2019

Needs Assessment Summary

PALLIATIVE CARE

phn GOLD COAST

An Australian Government Initiative

Palliative Care

Local health needs and service issues

• Carers require support to ensure they don't "burn out".

• Limited uptake of Advanced Care Plans (ACPs).

• Care coordination and support to general practice to be the centre of care where possible

• Residential Aged Care Facilities (RACFs) service high numbers of palliative patients.

• Current systems not always supportive to ensure planning, commissioning and delivery of integrated and coordinated service matrix.

• Access to integrated palliative care system across the health and social sector so people are supported as early as possible.

• Current limitations for ensuring that patient choice and wishes are respected.

• Options for better conversations about death and dying, and involvement.

• Need to ensure people can access good quality end of life care 24/7.

• Access to clear communication, and accessible information for patients, families and healthcare professionals.

• Provisions of care required to allow patients achieving their preferred place of death.

• Current systems not always established for the provision of clinical coordination of end of life care between providers.

• To ensure all providers are skilled and competent in delivering high quality palliative and EOL care.

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.

Actual data on patient outcomes for palliative care services in the Gold Coast 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 Gold Coast region, with its ageing population and higher proportion of older people in the 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 more appropriately focus their limited resources on more complex cases.

Key findings

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 in order 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.

What is commissioning?

In Primary Health Network (PHN) context, commissioning is a continual practice of purchasing services aligned to:

- local needs
- outcomes from strategic planning
- Gold Coast Primary Health Network's (GCPHN) unique objectives
- identified national priorities.

Scope

The key objectives for this health needs assessment was to provide evidence-based information to inform commissioning processes including:

- Establish local health needs through qualitative and quantitative data analysis
- Inform annual planning, reporting and evaluation processes for GCPHN
- Inform service planning and co-design mechanisms for effective palliative care commissioning

Focus areas identified by GCPHN's organisational objectives and relating to palliative care include:

- Activities aligning to and addressing the recommendations from the Integrated Care Alliance's Model of Palliative Care
- Primary and community-based programs delivering palliative care services to people in their home, including residential aged care facilities (RACFs)
- Activities focused on reducing preventable emergency presentations and admissions from the individual's home (including RACFs).

Methodology

A mixed methodology was used to ensure a comprehensive needs assessment incorporating quantitative data analysis, service mapping, patient journey mapping, consultation and co-design workshops.

Quantitative Data

Quantitative data indicators selected aimed to provide a detailed analysis of the drivers of service demand and levels of existing service utilisation to strategically guide future program investment for GCPHN. Data sources included but not limited to:

- Australian Bureau of Statistics Census data
- Social Health Atlases of Australia, Public Health Information Development Unit (PHIDU)
- Australian Institute of Health and Welfare (AIHW) Gen Aged Care Data Portal
- AIHW My Healthy Communities Data Portal
- Medicare Item Reports
- Data supplied by Gold Coast Health.

Other sources of data were explored to ensure a rounded and holistic view of data-informed need. Analysis was primarily limited to that data which was publicly available with a breakdown at a regional level. Where possible, indicators were examined at a subregional level.

Service Mapping

Service mapping was undertaken in a systematic way, commencing with the existing knowledge base that GCPHN has previously collected relating to aged care services and providers then assessed against deeper level analysis via desktop research.

Service mapping focused on a breakdown of service type, provider, geographic location, target population (e.g. mainstream or specific priority populations) and provider type (e.g. for-profit, not-for-profit, government).

Patient journey mapping

Patient journey mapping was utilised as an engagement tool to understand service issues and enablers from the perspective of health consumers. Patient journey mapping was developed in partnership with Palliative Care Queensland (PCQ) for their knowledge and expertise to effectively undertake consumer engagement.

PCQ captured several distinct patient journeys reflecting common palliative care pathways in the Gold Coast PHN region using the following approach:

Key Activities	Process
Determine Common Journey Types	Utilise the expertise of GCPHN and the Palliative Care Leadership Group to determine common journey types for the Gold Coast palliative care environment.
Identification of Gold Coast Common Journey Pathways (based on Common Journey Types)	Facilitate a two-hour workshop with local stakeholders (based on peak bodies' local networks) to identify common journey pathways based on the pre-determined common journey types Explore both positive and negative experiences within each common journey type Identify why individuals (health professionals or patients/residents/ family members) felt the experience was positive or negative
Develop Common Journey Pathways into a visual format (including a narrative) for co-design workshops	Develop a visual representation of the patient journey pathways to inform the co-design and planning phases of the project.

The aim of the patient journey mapping was to identify components of the local service system that are working well and highlight potential areas for improvement. Consumer interactions and experiences with a range of stakeholders were considered including but not limited to:

- Family, carers and informal support networks
- Specialist palliative care services (i.e. hospital and hospice)
- Community-based providers of palliative care
- Aged care service providers
- Primary health care services, particularly GPs
- Queensland Ambulance Service
- Pharmacies
- Community and psychosocial supports.

Target Consultation

Recognising the importance of the project and need for a collaborative approach a multifaceted consultation methodology was taken to inform this needs assessment.
In June 2018, Gold Coast PHN established high-functioning advisory mechanisms to provide expert input and advice into PHN core business and activities.

These groups were key in providing direct feedback on initial drafts of this report and include:
- GCPHN Community Advisory Council
- GCPHN Clinical Advisory Council
- GCPHN Primary Care Partnership Council

In July 2018, Gold Coast PHN established the Palliative Care Leadership Group to provide advice and guidance for the development of a needs assessment, regional plan and guiding implementation of subsequent activities that support people to continue to:
- live and die at home
- access appropriate primary health care services
- avoid unnecessary hospital transfers.

Consultation with the wider sector and community occurred through sector specific co-design workshops attended by 41 sector representatives including Gold Coast Health, a wide range of NGO support and palliative care providers, Hopewell Hospice, independent providers, consumers and carers.

Evidence

The Australian Commission on Safety and Quality in Health Care (ACSQHC) defines palliative care as care specifically tailored to assist with the effects of life-limiting illnesses1. 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).

Service demand

There were 3,512 deaths recorded for the GCPHN region during 2016, the most recent year for which data is available. The number of deaths recorded in the region has increased from 2,836 in 2006, an increase of almost 24% in the 10-year period.

The ten leading causes of death for the Gold Coast region over the period 2012-2016 represented 50% 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, 2012-2016

Cause of death (ICD classification)	Number of deaths	Proportion of all causes
Coronary heart disease (I20–I25) 2	,320 1	3.5
Cerebrovascular disease (I60–I69)	1,220	7.1
Dementia and Alzheimer disease (F01, F03, G30) 1	,188 6	.9
Lung cancer (C33, C34) 1	,033 6	.0
Chronic obstructive pulmonary disease (COPD) (J40–J44)	675	3.9
Colorectal cancer (C18–C21)	564	3.3
Prostate cancer (C61)	458	2.7
Cancer of unknown or ill-defined primary site (C26, C39, C76–C80)	404	2.3
Diabetes (E10–E14)	396 2	.3
Suicide (X60–X84)	381 2	.2

Source: AIHW, Mortality Over Regions and Time (MORT) books (PHN)

Given many of the deaths recorded within the region are related to a chronic cause many of these deaths are likely to have a distinguishable 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% of Australians wish to die at home2, however around half of all deaths occur in hospital.

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

Service utilisation

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

• public and private hospital facilities,

• residential aged care facilities and

• 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 general practitioners (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.

Palliative care delivered in hospital setting

AIHW's report Palliative care services in Australia 20183 identifies several key service issues at a national level, including:

• There were 62,800 palliative care-related hospitalisations reported from public hospitals in Australia in 2015-16, with a further 11,100 in private hospitals. This represented a 13.8% increase from the previous year.

