week	Average clinical hours worked per week	FTE number	Clinical FTE	FTE per 100,000 population	Clinical FTE per 100,000 population
New South Wales	91	39.9	30	90.9	68.3	1.1	0.9
Victoria	61	35.5	24.7	54.1	37.6	0.8	0.6
Queensland	49	40.6	34.5	49.8	42.3	1.0	0.8
Western Australia	30	37	31.8	27.8	23.8	1.1	0.9
South Australia	20	35	28.5	17.5	14.3	1.0	0.8
Tasmania	10	36.7	27.8	9.2	7	1.7	1.3
Australian Capital Territory	5	43.2	30.8	5.4	3.9	1.3	0.9
Northern Territory	5	36.6	34.8	4.6	4.3	1.9	1.7
National	271	38.3	29.7	259.2	201.4	1.0	0.8

Source: National Health Workforce Data Set 2018.

Prescribed medications

Prescribed medication is an important component of palliative care. These medications are defined as clinically relevant for patients with 'active, progressive and far advanced diseases for whom the prognosis is limited and the focus of care is quality of life'. These medications typically involve:

- analgesics for pain relief
- anti-epileptics to treat seizures
- anti-inflammatory and anti-rheumatic products to treat inflammation
- drugs for gastrointestinal disorders
- laxatives

While no regional data is available, national data on palliative care-related prescribing in 2018- 19 indicates that:

- 16,778 patients received an MBS-subsidised palliative medicine specialist service.
- 89,382 MBS-subsidised services were provided by palliative medicine specialist.
- $7 million was paid in benefits for MBS-subsidised palliative medicine specialist services in 2018-19, at an average of $416 per patient.
- Nationally, the rate of subsidised palliative medicine specialist services provided in 2018-19 was 355 per 1,000 population.

Performance of palliative care services

The Australian Palliative Care Outcomes Collaboration (PCOC) is a national program that utilises standardised clinical assessment tools to measure and benchmark patient outcomes in palliative care[8]. Participation in PCOC is voluntary and can assist palliative care service providers to improve patient outcomes. It is administered by the Australian Health Services Research Institute based at the University of Wollongong. PCOC's data collection covers more than 250,000 people who have received palliative care over the last decade. National data for 2017 shows that[9] :

- Just over half of all episodes completed were in an inpatient setting (53.4 per cent), with the remainder completed in the community (46.6 per cent).
- Palliative care episodes were disproportionately accessed by socioeconomic status, with those people in higher socio-economic status categories reporting higher episodes of palliative care in both inpatient and community settings.
- The average age of people undertaking a palliative care episode was 72.8 years.
- There was a total of 228 episodes reported for patients under 25 years of age, which represented only 0.4 per cent of all episodes.
- A higher proportion of males (53.2 per cent) underwent palliative care episodes compared to females (46.8 per cent).
- Over three quarters of episodes of palliative care (77.6 per cent) were for patients with a cancer diagnosis, despite patients suffering from other chronic life-limiting conditions such as heart

8 Palliative Care Outcomes Collaboration (PCOC), Australian Health Services Research Institute, University of Wollongong https://ahsri.uow.edu.au/pcoc/index.html
9 Palliative Care Outcomes Collaboration (2018) Palliative care services at a glance, 2017 data tables Australian Health Services Research Institute, University of Wollongong

failure, COPD or dementia have symptoms as severe and distressing as those of cancer patients.

- Over three quarters of episodes of palliative care (77.6 per cent) were for patients with a cancer diagnosis.

Analysis of the patterns of national outcome data collected through PCOC from 2009 to 2016 shows:

- More patients are having palliative care commence within two days of when they are ready.
- The time patients spend in the unstable phase has been getting shorter
- The proportion of patients reporting absent or mild distress at the end of a phase has been improving, with slightly better outcomes in the inpatient setting
- The number of family members and carers experiencing moderate or severe problems at the end of a phase of care has been decreasing over time.