• Over half of these (52%) were for people aged 75 years and over.

• 51% of patients who die as an admitted patient at a hospital received palliative care

• Almost half (48.2%) of palliative care hospitalisations involved a type of cancer as the principal diagnosis, with the next most frequent diagnoses stroke (4.2%), heart failure (3.4%) and influenza and pneumonia (3.4%)

• 53% of patients admitted to hospital for palliative care died in hospital, while around 29% of patients were discharged to their own accommodation or usual residence (including usual residents of aged care facilities) and 8% are transferred to another acute hospital facility

• The average length-of-stay for palliative care-related hospitalisations in public hospitals, including same-day separations, was 10 days.

Table 2 shows the change in Gold Coast Health palliative care-related hospital separations and associated bed days over the period 2011 to 2017, as well as projections over the next five and ten years.

2 Swerissen, H and Duckett, S., (2014). Dying Well. Grattan Institute: Melbourne
3 AIHW (2018). Palliative care services in Australia, AIHW: Canberra

Table 2: Number of palliative care-related separations and occupied bed days in Gold Coast Health facilities, 2011 to 2017 actual, 2022 and 2027 projected									
Age group (years)	2011	2012	2013	2014	2015	2016	2017	2022 (proj.)	2027 (proj.)
Separations									
0-14	0	1	1	3	0	1	0	2	2
15-44	44	40	24	46	41	43	57	43	47
45-69	276	266	320	271	333	298	299	414	500
70-84	296	277	267	256	417	341	335	573	742
85+	100	89	100	112	155	160	163	278	430
Bed days									
0-14	0	15	10	33	0	6	0	13	17
15-44	443	396	141	472	315	309	529	351	395
45-69	2,659	2,877	2,967	2,794	2,509	2,442	2,147	3,300	3,829
70-84	3,071	2,531	2,250	2,034	3,203	2,678	2,346	4,417	5,505
85+	788	660	605	934	1,137	1,101	967	2,036	2,998
Source: Gold Coast Hospital and Health Service, Strategy and Health Service Planning Branch									

This shows a total of 854 palliative care-related separations occurred in 2017, which represented a total of 5,989 occupied bed days at an average length of stay of around 7 days.

The most separations were recorded for the 70 to 84-year age group, while the highest average length of stay was for patients aged 15-44 years. By 2027, it is projected that the number of palliative care-related separations will double to over 1,700 separations.

Palliative care delivered in primary care and community settings

There are a number of items listed on the Medical Benefits Schedule (MBS) for palliative care treatment by palliative medicine specialists, but not specifically for palliative care provided by GPs, other specialists (e.g. geriatricians, oncologists) or allied health.

The most recent publicly available data from 2015-16 shows that in the Gold Coast r egion only 96 services were claimed by four providers for any palliative medicine specialist items listed on the MBS4. This equates to a crude rate of MBS-subsidised palliative services of around 16.8 per 100,000 people for the Gold Coast region, compared to the national rate of 310.4 per 100,000 population. All of these services were claimed under MBS item 3005, for a palliative specialist initial attendance at consulting rooms or hospital. However, it is acknowledged that this is likely to have since increased due to the creation of specialist palliative outpatient clinics locally that utilise MBS charging as a component of the resourcing.

4 Department of Human Services, Medicare Australia Statistics, http://medicarestatistics.humanservices.gov.au/

MBS items used by GPs treating palliative care patients are likely to be recorded across a range of other non-specific MBS items such as standard attendances (including after hours and within RACFs) and chronic disease management. Available data relating to the provision of palliative care by GPs is limited to the nationally representative Bettering the Evaluation and Care of Health (BEACH) survey which was administered using an ongoing data collection process up until 2015-165.

National reported by the BEACH survey indicated that about 1 in every 1,000 GP consultations reported were palliative care-related. Interestingly, the rate of palliative-care related GP encounters was lower in Major Cities (0.7 per 1,000 encounters) compared to Inner Regional (2.0 per 1,000) and Outer Regional (1.5 per 1,000) locations. Most of the GCPHN region is categorised as 'Major City'.

This may indicate a greater proportion of palliative care services are provided by specialist palliative services in those regions that are more likely to have them (e.g. large public hospitals, hospices). A more recent survey commissioned by the Department of Health into the provision of palliative care within general practice6 indicates that GPs may be providing more palliative care than previously thought. It suggests the rate of palliative care-related GP attendances is closer to 1 in every 100 consultations rather than the 1 in 1000 figure quoted earlier.

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 care7. 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 that8:

• Just over half of all episodes completed were in an inpatient setting (53.4%), with the remainder completed in the community (46.6%).

• 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% of all episodes.

• A higher proportion of males (53.2%) underwent palliative care episodes compared to females (46.8%).

• Over three quarters of episodes of palliative care (77.6%) were for patients with a cancer diagnosis, despite patients suffering from other chronic life-limiting conditions such as heart 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%) 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.

At a local level, PCOC data is available for the specialist palliative care services delivered in public facilities at Robina Hospital and Gold Coast University Hospital and the privately-operated Hopewell Hospice. BlueCare, an NGO who provide community palliative care services for Gold Coast Health have previously submitted data to PCOC but data from 2017 was not available for analysis.

Table 3 compares the patient outcomes of the four Gold Coast Health specialist palliative services and Hopewell Hospice against the PCOC benchmarks. The outcomes for all Queensland inpatient and community setting services are also included for comparative purposes.

5 Bettering the Evaluation and Care of Health (BEACH) survey 2015-16, Family Medicine Research Centre, University of Sydney http://sydney.edu.au/medicine/fmrc/beach/

6 Department of Health (2017). Research into awareness, attitudes and provision of best practice advance care planning, palliative care and end of life care within general practice.

7 Palliative Care Outcomes Collaboration (PCOC), Australian Health Services Research Institute, University of Wollongong https://ahsri.uow.edu.au/pcoc/index.html

8 Palliative Care Outcomes Collaboration (2018) Palliative care services at a glance, 2017 data tables Australian Health Services Research Institute, University of Wollongong

Table 3: PCOC patient outcomes data reported for hospital/hospice palliative care services in GCPHN region, Jul to Dec 2017

Outcome			PCOC benchmarks	Robina Hospital Specialist Palliative Unit - Inpatient	Robina Hospital Consultation Service	GCUH Consultation Service	Hopewell Hospice	Robina Hospital Specialist Palliative Unit - Community	All Qld inpatient services	All Qld community services
Patient volumes	Patients			234	87	250	80	246	3,161	1,303
	Episodes			277	91	297	80	283	3,800	1,561
	Phases			787	133	564	154	464	7,879	2,747
Median age at episode start				71	77	69	76.5	71	72	72
Median episode length in days				7	1	3	5	18	5	26
Patient outcomes	% of episodes starting day of or day after patient is ready for care to start		90	97.0	98.9	99.0	100	59.5	98.4	81.7
	% of patients with three days or less in unstable phase		90	91.1	100	85.7	-*	70.3	86.6	74.4
	% of patients who started episode with absent / mild symptoms ended with absent / mild	Pain PCPSS	90	94.0	91.4	87.5	76.7	70.5	92.6	80.7
		Pain SAS	90	93.3	95.3	NA	87.3	75.5	92.6	84.6
		Fatigue	90	95.6	100	NA	93.8	69.7	91.8	80.7
		Breathing problems	90	98.5	100	NA	98.6	75.6	96.0	87.4
		Family / carer	90	95.8	96.2	93.3	91.9	70.9	92.6	74.4
	% of patients who started episode with moderate /	Pain PCPSS	60	61.5	51.7	59.1	75.0	40.0	61.9	40.8
		Pain SAS	60	61.6	52.9	NA	69.2	18.8	58.8	32.2
		Fatigue	60	78.4	-*	NA	100	9.6	52.1	26.8

Workforce

Reliable data relating to the size and breakdown of the palliative care workforce is not currently available for the Gold Coast region.

•Nationally, there was a total of 153.1 full-time equivalent (FTE) specialist palliative medicine physicians working in clinical positions in 2016, of which 45.4 FTE work in Queensland[9].

• The majority of specialist palliative medicine physicians work mostly in the hospital setting (74.8%), followed by 'other community health care services (8.9%) and outpatient service (8.1%).

• There were an estimated 2,719 FTE palliative care nurses employed in a clinical role nationally in 2016. Of these, 549.4 FTE were working within Queensland. Most of these roles are working in the hospital setting (52.4%), followed by 'community health care services' (24.1%) and hospices (13.7%).

Prescribed medication

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'10. 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 to treat constipation)

• psycholeptics to tranquillise/depress the central nervous system

• stomatological preparations to treat diseases of the mouth.

While no regional data is not available, national data on palliative care-related prescribing in 2015- 16 indicates that:

• Around 83,000 palliative care medications were prescribed to around 52,000 patients.

•78.6% of palliative care-related prescriptions were subsidised in full or part by the Pharmaceutical Benefits Scheme (PBS).

• The most commonly prescribed medication type was laxatives (28.3%) followed by analgesics (22.0%), and anti-inflammatory and anti-rheumatic products (18.0%).

• Almost 90% of palliative-care related prescribing was done by GPs, with palliative medicine specialists only prescribing 2.4% of palliative care-related medications.

• There were differences in the medications prescribed by type of clinician, with GPs most frequently prescribing laxatives (28.6%) and palliative medicine specialists mostly prescribing analgesics (46.6%).

Service Mapping

GCPHN shares an aim with the Gold Coast Hospital and Health Service (HHS) to enhance, integrate and collaborate community and primary palliative care services. This service mapping activity provides an overview of the current service environment, including definitions of both palliative care and specialist and generalist palliative care.

To ensure consistency at a local level, Gold Coast HHS has undertaken a significant body of work through their Integrated Care Alliance [11](The Alliance) in categorising types of palliative care providers:

Generalist Palliative Care (Primary Generalist Provider, Primary Specialist Provider):
Generalist Palliative Care is palliative care provided for those affected by a life-limiting illness as an integral part of standard clinical practice by any healthcare professional that is not part of a specialist palliative care team.

Not all people approaching the end of life need specialist palliative care. Generalist palliative care is provided in the community by a Primary Generalist Provider which can include; general practice teams, allied health teams, community nurses, residential care staff, community support services and community paediatric teams, however, in general, the substantive work of a primary generalist provider is not in the care of people who are dying.

Generalist palliative care can also be provided by Primary Specialist Providers, defined by Palliative Care Australia as a specialist that has first contact with the patient with a life-limiting illness. Primary specialist providers include oncologists, renal, cardiac or respiratory physicians. In general, their substantive work is not in palliative care. The care of a primary specialist provider is generally received in hospital.

Providers of generalist palliative care will have defined links with specialist palliative care team(s) for the purposes of support and advice, or in order to refer persons with complex needs. If palliative care is a performed on a regular basis or they simply have an interest in this type of care, these health providers have access to education and learning to support their practice.

Generalist Palliative Care Providers

General Practitioners

GPs are typically the key navigator of an individual's care and often have long-standing relationships with individuals. GPs support palliative care patients in their practice or through home visits and play a vital role in the delivery of advance care planning due to the often long-term and trusting relationship they have with their patients. GPs play an important role in identifying and assessing palliative care needs, pain management, medication management, bereavement support, and can be pivotal in the promotion of early referral to supportive and palliative care services.

Non-Government Organisations

There are a wide range of Non-Government Organisations (NGOs) on the Gold Coast region that provide different levels of community palliative care services. Care can range from complex nursing care, home care, personal care and bereavement, often with supports available 24/7. Cost of the individual's community care can often be subsidised under the Commonwealth Home Support Programme (CHSP) or a Home Care Package (HCP), depending on individual eligibility. NGOs work closely with both GPs and specialist palliative care services to ensure patients are receiving best practice and high-quality care.

Allied Health

Many different allied health groups contribute palliative care individually and as part of multidisciplinary care teams. Allied health can be provided in the community or hospital setting. Allied health can range from counsellors, dieticians, occupational therapists, pastoral care workers, pharmacists, podiatrists, psychologists and social workers.

Allied health plays a key role in palliative care by:

- Assisting patients in maintaining function and independence
- Providing education for patients and families receiving support
- Sharing knowledge about the progression of disease
- Helping patients and family achieve their goals.[12]

Private Providers

While limited data is available for private providers, they play a key role in palliative care service provision in the Gold Coast. Private providers refer to fee-for-service practitioners, private health funds and private hospitals. The private sector provides generalist and specialist palliative care services to individuals, without government subsidies both in the community and hospital setting. While the private sector is not a key focus of the scope of this needs assessment, private services need to be acknowledged and taken into consideration when planning services.

11 Gold Coast Health, Integrated Care Project, Centre for Health Innovation, 2018

Private Providers

As an example, Bupa is piloting a Palliative Care Choice Program13 in partnership with the St Vincent's Private Hospital in Brisbane. Following multidisciplinary assessment, the program offers a range of services tailored to the person's needs including physician, nursing, psychological, social, and spiritual support. Patients can access the palliative care unit directly at St. Vincent's Hospital if needed. The patient or their carer is given the flexibility to make choices about end-of-life care to ensure preferences are met.

Hospice

There is one hospice located on the Gold Coast, Hopewell Hospice. Hopewell is an 8 bed, (minimum 1 public bed) hospice and is available to people with advanced, progressive disease where treatment is no longer available, and the individual is unable to continue to stay at home. Hopewell Hospice provides a home-like environment, holistic palliative and respite care, 24-hour on-site nursing, ancillary services and follow-up bereavement services. Hopewell Hospice has a unit for supporting children, parents and families around grief and loss and a day respite care centre.

Specialist Palliative Care

A specialist palliative care provider is a medical, nursing or allied health professional recognised as a palliative care specialist by an accrediting body or who substantively works in a specialist palliative care service if an accrediting body is not available.

A palliative care specialist has the specialist knowledge skills and expertise in care of people living with a life-limiting illness and their families and carers, including in the management of complex symptoms, loss, grief and bereavement.

Specialist Palliative Care Services

The majority of specialist palliative care services on the Gold Coast are situated in the Robina Hospital with the Specialist Palliative Unit Inpatient and Community Care teams.
Palliative Care Consultation and Liaison Service teams available at both Robina Hospital and the Gold Coast University Hospital (GCUH) in Southport.

Robina Hospital has a 16-20 bed inpatient palliative care unit is focused on delivering short term, pain and symptom control with the aim for patient to be discharged back into their home (including residential aged care facilities) or in some cases the local hospice.

Gold Coast HHS Specialist Palliative Care service assists in patient care and is designed ensure GPs remain central to care of patient. The specialist palliative care service follows national best practice guidelines. A patient may be seen as a one-off consult, or for a short period until their needs are no longer specialist, or on an ongoing basis for especially complex patients.

A 'pop up' paediatric service is also available at GCUH, with staffing shared across Oncology, Haematology and Palliative Care. This service cares and supports for children with life-limiting illness and their families.

12 https://www.caresearch.com.au/caresearch/tabid/2744/Default.aspx
13 https://www.bupa.com.au/health-and-wellness/programs-and-support/member-support- programs/palliative-care-choices-program

Alternative Therapies

Alternative therapies can often be accessed by people receiving mainstream palliative care services. Therapies may include acupuncture, aromatherapy, herbal medicines, hypnosis and, complementary pain treatments. Data is limited on who and how often these alternative therapies are being utilised in the Gold Coast region, as it's often not disclosed to the treating health professional.