Advance care planning

Advance care planning is the process of planning for future health and personal care whereby a person's values, beliefs and preferences are made known so they can guide clinical decision-making at a future time when that person cannot make or communicate their decisions. Advance care planning is a priority for quality person centered or end of life care and promotes an individual's choice and control over healthcare decisions.

An advance care directive is a type of written structured advance care plan recognised by common law or specific legislation that is completed and signed by a competent adult[10].An advance care directive will typically document the persons values, beliefs, and specific preferences for future care and/or include the appointment of a substitute decision maker. A substitute decision maker may be required to make medical treatment decisions on behalf of a persons whose decision-making capacity is impaired[11].

In Queensland, there are three ways individuals can record their choices for future healthcare:

- **Enduring Power of Attorney -** An Enduring Power of Attorney process allows the individual to choose a trusted relative or friend to manage your personal matters (including healthcare) and financial matters.
- **Advance Health Directive -** An Advance Health Directive is a formal way to give instructions about the individuals future healthcare. It is sometimes called a living will. It will only take effect if the individual does not have capacity to make decisions.
- **Statement of Choices -** A Statement of Choices allows the individual to record their personal values and preferences for healthcare.

Despite the recognised benefits of formally documenting, one's advance care planning preferences, available estimates suggest less than 30 per cent of Australians have completed an advance care directive[12].

There are no dedicated MBS item numbers for Advance Care Planning, instead it is undertaken as part of standard GP consultations, health assessments, chronic disease management plans or case conferencing items.

As such, there is no regional data to indicate the number of Advance Care Plam (ACP) services being undertaken by GPs. A study to investigate the prevalence, characteristics, and accessibility of statutory and non-statutory advance care directives for older people at the point of care in Australian health and residential aged care services was completed. This study conducted an audit of 4,187 health records of individuals aged 65 years or over in participating general practice, hospitals, and residential aged care facilities.

10 Rhee JJ, Zwar NA, Kemp LA. Why are advance care planning decisions not implemented? Insights from interviews with Australian general practitioners. Journal of Palliative Medicine. 2013;16(10):1197-204.
11 Australian Health Ministers' Advisory Council. National Framework for Advance Care Directives. Canberra, Australia: Commonwealth Government of Australia; 2011.
12 Deterring KM, Buck K, Ruseckaite R, Kelly H, Sellars M, Sinclair C, et al. Prevalence and correlates of advance care directives among older Australians accessing health and residential aged care services: multicentre audit study. BMJ Open. 2019;9(1): e025255

The study had the following outcomes:

- Prevalence of having at least one advance care directive in the person's health record was 25 per cent.
  - Of these, only 6 per cent of participants had a statutory advance care directive outlining their preferences for care.
  - 12 per cent of participants had a statutory advance care directive appointing a substitute decision-maker.
  - 12 per cent had a non-statutory advance care directive.
- Prevalence rates were highest in residential aged care facilities, with 38 per cent of residents having one or more advance care directives
  - In comparison, approximately 11 per cent of people in hospitals.
  - 6 per cent of people of attending general practices had an advance care directive in their health record.

Analysing data uploaded by Gold Coast residents to Queensland Health electronic hospital record (the viewer), a large increase was seen across all document types (statement of choice, advanced health directive and enduring power of attorney) from 2017.18 to 2019-20. There was a total of 1,006 Gold Coast residents who had completed Statement of Choices in 2019-20[13].