Consultation with clinicians acknowledged a range of issues with alternative therapies including lack of supporting research into effectiveness, lack of disclosure of therapy types which may lead to complications or impaired effectiveness of prescribed medications and, treatments and misinformation provided by alternate therapists such as terminal individuals being led to believe they are being cured.

A full list of palliative care service mapping data can be referred to in Appendix 1, Service Mapping.

Consultation

Patient journey mapping

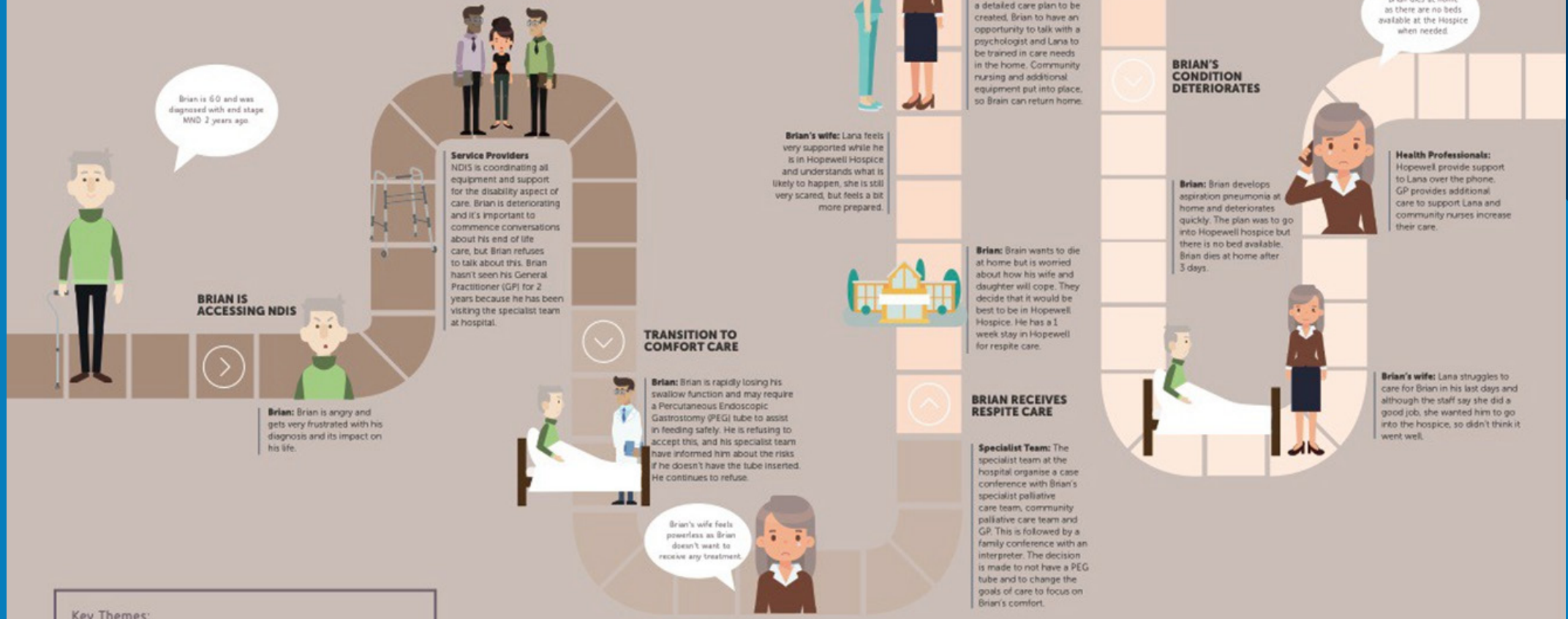
One of the key items taken to stakeholder consultation was patient journey mapping. These visual representations of typical patient journeys developed in partnership with PCQ supported the consumer engagement component of the consultation. Four common pathways were documented for further consultation including:

- Culturally and linguistically diverse (CALD) and NDIS at-home palliative care pathway, 'Brian'.
- RACF palliative care pathway, 'Mary'.
- Paediatric palliative care pathway, 'Cooper'.
- Complex specialist palliative care pathway, 'Wayne'.

The four common pathways were validated by GCPHN and the Palliative Care Leadership Group. Note: The Leadership Group was established to provide local, strategic input and advice on project and its deliverables

Brian's journey

Brian emigrated from Greece when he was 40 and is an Australian citizen, his spoken English is limited but understands it well, his daughter usually assists with interpretation. He and his family are still very angry about Brian's diagnosis at such a young age, particularly after moving to Australia less than 20 years ago. Brian and his family have disconnected from their small circle of friends and there is a financial burden because Brian is unable to work, and he has limited savings. Brian receives support from National Disability Insurance Scheme (NDIS) and is a part of the local Motor Neurone Disease (MND) Association support group.



Key Themes:

- Disconnection from primary care/GP when under a specialist team
- Psychosocial support - no just medical (ie deal with anger)
- CALD population groups
- Case conferencing is a successful way to address all Brian's needs, driven by specialist palliative care team & involve a GP again
- Hopewell Hospice has high demand, limited capacity to deliver (by number of beds available)
- Funding source challenge between NDIS (Functionality focused) and Palliative Care (Health Funding)

Mary's journey

Mary is a Gold Coast local with three children; one (John) who lives in Brisbane, while the others live interstate. Mary's husband died 5 years ago, after which she decided with the help of her family to move into a Residential Aged Care Facility (RACF). Mary suffers from heart failure and several other co-morbid conditions. She requires some support to shower and needs a wheelchair to move long distances. She was previously active with a local craft group but hasn't seen them since moving into the RACF.

Mary is 92 and has lived in a RACF on the Gold Coast Northern Region for 5 years

MARY MOVES INTO RACF

RACF

Hospital: Mary often cancels her specialist appointments at the hospital as she feels she is being a burden by needing a staff member to help transport her in her wheelchair.

GP: Mary had to change GPs when she entered RACF as her existing GP did not visit the area. Her new GP is unable to provide after-hours visits.

Ambulance: Mary is transferred to the Robina Hospital emergency department (ED) by Queensland Ambulance Service.

Mary: Mary has feelings of sadness and isolation as she becomes disconnected from her local community due to moving into a RACF from the South Region of Gold Coast. As a Catholic, Mary enjoys attending church weekly and meeting with the visiting pastoral care volunteers and delta dog visit all at the RACF.

MARY HAS A FALL

Mary: Mary has a fall at her RACF on a Friday at 8pm. She is found on the bathroom floor by another resident who heard her yelling around half an hour later. Mary didn't have her call bell around her neck and couldn't reach the wall call bell. She waits on the floor for 45 minutes with a carer.

RACF Nurse: The on-call registered nurse (RN) is called to the RACF for review and arrives after another 45 minutes. The RN calls an ambulance as it appeared she has a fractured hip and is experiencing severe pain.

Family: Her family is concerned that she won't receive the care she requires if she returns and becomes 'bed bound'.

Mary is triaged as low priority and waits for 3 hours in ED

Hospital: Mary waits in ED for 3 hours for a review. The ED team is extremely busy and Mary is triaged as a low priority. She waits on a bed by herself, is provided pain relief and a nurse pops past regularly to check on her. At the 3-hour mark, the doctor is reminded that she has been there for 3 hours and quickly orders scans, provides medicine and organises admission to a general medical ward.

Doctor: Mary's doctor tries to decide on the best way forward – to operate or treat conservatively? As Mary has no cognitive issues she is able to make the decision herself, but it's a difficult conversation to have.

Mary: Mary decides she doesn't want the operation, as she has lived a good life and would rather just go back to her residence to have conservative treatment.

Mary is in a single room in the general ward waiting on surgery for her fractured hip. Doctors are concerned that due to her age and her heart condition she "might not make it". She does not have an advance care plan as her family have struggled to talk about dying with her husband's quick death 5 years ago.

MARY REQUIRES SURGERY

Hospital: The ambulance arrived quickly to transfer Mary back to the RACF so hospital staff didn't have a chance to chat to Mary about Goals of Care or Advance Care Planning.

MARY RETURNS TO RACF

RACF: The discharge nurse hands Mary's case over to the RACF Manager. Mary's needs have changed, now requiring a high level of care placing further burden on the RACF's limited staffing and available equipment.

MARY'S CONDITION DECLINES

Mary: Mary is increasingly drowsy, has increased pain and restlessness and is provided a syringe driver by her GP. At midnight Mary begins screaming in pain, and becomes increasingly restless, as the syringe driver battery has run out.

RACF: The only RN is at another facility assisting with a fall and is unable to get there within the hour, so RACF staff call an ambulance. Mary is without pain relief for at least 3 hours.

Ambulance: Ambulance arrives and takes Mary back to the ED.

Hospital: ED staff give Mary and her son John a private room and a social worker sits with them. Mary dies in ED 3 hours later.

A BEREAVED FAMILY

Hospital: The funeral directors provide support to John and his family.

Family: Mary's family are grieving, they are not given any formal debrief. Mary's children attend the funeral. They all remain very angry with what happened.

Mary's family is very angry about her death and they receive no formal debrief.

RACF: The RACF staff assist John and family to clean out her room but become aware how angry the family are, overhearing them talk about the "bad care she received". The RACF priest provides support to the other residents who knew Mary.

Family: Mary's son John visits as much as possible, while her other family make arrangements to visit from interstate.

Priest: The RACF priest visits Mary to attend to her spiritual needs.

GP: Mary's GP is unavailable to visit until two days after she returns from hospital. Mary is reviewed by her GP and is diagnosed with aspiration pneumonia. She is treated with antibiotics which has limited effect, after which her GP informs staff that she is palliative.

Mary's care transitions from curative care to palliative care.

RACF: The RACF Manager organises an assessment of Mary's needs to be done to seek additional funding for her increased care needs. An Activities Coordinator brings some music and organised for Delta dogs to visit.

RACF

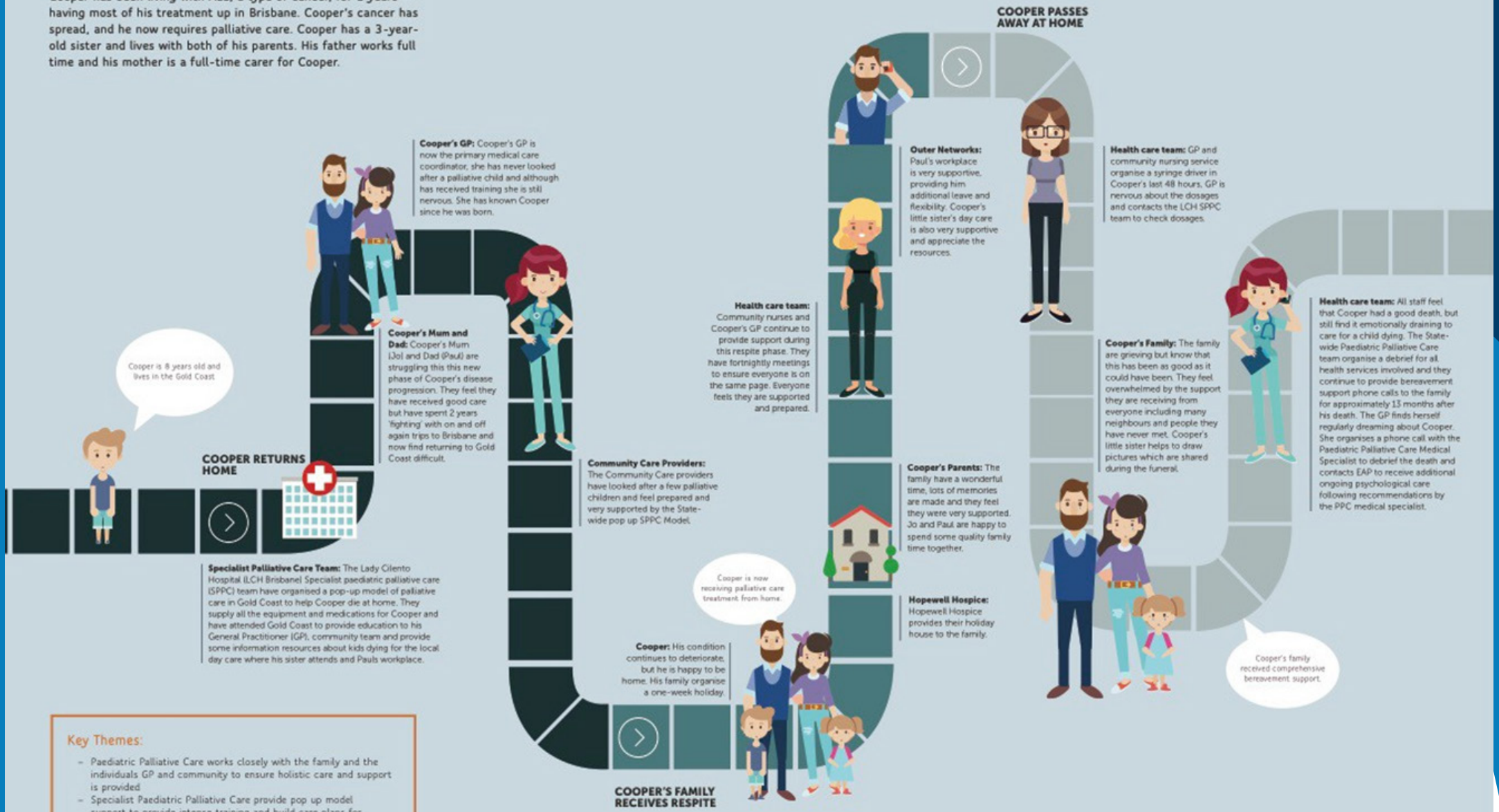
Mary returns to the RACF, where she is largely confined to her room at the end of a hallway, rarely seeing other residents and unable to go to activities. She experiences increasing feelings of isolation. Mary deteriorates quickly and requires assistance for feeding in her bed, but staff struggle to get there and she often tries to feed herself "to save them time".

Key Themes:

- People often have to relocate from their communities to access a RACF that has a vacancy
- Limited capacity for RACF staff to respond in a timely way to resident emergencies such as falls
- Limited capacity for RACF to respond and resource timely high care needs
- Unnecessary emergency presentation
- Lack of bereavement support
- Queensland hospital emergency departments have a 4-hour target to get people seen, treated and exited from emergency

Cooper's journey

Cooper has been living with ALL, a type of cancer, for 2 years – having most of his treatment up in Brisbane. Cooper's cancer has spread, and he now requires palliative care. Cooper has a 3-year-old sister and lives with both of his parents. His father works full time and his mother is a full-time carer for Cooper.