Table 4. Advance care planning documents uploaded to the Queensland Health electronic hospital record (The Viewer), Gold Coast residents, 2017-18 to 2019-20

Document type	2017-18	2018-19	2019-20
Statement of Choices	483	467	1,006
Advance Health Directive	16	129	311
Enduring Power of Attorney	23	167	810

Source. Office of Advance care Planning – Queensland Health

Gold Coast has implemented a number of programs that have focused on palliative care and increasing advanced care planning in RACF's over recent years these have included:

- Advance Care Planning in RACFs Project (June 2017 – December 2018)
- The Advance Project (1 Jan 2019 – 30 March 2020)
- Enhanced Primary Care (Clinical Educator- Palliative) (1 June 2019 – 30 June 2020)
- Greater Choices for at Home Palliative Care (June 2017 – October 2021)
- Specialist Palliative Care in Aged Care (SPACE) (1 Nov 2020 – 30 June 2024)

13 Office of Advance care Planning – Queensland Health

Service system

Services	Number in the GCPHN region	Distribution	Capacity discussion
Gold Coast Health, Inpatient Facility (Specialist Palliative Care)	1	Robina Hospital	• One public purpose-built 16 bed palliative care unit is available for residents of the Gold Coast at Robina Hospital • The Palliative care unit is not a long-term facility, and patients who have issues which needed initial input from the unit may be discharged to more appropriate care including the generalist services and residential aged care facilities (RACFs) or the private hospice
Gold Coast Hospital and Health Service Specialist Palliative Care in Aged Care	1	Robina Hospital	• Project providing in reach support to upskill RACF staff to improve ability • Funded from 2020 to 2024
Hopewell Hospice	1	Arundel	• Seven beds located a few kilometres from GCUH, it's often used for terminal care that has one non-private bed available
Gold Coast Health Community Service	1	Gold Coast wide	• The Community Service team provide a consultative service in patients' homes and provide support to the GP and other teams when necessary. There are no services currently to residential aged care facilities (nursing homes or hostels)
Gold Coast Health Bereavement Services	1	Gold Coast wide	• When a palliative care patient passes away, the family, including significant others, receive follow up consultations by a Social Worker, Chaplain, Community Nurse or Medical Officer as appropriate. While their bereavement needs are constantly assessed from the first meeting with the patient and family, their immediate needs are assessed in the week following the passing of the patient. Ongoing support is arranged as is appropriate through other community services

Gold Coast Health, Consultation and Liaison Service (Specialist Palliative Care)	1	Gold Coast University Hospital	• Symptom assessment, support and management advice, family support, case/family conference, care planning discussion, triage admissions and discharge advice
Gold Coast Health, Outpatient/ Community Facility (Specialist Palliative Care)	2	Robina and Gold Coast University Hospital	• Assessment and ongoing management via outpatient Clinics and community home visits • Liaison with GPs and community nurses.
Gold Coast Health, Inpatient Facility (Children's Palliative Care Service)	1	Gold Coast University Hospital	• Works closely with Children's Health Queensland • Not a standalone service, staff are shared across multiple services
BlueCare, Ozcare and Anglicare (funded by Gold Coast Heath)		Gold Coast wide	• Complex nursing care, personal care, and support to help patient stay at home, includes post-death support • Other NGOs including Aquamarine Care, RSL Life Care at Home Kalwun Home and Community Care are also reported to provide limited services
Aged care service providers	Numerous	Gold Coast wide	• Numerous aged care providers across the GCPHN region report providing generalist palliative services, but do not provide specialist palliative care support • This can include domestic and personal care, home maintenance and modifications, equipment, social support clinical services, respite, and counselling
General Practitioners	858	Gold Coast wide	• Critical role in coordinating care and making referrals, identifying and assessing palliative care needs pain management, medication management, bereavement support and advance care planning