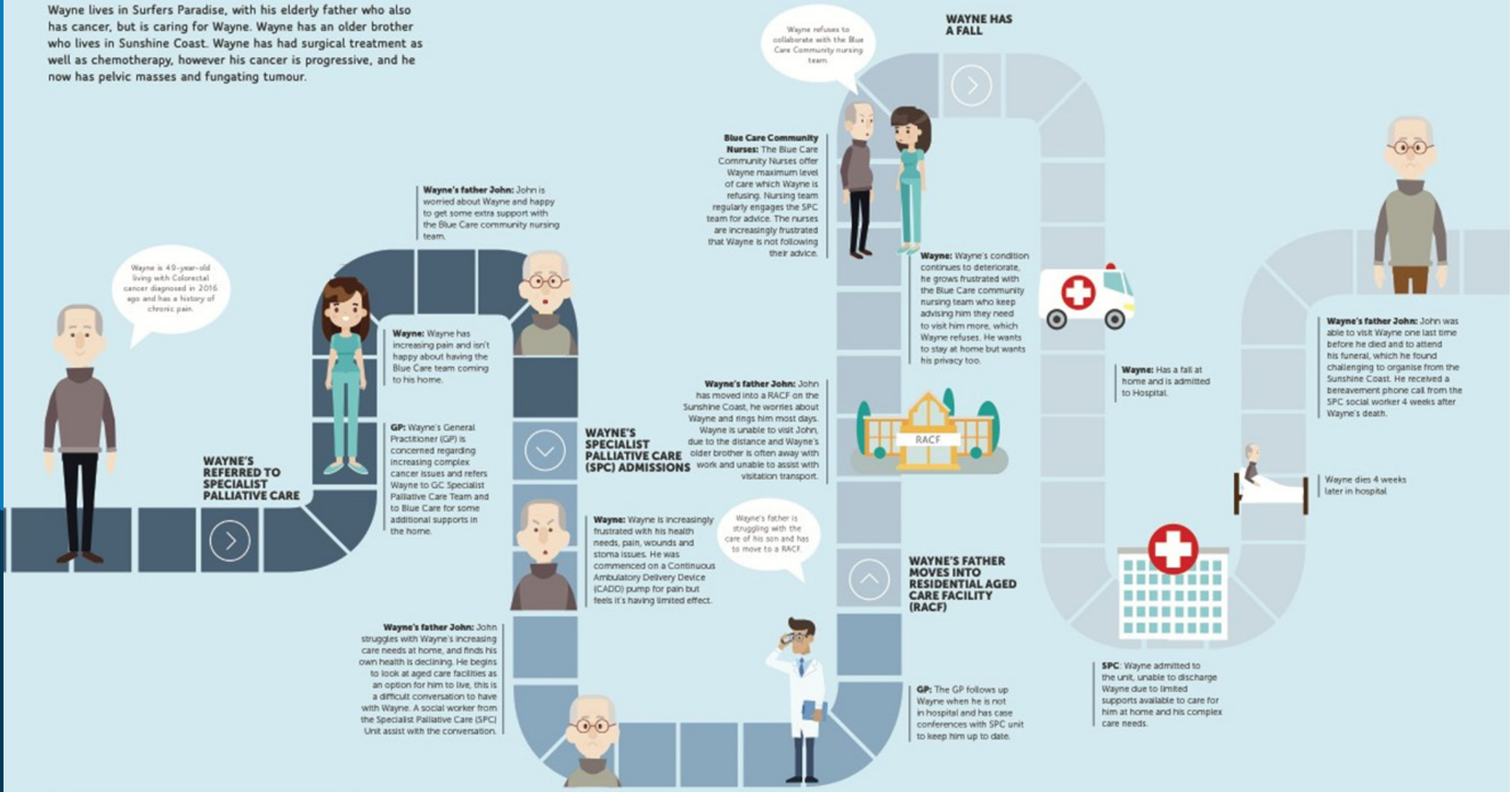


Key Themes:

- Paediatric Palliative Care works closely with the family and the individuals GP and community to ensure holistic care and support is provided
- Specialist Paediatric Palliative Care provide pop up model support to provide intense training and build care plans for regional patients.
- Paediatric Palliative Care is psychosocially challenging for all involved including health professionals.
- Paediatric Palliative Care provides an exceptional bereavement support to families

Wayne's journey

Wayne lives in Surfers Paradise, with his elderly father who also has cancer, but is caring for Wayne. Wayne has an older brother who lives in Sunshine Coast. Wayne has had surgical treatment as well as chemotherapy, however his cancer is progressive, and he now has pelvic masses and fungating tumour.



Key Themes:

- Social issues, carer burden
- Challenge of caring for people living alone at home
- Complex care needs
- Challenge for people in aged care facilities to visit relatives in hospital / disconnected families

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 Gold Coast 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 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 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

  o Navigate the right level of care and provider of home support for a loved one is challenging, and there is minimal support for this.

  o Significant modification costs often borne by families.

  o 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.

Gold Coast Primary Health Network Community Advisory Council
A number of 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 Gold Coast 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 Gold Coast 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 needs 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.

Additional information

Research into awareness, attitudes and provision of best practice advance care planning, palliative care and end of life care within general practice[14] explored the challenges faced by GPs when practicing palliative care, including delivery of care in varied settings, appropriate timing to deliver Advance Care Planning (ACP) conversation and lack of communication between locum services, RACFs, specialists, ambulance services and hospitals.

The study supported a number of opportunities explored in this report including PHNs playing a role in navigating available education and promoting locally applicable education and resources, community ACP awareness, and capacity building around symptom management, service awareness, navigation and referral pathways.

With the recent shift to consumer directed care in the NDIS and Commonwealth Home Support Program (CHSP) Transitioning Australian Respite[15] report reflects on the probable changes to the way respite care is understood and implemented in Australia. With a high focus in the Gold Coast region towards supporting people caring for their loved one and the reported high levels of stress experienced by carers. It is important to consider carers' needs and provide support to them in their own right, something which is not directly addressed in the NDIS and CHSP reforms. Supporting innovative, flexible and informal respite mechanisms is recommended for the Gold Coast region.

14 https://www.health.gov.au/internet/main/publishing.nsf/Content/EF57056BDB047E2FCA257BF000206168/$File/Palliative-care-and-end-of-life-care-within-gp-research.pdf

15 https://www.sprc.unsw.edu.au/media/SPRCFile/Transitioning_Australian_Respite.pdf

What we understand works

Integrated models of palliative care are becoming increasingly important as the population ages and as the number of people living with multiple chronic conditions increases leading to more complex care requirements.
The future need for palliative care: with a London focus16 highlights the importance of supporting people to stay and die at home by embedding two key elements; presence and competence to support people to successfully age and die at home.

- Presence: 24/7 availability and home visits

- Competence: symptom control and communication.

Key learnings from this study should be considered when considering future models of palliative care.

A number of models of care have been identified through a process of consultation with GCPHN, the Leadership Group and GCPHN advisory mechanisms and desktop evidence review. The groups were asked to submit models of care which have worked well in other areas, and which would have successful elements that could be adapted to meet the local health needs and service issues of the Gold Coast region. In general, the identified models are focused towards:

- Supporting people to continue to live die at home

- Reducing preventable emergency department presentations and hospital admissions

- Supporting GPs to remain at the centre of a person's care throughout their palliative care journey.

The examples below are indicative of the type of service responses that could respond to the identified local health needs and service issues.