Consultation

Gold Coast Aged and Palliative Care Steering Group

- SPACE Project – working in RACF is challenging due to the competing needs for the education and training of RACF staff particularly with the increase in training required in relation of COVID and meeting the new quality standards.
- Workforce – Local hospice has found it challenging to engage GP to provide clinical governance due to fact that the model does not provide adequate income for GP. Hospice reviewing the model to determine ongoing sustainability options.
- With over 900 GP on the Gold Coast, they are unlikely to see many palliative patients per year (10 to 20) and as such may not prioritise the area for extra training or professional development.
    - GPs may only have one to two that require specialist palliative care
    - Many GPs do Program of Experience in the Palliative Approach (PEPA) programs each year, there has been a decrease since the PEPA program stop paying GPs to complete the program.
- Palliative Care Health Pathway – availability on the GCPHN website has provide GP with access to information when required.
    - 1,127 unique page views for the Palliative care health pathways whilst hosted on GCPHN website (January to June 2021)
- Two main challenges supportive and Specialist Community Palliative Care Service Delivery teams face are:
    - Lack of funding for people under 65 years of age as not eligible for packages (only option is to self-fund at the moment, Gold Coast health have been able to fund a small number – but this is reducing their budget for service delivery)
    - GPs not providing home visits
        - Currently with Medicare covid phone payments GPs are engaging more

Clinical Council

In August 2021, Gold Coast PHN utilised the Clinical Council as an engagement mechanism to discuss emerging issues relating to palliative care in the GCPHN region. Key issues and themes raised include:

- As RACFs largely undertaking palliative care – important to note Royal Commission – notes issues of adequate staffing, particularly in the afterhours.
- GPs don't do much in home palliative care as not remunerated appropriately to do so, it is not viable. Most will do some for longer term existing patients but would be unlikely to deliver home support for someone they did not already know.
- Increasing personal care responsibilities and part time nature of work in general practice makes it difficult to service in home palliative care, particularly in the afterhours.
- In home palliative care needs family support. In the GCPHN region often elderly patients had moved to the GCPHN region from interstate so they do not have the supports at home required.
- Limited private options – most people with specialist palliative care needs end up in in the public systems.

- Patients make choices about GP services. They may attend a mixed billing practice for longer term, complex issues but visit bulk billing for quick fix things like prescriptions.
- Home nursing services are very important in delivering at home palliative care, they have great expertise but need to link in / be networked better with the specialist services
- Details of Pharmacies stocking palliative care medication being added to health pathway
- GCPHN has previously explored supporting palliative care volunteers but there was little interest from relevant NGOs and initiative did not progress.
- Despite increase in promotions of ACP etc, and some increase in number of ACP being completed, the broader understanding of consumers understanding of ACPs remains limited.

Primary Care Partnership Council

In July 2021, Gold Coast PHN utilised the Primary Care Partnership Council as an engagement mechanism to discuss emerging issues relating to palliative care services in the GCPHN region. Key issues and themes raised include:

- Underfunded leading to issues regarding continuity and access – some get access to funding some don't. Access restricted to when people are in very late stage of illness. Should be support for journey with psychologists, emotional as well as physical. Access fragmented and comes too late.
- When a person comes back from hospital with new diagnosis – palliative. Not well understood. Not clear on the implications and next steps. Limited support available to travel that journey, people become anxious. Language used in form from hospital - "palliative" what does that mean in terms of ongoing care.
- Perusing more at home, emphasis on palliative education on workforce already visiting in homes, home care workers – likely to not have received training regarding grief loss etc. Registered nurses have pall training. Key component workers less prepared.
- Capacity building for carers - what is available and the services they can access.

Gold Coast Primary Health Network Clinical Council

In June 2018, Gold Coast PHN utilised their Clinical Council as an engagement mechanism to discuss emerging issues relating to palliative care services in the GCPHN region. Key issues and themes raised include:

- Cost across several domains, the cost of non-PBS listed palliative medications and their lack of availability at some pharmacies across the GCPHN region. With RACFs not serviced under state funded palliative care services, their residents have little options but hospital admission to access palliative care services.
- Clinical handover in both public and private settings can be challenging. Case conferencing and discharge planning can help to ensure the GP remains the centre of a person's care, however telehealth services are rarely utilised due to a lack of MBS subsidies in metropolitan locations such as the Gold Coast. Both specialist services and GPs have raised the desire to ensure GPs are position as a central and ongoing part of a patient's care, but some instances reported this was not the experience.