16 https://www.kcl.ac.uk/nursing/departments/cicelysaunders/attachments/The-future-for-palliative-care- with-a-London-focus-Irene-J.-Higginson-April-2018.pdf
17 https://www.swslhd.health.nsw.gov.au/peach/model.html

Model: Personalised packages of palliative care	
Description	The provision of personalised palliative care packages to individuals to support them to continue to live and die at home. Packages can provide specific supports for day, evening and night time to meet the individuals care needs in order to stay at home. Key considerations of this model in a local context include: • Clinical governance remains with the client's GP • Case management remains with the hospital community nursing team • Centralised intake hub for all 5 participating hospital facilities • Coordinated arrangements for medications, equipment and consumables
Program example/s	Palliative Extended and Care Home[17] (PEACH) Model of Care Palliative Care Home Support Program HammondCare
Evidence	McCaffrey N, et. al. Is home-based palliative care cost-effective? An economic evaluation of the Palliative Care Extended Packages at Home (PEACH) pilot. BMJ Support Palliat Care. 2013 Dec;3(4):431-5
	Luckett T, et. al. Elements of effective palliative care models: a rapid review. BMC Health Serv Res. 2014 Mar 26;14:136
Alignment to Health Needs and Service Issues	• Community led, after hours in-home (including RACF) care • Delivering coordinated community palliative care • GP-centred model • Advance Care Planning • Use of telehealth/video conferencing to provide after-hours access to clinical nursing support

Model: Nurse Practitioner-led models of palliative care	
Description	There are a range of settings in which nurse practitioner-led palliative care models exist, such as in an RACF, GP clinic, independent or regionally-based. Nurse practitioner-led palliative care focuses on providing clinical care, clinical leadership, education and research. Nurse practitioners can often undertake time intensive aspects of care of older people with complex needs.
Program Example/s	Resthaven Nurse Practitioner Model of Care[18] Nurse Practitioner – Aged Care Models of Practice Initiative[19]
Evidence	Davey, R., Clark, S., Goss, J., Parker, R., Hungerford, C., and Gibson, D. 2015. National Evaluation of the Nurse Practitioner – Aged Care Models of Practice Initiative: Summary of Findings. Centre for Research & Action in Public Health. UC Health Research Institute. University of Canberra. Canberra.
Alignment to Health Needs and Service Issues	• Advance Care Planning • Reduction of avoidable emergency department presentations • Education and capacity building in primary care and RACFs

18 https://www.resthaven.asn.au/enhancing-palliative-approach/
19 https://www.canberra.edu.au/research/institutes/health-research-institute/annual- reports/reports/NPACM-Summary-of-Findings-Dist-Low-res.pdf
20 http://www.hammond.com.au/research/palliative-care-home-support-program-qualitative-evaluation
21 Elton Consulting, Hope Healthcare Specialist Palliative Care Services Evaluation, 2009

Model: Palliative Care Day Hospitals	
Description	Models of care providing day hospitals and in-reach nursing services allow access to hospital level services without actually being admitted, easing pressure on rising demand for acute care beds and supporting people to continue to live in their own home until death.
Program Example/s	*Hammondcare Home Support Program*[20] *Hope Healthcare Specialist Palliative Care Services Evaluation 2009*[21]
Evidence	Elton Consulting, Hope Healthcare Specialist Palliative Care Services Evaluation, 2009 Stevens E, Martin CR, White CA.The outcomes of palliative care day services: a systematic review.Palliat Med. 2011 Mar;25(2):153-69. Bradley SE, Frizelle D, Johnson M.Patients' psychosocial experiences of attending Specialist Palliative Day Care: a systematic review.Palliat Med. 2011 Apr;25(3):210-28
Alignment to Health Needs and Service Issues	• Supports service integration and coordination • Supports palliative patients with complex needs • Improves access to specialist palliative care services • Reduces social isolation

Model: Compassionate Communities Models	
Description	Compassionate Communities aims to build and enhance existing partnerships with local community groups; identify mechanisms to support these stakeholders in delivering palliative care support; developing information resources for service providers; operating as a central body to showcase and link compassionate communities across Queensland.
Program Example/s	Latrobe University Health End of Life Project (HELP)
Evidence/Rationale	The Nous Group (2018). Final Report: Compassionate Communities Feasibility Study. Available at: http://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/09/Compassionate-Communities-Final-Report-min.pdf Abel, J et al (2011). Compassionate community networks: supporting home dying. BMJ Supportive & Palliative Care,1:129–133. Samar, AM et al (2018). What sources of bereavement support are perceived helpful by bereaved people and why? Empirical evidence for the compassionate communities' approach, Palliative Medicine, 32(8),1378–1388
Priority Areas	• Service Integration • Community Education • Service provider education • Community development • Community partnerships • Death and compassion literacy

Throughout the consultation with Gold Coast PHN advisory mechanisms, several key components of successful models of generalist palliative care were identified and need to be considered for prospective models of care. These elements include respite care, the use of volunteers and consumer and carer education.

Opportunities

Commonwealth and state priorities

The National Palliative Care Strategy 201022 represents the combined commitments of the Australian, state and territory governments, palliative care service providers and community-based organisations to the development and implementation of palliative care policies, strategies and services that are consistent across Australia. The National Strategy's four goals include:

- Awareness and Understanding
- Appropriateness and Effectiveness
- Leadership and Governance
- Capacity and Capability

The National Palliative Care Standards (Edition 5) 23 (The Standards) articulate and promote a vision for compassionate and appropriate specialist palliative care. The standards emphasise the importance of delivering patient centred, age a ppropriate to all people, including those of vulnerable populations. The standards can be referred to below:

The Standards highlight the importance having appropriate governance mechanisms in place to support best practice specialist palliative care.

A range of other strategic reforms, priorities and plans provide an evolving context for the regional planning and development of models of palliative care. This includes:

- Roll-out of My Health Record[24]
- Gold Coast PHN's Strategic Plan 2017 – 2022[25]
- Principles for Palliative and End-of-Life Care in Residential Aged Care[26]
- Queensland Health State-wide strategy for end-of-life care 2015[27]
- Queensland Health Palliative Care Services Review[28] (current)
- Australian Productivity Commission's report entitled Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services29 (Chapters 3 and 4)
- Australian Commission on Safety and Quality in Health Care's National Consensus Statement: Essential elements for safe and high-quality end-of-life care30
- Ambitions for Palliative and End of Life Care: A national framework for local action 2015- 202031

As part of the 2017-18 Budget, the Commonwealth Government is providing $8.3 million over three years for the Greater Choice for At Home Palliative Care32 measure which will improve palliative care coordination through Primary Health Networks (PHNs). Gold Coast PHN was awarded funding under the measure which aims to better coordinate and integrate primary, secondary, tertiary and community health services to support at home palliative care. It is envisaged that this will achieve the following:

- PHNs will implement sustainable system changes to strengthen integration and coordination of services for people receiving palliative care at home.
- Working in partnership with other palliative care providers such as community services, specialist palliative care providers and aged care facilities, PHNs will develop integrated models of care that will enable early referrals to palliative care and strengthen community support for their families and carers.

22 Department of Health, Supporting Australians to Live Well at the End of Life – National Palliative Care Strategy 2010
23 http://palliativecare.org.au/standards
24 https://www.myhealthrecord.gov.au/
25 https://www.healthygc.com.au/GCPHN/media/Site-Pages-Content/GCPHN/Strategic-Plan-2017-2022.pdf
26 http://palliativecare.org.au/wp-content/uploads/dlm_uploads/2017/05/PCA018_Guiding-Principles-for-PC- Aged-Care_W03-002.pdf
27 https://www.health.qld.gov.au/ data/assets/pdf_file/0022/441616/end-of-life-strategy-full.pdf
28 https://www.qld.gov.au/ data/assets/pdf_file/0016/14272/consultation-paper.pdf

• PHNs will enable greater choice for their local communities through staged approaches to improve sector partnerships, networks, programs, tools and resources in collaboration with specialist palliative care providers.

• Specific models of care coordination will respond to local community needs, be placed based and tailored to suit the requirement/needs of each community.

• Implementation will require co-design of coordinated approaches with the local health/hospital network and the local community to implement home based palliative care.

• Clear governance, communication and accountability frameworks, such as Memorandum of Understandings (MOU) will also strengthen care-coordination and service linkage.