- Resourcing is often an issue with timely access to palliative beds and other potential resources when the case is often urgent. With the Gold Coast Hospice resourced with generally only 1 public bed (and 7 private) a lot of the demand for acute service falls to the public inpatient facilities.
- An opportunity for education to take place through peer-to-peer learning or shared learning with GPs and allied health providers was identified in the GCPHN region relating to the continuing holistic care (e.g., allied health treatment) of a person once they begin accessing palliative care services.

Gold Coast Primary Health Network Community Advisory Council

In June 2018, GCPHN undertook engagement with their Community Advisory Council (CAC) to review and evaluate the Older Persons Needs Assessment Summary developed in late-2017, which included a component on palliative care. Ninety three percent of CAC members either agreed or strongly agreed on the needs identified in the document.

Additional engagement with the group identified a range of areas where improvement is needed:

- Service Access and Navigation
  - Navigate the right level of care and provider of home support for a loved one is challenging, and there is minimal support for this.
  - Significant modification costs often borne by families.
  - After hours GPs (at their discretion) can decline home visits for palliative patients leaving emergency presentation the only option.
  - Members of the CAC identified the importance of their own GP remaining actively involved in their care.

Several opportunities were raised including:

- The utilisation of volunteers in palliative care to support the individual and their families with housework, physical activity, or social support
- Positive feedback was received regarding palliative care nurse services in the GCPHN region and a call made for more palliative providers in community and RACFs
- Opportunities for more consumer directed care are on the horizon with the upcoming aged care funding changes.

Gold Coast Primary Health Network stakeholder consultation 2017

In September 2017, Gold Coast PHN carried out stakeholder consultation with the intention to identify gaps and explore opportunities to improve coordination and integration of palliative care services across the GCPHN region. Visions were created to support a more efficient and effective local palliative care system. Some of the emerging visions include:

- Access to flexible 24/7 carer and nursing support.
- Upskilling of general practice/community services/emergency department/RACFs in identifying patients who are at risk of dying within 12/12 and aided through Advance Health Directives and Advance Care Planning (ACP).
- Palliative care embedded as a part of normal patient care and inclusive of family and caregiver.
- Better connected infrastructure/networks and system navigation.

In addition, there were a range or barriers identified to achieving these visions, which included but were not limited to:

- stigma
- lack of access to knowledge
- discharge summaries and handover
- lack of carer support.

Palliative care services co-design workshop

In September 2018, a co design workshop with 41 sector representatives was held with the aim of informing the design and delivery of a regionalised approach to Gold Coast PHN's investment in primary and community-based palliative care services. The outcomes of the co-design workshop along with the findings of the need's assessment will directly inform the development of Gold Coast PHN's 3-year strategic service planning report for palliative care.

The co-design workshop was designed to maximise participation, incorporating a variety of feedback mechanisms including small group sessions, whole-of-room sessions, or individual opinion in an anonymous format. Informal breaks were included for networking and further discussion and integration amongst the group.

Key themes emerged from the co design workshop included:

- **Workforce capacity building** – The need for meaningful, appropriate, accessible workforce capacity building across primary care and palliative care sectors was a prominent theme. It was reported that confident, skilled, and connected staff would lead to a reduction in potentially preventable hospitalisations.
- **Community awareness and education** - While some difficulties were reported in measuring community awareness and education outcomes, it was still a leading theme throughout the workshop. Some recurring areas for education and awareness identified were Advance Care Planning, service awareness, and health and death literacy.
- **Advance Care Planning** – Advance Care Planning continues to carry significant importance across palliative care sector on the Gold Coast. It has been reported that uptake remains low, which can be attributed to the difficulty and complexity of the paperwork involved. However, it is reported that having an Advance Care Plans in place results in a more informed, seamless, coordinated, and appropriate journey for the individual in line with their values, beliefs and wishes at the end of life.

- **Service navigation and coordination** – While activities around service navigation and coordination were strongly supported by attending representatives, measures to improve this can often be challenging in a constantly evolving and time-poor sector. Activities proposed to improve service navigation and coordination on the Gold Coast were dependent on having a key a navigator role to support individuals through their palliative care journey.
- **Sector collaboration** - A key focus area explored at the workshop was sector collaboration, which is particularly important in the palliative care sector due to frequent transitions between emergency department, hospital inpatient wards, residential aged care facilities, community care and GPs. Some of the key activities explored to support sector collaboration included leadership groups, compassionate communities style programs and increased support for case conferencing.
- **Volunteer programs** – The invaluable support of the volunteer workforce in palliative care was widely cited across the palliative care workshop. Volunteer programs are perceived as cost-effective and can prevent or reduce social isolation and loneliness of individuals. The importance of appropriately skilled palliative care volunteers was raised due to the highly emotional and challenging environment they will be exposed to.

Evaluation and Learning

The Advance Project

- The findings from this project suggest that successful implementation of the Advance Project model of initiating ACP and PC needs assessment in general practice is dependent on several factors. These factors include the preparedness of general practice, general practice staff attitudes to support behaviour change, and ongoing support and incentives available for general practice.
- The project identified that implementing new routines/changes takes time and ongoing practical support for general practices is essential for sustainability in the short and long term.

Enhanced Primary Care (Clinical Educator- Palliative)

- A large portion of the staff who provide direct care for residents are unregistered staff with minimal healthcare education. A Certificate III in Aged Care is the preferred qualification but is not required. Therefore, education provided needed to be adaptable across a wide range of skills, knowledge, and scopes of practice appropriate to various staff.
- Formal education sessions were reportedly well-received. However, experience and published evidence suggest that the best learning outcomes for nurses are achieved with real-time, hands-on clinical education. The PC-CNE role had limited scope for hands-on clinical teaching. Instead, it was based on formal “classroom-style” education methods.
- GPs expressed interest and support for the education program and the upskilling of staff working in RACFs but were difficult to engage. Electronic correspondence (email and telephone) had a poor response, with better engagement achieved via face-to-face interactions.

Palliative Shared Care

- Several structural and systemic barriers were identified for the development of Palliative Shared Care arrangements. These were:
    - The absence of a real-time detailed shared information management system across all parts of the health system.
    - Adequate remuneration for general practice to cover things like after-hours call outs to people in their home.
- The development of Palliative Shared Care arrangements for the Gold Coast health system did not progress due to the COVID-19 pandemic and lack of sector capacity, systems, and resources.

2018 Palliative Care Regional Plan

The Regional Plan[14] identified five strategic priorities in response to the local health needs, service issues and opportunities determined through needs assessment and co-design processes. These key priorities areas were:

- workforce capacity building
- volunteer availability
- sector collaboration
- community awareness and education
- service navigation and coordination.

The below projects initiatives align with the Regional Plan key priorities areas.

Workforce capacity building

The Advance Project

The Advance Project aimed to increase GPs, nurses and practice managers' ability to initiate conversations about advance care planning (ACP) and screening for palliative care (PC) needs. The project achieved this outcome by providing face-to-face training to 127 General Practice staff (56 GPs, 48 general practice Nurses and 23 Practice Managers). And by providing intensive support to six general practices to implement ACP processes in their practice and support the evaluation of project resources.

There was strong evidence that those workshops increased the confidence of attendees to discuss ACP and start the conversation with patients. Additionally, the workshops increased the understanding of QLD ACP processes and online project resources to start the conversation and screen the palliative care needs of patients. The GCPHN had a positive role in supporting general practice change. General practices that engaged with the PHN for advice during and before implementing the project and took up the offer of mentoring appeared to be more successful in implementing clinical practice changes.