Significant opportunities exist on the Gold Coast through this funding, which will improve access to safe, quality, palliative care at home and support palliative care systems and services in primary health care and community care. This includes activities aligned to PHN identified priority areas of developing a new model of care or tool (see below) and capacity building among health professionals.

Concurrently, the Gold Coast Integrated Care Alliance has undertaken significant work in redesigning a palliative care model of care for the Gold Coast region that aligns with best practice guidelines. The model consists of 15 recommendations spanning across Gold Coast Specialist Palliative Care Services, community organisations and primary care.

Recommendations include increased resourcing to Gold Coast Specialist Palliative Care Services and community teams, GP capacity building, RACF centres of excellence a pilot study for selected RACFs with increased resources and support aiming to reduce preventable hospitalisations and emergency department presentations, development of a knowledge sharing platform, enhancement of bereavement services, volunteer programs and education for ACP. All recommendations align to consistent themes below:

• Patient and carer-centred approach

• High involvement of the patient's primary care provider (GP)

• Generalist services working with support as needed by specialist palliative care services

• Community-based services designed to navigate the patient and carer to the best available, needs-based services

• Aim to prevent unnecessary hospital admissions.

29 https://www.pc.gov.au/inquiries/completed/human-services/reforms/report/human-services-reforms.pdf
30 https://www.safetyandquality.gov.au/wp-content/uploads/2015/05/National-Consensus-Statement-Essential-Elements-forsafe-high-quality-end-of-life-care.pdf
31 http://endoflifecareambitions.org.uk/
32 http://www.health.gov.au/internet/main/publishing.nsf/Content/greater-choice-home-palliative-care- measure-faq

A key priority for this project is align to the ICA Model of Care recommendations relevant to the scope of the GCPHN and focus on implementation and support required for these activities.
A range of other projects happening at a state and federal level will provide GCPHN with further opportunities to leverage existing resources at a local level. National projects funded by the Department of Health include:
• The Palliative Care Education and Training Collaborative (consisting of Palliative Care Curriculum for Undergraduates or PCC4U, and Program of Experience in the Palliative Approach or PEPA)

• Palliative Care Online Training Portal

• Palliative Care Outcomes Collaboration (PCOC)

• Palliative Care Australia for infrastructure support and operational activities

• Advance Care Planning Australia

• CareSearch, an online portal with database of palliative care related evidence and guidance

• End-of-life Essentials for Acute Hospital Clinicians

• The Australian carer toolkit for advanced disease

• caring@home project, Metro South Hospital and Health Service.

Most recently, as part of the 2018-19 Budget, the Commonwealth Government has committed over $32 million over four years from 2018-19 for the Comprehensive Palliative Care in Aged Care measure which will improve palliative care for older Australians living in residential aged care. It supports new and innovative approaches to how care is delivered by state and territory governments to improve palliative and end-of-life care coordination.

Locally Driven oppourtinies

Through the needs assessment and consultation several key themes have evolved. These key themes represent opportunities for improvement or enhancement of existing services to lead to improved experience, value and outcomes of the services Gold Coast PHN commission, coordinate and support. These opportunities align to the health needs and service issues.

Opportunity	Alignment to Health Needs and Service Issues
Opportunity one: Workforce capacity building	• Maintaining the role of GPs in coordinating care for palliative patients is important to clinicians, consumers and carers. • GPs and other primary care providers may not regularly provide palliative care to their patients, which may influence levels of knowledge and confidence • Low uptake, awareness and confidence in relation to advance care planning, including documentation, legal requirements and how to approach conversations, for both service providers and community members. • While many palliative care-related training and information resources exist for GPs and other primary and community care providers, there are low levels of uptake and awareness • Limited funding is available to support community services to provide after-hours in-home care, offer respite nursing support or purchase appropriate equipment to enable palliative care to be provided in a patient's home (including residents of RACFs).
Opportunity two: Community awareness and education	• Maintaining the role of GPs in coordinating care for palliative patients is important to clinicians, consumers and carers. • Low uptake, awareness and confidence in relation to advance care planning, including documentation, legal requirements and how to approach conversations, for both service providers and community members. • Fatigue and burnout for families supporting loved ones at home is a significant issue, particularly those with limited practical and social support.
Opportunity three: Volunteer programs:	• Fatigue and burnout for families supporting loved ones at home is a significant issue, particularly those with limited practical and social support.
Opportunity four: Service navigation and coordination	• GPs experience challenges in making palliative care-related attendances, particularly in the after-hours period, due to issues with accessing homes or aged care facilities, availability of medications, coordination with onsite nursing staff and communication with deputising services. • Fatigue and burnout for families supporting loved ones at home is a significant issue, particularly those with limited practical and social support. • Families report difficulty with understanding and navigating the palliative journey of loved ones including equipment requirements. • Only one public hospice bed is typically available on the Gold Coast, with the majority of demand for services met by public inpatient or community outreach or visiting services.

Organisation	Type	Program/Service Name	Location	Accessibility	Description
Gold Coast Health	Inpatient Facility	Specialist Palliative Care	Robina Hospital	Assessment by local palliative care service required before admission 1 public purpose-built 16 bed palliative care unit at Robina Hospital.	Multidisciplinary team Patients are admitted for short periods of pain and symptom control, or care during the last days of life when care at home is not appropriate. Patients not admitted for respite
Gold Coast Health	Consultation and Liaison Service	Specialist Palliative Care	Robina Hospital & Gold Coast University Hospital (GCUH)	Triage and referral by MDT Team. Provides consultative care five days a week. Does not admit patients.	Symptom assessment, support and management advice, family support, case/family conference, care planning discussion, triage admissions, discharge advice
Gold Coast Health	Outpatient / Community Facility	Specialist Palliative Care	Robina Hospital & GCUH	There is no gap to pay Telehealth service Phone and outpatient support to RACFs	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	GCUH	Children living with life-limiting illness and their families	Works closely with Childrens Health Queensland Not a stand-alone service, staff are shared across multiple services

Organisation	Type	Location	Accessibility	Description
BlueCare, Ozcare and Anglicare (funded by Gold Coast Health)	Community outreach	Gold Coast-wide	Cost of services determined by patient's eligibility for My Aged Care. Can access through self-funded services.	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.
Hopewell Hospice	Hospice	Located at Arundel with some outreach	8 beds, 1 public bed used by GCH Inpatient Unit Referrals can be made directly to the Hospice – self-referral, family, a GP or other health professional. A nurse visit will take place prior to admission	Care at the End of life including palliative and end of life care, that includes in home respite care, 24-hr on-site nursing, ancillary services and follow-up bereavement services Also provide short courses for family and carers of people with chronic and terminal conditions and education services for health professionals
Various	Aged care service providers	Gold Coast-wide	Accessible through a range of government-subsidised programs and packages, such as Commonwealth Home Support Programme, Home Care Packages, residential aged care facilities (RACF) and Queensland Community Services.	Numerous aged care providers across the 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.
Various	General practitioners	Gold Coast-wide	759 GPs on the Gold Coast across 180 practices, supported by non-GP staff working in general practice (e.g. nurses, allied health professionals, practice managers and administration).	Critical role in coordinating care and making referrals, identifying and assessing palliative care needs, pain management, medication management, bereavement support and advance care planning.

Gold Coast Primary Health Network

Primary Care Gold Coast (ABN 47152953092), trading as the Gold Coast Primary Health Network.

Level 1, 14 Edgewater Court, Robina 4226 | PO Box 3576 Robina Town Centre QLD 4230
P: 07 5635 2455 | F: 07 5635 2466 | E: info@gcphn.com.au | www.healthygc.com.au

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

Gold Coast Primary Health Network gratefully acknowledges the financial and other support from the Australian Government Department of Health.

phn GOLD COAST

An Australian Government Initiative