Enhanced Primary Care (Clinical Educator- Palliative)

The Enhanced Primary Care (Clinical Educator-Palliative) pilot project aimed to deliver palliative and end of life (EOL) education and development training to RACFs. The project utilised a Specialist Palliative Care (PC) – Clinical Nurse Educator (CNE) model. Five (5) sites were selected for participation in the project. Two (2) full-day education sessions were delivered with a total of 37 participants, with 100 per cent of participants who self-reported increased knowledge and skills to impact their practice positively. The PC-CNE supported trial sites to implement/review palliative, EOL and ACP policies and procedures.

In March 2020, in response to the COVID-19 pandemic, the Australian Government implemented restrictions whereby the PC-CNE could not access trial sites. This led to the planned service delivery being suspended. As a result, the PC-CNE position was diverted to a clinical COVID-19 response team provided by Gold Coast Health (GCH).

14 Gold Coast Primary Care Network Palliative Care Regional Plan

Program of Experience in the Palliative Approach (PEPA Program)

GCPHN collaborated with GCH and Program of Experience in the Palliative Approach (PEPA) to design and implement '***Live well. Die well: a multidisciplinary approach to palliative care'*** conference targeting allied health and nursing professionals. The conference was initially planned for June 2020 (with 126 registrations within the first two weeks of with 15 trade display requests). However, due to the COVID-19 pandemic, the conference was postponed twice (2020 and 2021). A new proposed date is planned in 2022 for medical professionals and 2023 for allied health professionals, including nursing.

Specialist Palliative Care in Aged Care (SPACE) project

The SPACE project aims to improve access to specialist palliative and end-of-life care for older people living in residential aged care facilities (RACFs). A key aim of the project is to increase the capacity and capability of general practice and aged care staff to deliver care at the end of life.

The project has been well received by GPs and RACF staff, with GPs actively contacting RACFs to ensure they were part of the program. RNs within RACFs reported that their increased knowledge gained through the project assisted them in managing symptoms better, and RACF staff reported feeling generally better supported.

Volunteer Availability

Explored Volunteer Availability Initiative across the Gold Coast

A deliverable of the Greater Choices for at Home Palliative Care funding included a co-design workshop to identify ideas and concepts for regional home-based palliative care volunteer services, including Justice of the Peace volunteers. The workshop, held in May 2019, had limited attendance and response from community organisations and service providers.

Service navigation and coordination

Palliative Care Shared Care and Health Pathways

The Palliative Care Shared Care and Health Pathways were a deliverable of the Greater Choices for at Home Palliative Care funding. Palliative Care Health Pathways were developed in partnership with Gold Coast Health (GCH) and localised to include Gold Coast community service providers. It was initially hosted on the GCPHN website and transitioned to Gold Coast Community Health Pathways in June 2021.

The development of a Shared Care Framework for the Gold Coast health system was put on hold due to the COVID-19 pandemic and lack of sector capacity, systems, and resources in place.

Community awareness and education

Development of health literacy tools

The development of health literacy tools was a deliverable of the Greater Choices for at Home Palliative Care funding. An online resource called *Planning your Future Care Today* has been developed to provide simple information to adults about Advance Care Planning. The online resource, aimed at all ages but with greater emphasis on middle age and older persons, encourages readers to start the conversation and complete documents at any age, regardless of their health status. Delays in the development of this resource arose due to COVID -19. The online booklet is to be published and promoted in July 2021.

Programs implemented on the Gold Coast

Gold Coast has implemented several programs that have focused on increasing advanced care planning in RACF's over recent years. These have included:

- Advance Care Planning in RACFs Project (June 2017 – December 2018)
- The Advance Project (1 Jan 2019 – 30 March 2020)
- Enhanced Primary Care (Clinical Educator- Palliative) (1 June 2019 – 30 June 2020)
- Greater Choices for at Home Palliative Care (June 2017 – October 2021)
- Specialist Palliative Care in Aged Care (SPACE) (1 Nov 2020 – 30 June 2024)

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Gold Coast Primary Health Network

"Building one world class health system for the Gold Coast."

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