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

PALLIATIVE CARE

Regional Plan



2018



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History

Primary Health Networks (PHNs) are responsible for working with general practitioners and other primary health care providers in partnership with secondary care providers and hospitals to deliver an efficient and effective health system.

Gold Coast Primary Health Network's (GCPHN) aim is to facilitate improved outcomes for people in our communities, particularly those at risk of poor health outcomes. We aim to achieve this by increasing efficiency and effectiveness of health services and improving coordination of care.

GCPHN is responsible for supporting existing services and commissioning new services to address identified local health needs and services issues within the Gold Coast region.

In 2018, GCPHN received pilot funding under the Department of Heath's *Greater Choice for At Home Palliative Care Measure*. Through this investment, we will implement sustainable system changes to strengthen integration and coordination of services across the Gold Coast region for people receiving palliative care at home.

To ensure shared commitment and maintain accountability of activities carried out by our organisation under the *Greater Choice* program, we have committed to undertaking a comprehensive regional planning exercise in consultation with the sector. This plan documents a way forward to improving the health outcomes of people with palliative care needs within the Gold Coast region.

Greater Choices for At Home Palliative Care

OBJECTIVES

- Improve access to palliative care at home that is flexible and responsive (including after-hours community based care).
- Right care at right time; reduce unnecessary hospitalisations.
- Generate and use data to support continuous improvement of services across sectors.



Palliative Care Service Delivery

The aim is to achieve integrated palliative care service delivery across all clinical settings

Level of Care Primary Provider Role Specialist Role Assesses patient needs. SPECIALIST CARE Negotiates, agrees and formalises Negotiates, agrees and formalises arrangements for care with the arrangements for the patient's patient's primary care provider. care with the Gold Coast Health (GCH) Has ongoing high level involvement Palliative Care Service. in the care of the patient. Consults with the GCH Palliative Care Responsible for coordinating the Service and provides care management of the patients needs as agreed. coordinator of care (lead agency). After hours service providers. Assesses patient needs.

SPECIALIST CARE

- Negotiates, agrees and formalises arrangements for care with the patient's primary care provider.
- Has ongoing high level involvement in the care of the patient.
- Shares care with the patient's primary care provider.
- May be the coordinator of care (lead agency) as negotiated and agreed.
- After hours service providers.

3

- Negotiates, agrees and formalises arrangements for the patient's care with the GCH Palliative Care Service.
- Shares care with the Specialist Palliative Care Service.
- May be the coordinator of care (lead agency) as negotiated and agreed.

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- · Assesses patient needs.
- Negotiates, agrees and formalises arrangements for care with the patient's primary care provider.
- Provides episodic assessment, care planning and/or advice to the patient's primary care provider.

2

- Responsible for coordinating the management of the patient's needs – coordinator of care (lead agency.)
- Consult with the GCH Palliative Care Service if there is a variation to standard protocols of care and if advice is needed.
- Provides after hours service to the patient.

IMARY CARE

 Supports the network of primary care providers through the provision of advice, information, training and professional development and resources.

1

- Responsible for coordinating the management of the patients needs – coordinator of care (lead agency).
- Provides after hours service to the patient.
- Develops palliative care skills through professional development.

The triangle represents the palliative care patient population

Foreword

We are pleased to present this three-year plan for palliative care services in the Gold Coast region, which supports our vision to build one world class health system for the Gold Coast.

Most often, our work as a Primary Health Network (PHN) is focused on planning and commissioning health services that support people to live well. The *Palliative Care Regional Plan* takes a holistic view of what it means to live well, by supporting people to die well.

As the population in the Gold Coast region grows and becomes older, the number of deaths each year will continue to increase. Accordingly, we anticipate the demand for effective, community-based palliative care services for people living with various types of life-limiting illnesses will also increase.

It is estimated that 70 per cent of Australians wish to die at home, but around half of all deaths occur in hospital. Stigma, limited community awareness and understanding of palliative care and service gaps, all contribute to preventing people from benefiting from timely access to palliative care.

The Regional Plan aims to create a local health system that delivers high-quality and accessible palliative care that enables individuals and their families to receive the care and support they need to die comfortably, with dignity and in the place of their choosing.

I am pleased to endorse the Regional Plan's five key priorities:

- · Workforce capacity building
- Volunteer availability
- Sector collaboration
- Community awareness and education
- Service navigation and coordination

The Regional Plan was developed through consultation with key sector stakeholders, including our Gold Coast Health partners, primary care providers, and the carers and representatives

of people who have undertaken the palliative care journey in the Gold Coast region. This has started the conversation about what effective and efficient palliative care in the Gold Coast region looks like, and what is needed to achieve it.

Our stakeholders agree these priorities present an opportunity to enhance palliative care services in our region, leading to a local health sector that better supports people to die in their place of choice and prevent unnecessary hospitalisations.

Whilst achieving our triple aim of improving consumer, carer, family satisfaction with services, improving care outcomes for people with palliative needs and increasing provider satisfaction with the support we provide as a Primary Health Network.

This plan has been developed alongside the *Older People* (with a focus on after-hours and Residential Aged Care Facilities (RACF)) Regional Plan, which aims to support our region's older adult population as they prepare for and approach the end-of-life with the information and support they need.

The *Regional Plan* has also been designed to align with the significant body of work being led by GCH and GCPHN Integrated Care Alliance to develop an agreed model of care for palliative care within the region, which we are pleased to be involved with.

The plan relies on a purposeful and productive relationship between sectors such as primary care, aged care, community services and GCH. It has been endorsed by the Gold Coast Integrated Care Alliance and the boards of GCPHN and GCH. We encourage continued engagement to turn our vision into a reality, and drive positive changes for our region's people with palliative needs, now and into the future.

Matt Carrodus

CEO

Gold Coast Primary Health Network

How to read this plan

This plan has three key sections:

PART ONE describes the context and background for the plan at the national, state and local levels. It summarises key policies and frameworks, and demographic and population health statistics.

PART TWO outlines the health needs and service issues identified for a palliative care in the Gold Coast region. It describes the scope of the plan, and what the GCPHN aims to achieve through the development of this three-year plan.

PART THREE presents the five key priorities forming the basis of this plan, relevant activities, and the indicators that will be used to measure success.

Each priority is supported by short and long term actions that can be evaluated in an ongoing and meaningful way.





Intentions for Investments

- Palliative Care Volunteers Network: supportive communities of volunteers/befriending schemes, to provide support for the carer in daily tasks, a listening ear, or direct support to the person with an illness.
- Community Awareness and Education activities: palliative care initiative to encourage people
 to talk more openly about dying, death and bereavement, and to make plans for the end of life,
 including Advance Care Plans.
- Integrated Multidisciplinary Model of Care: providing improved health care experiences and outcomes for residents of Residential Aged Care Facilities (RACF) with complex clinical and care needs.
- Palliative Shared Care for the Gold Coast health system (across primary and acute care).
- Palliative Care Health Pathways for the Gold Coast health system (across primary, community and acute care).



Glossary

Common terms used in this regional plan are defined below:

Advance care planning promotes care that is in line with a person's values, beliefs and preferences. It plans for a person's future health care needs, for a time when they may no longer be able to make or effectively communicate those decisions themselves.

After-hours refers to the unsociable hours of between 6pm and 8am Monday to Friday, and between 12pm Saturday and 8am Monday, generally relating to the time a person's regular general practice or care provider is closed.

Care coordination is the deliberate organisation of a person's care activities between a range of participants involved in that person's care in order to achieve the most appropriate delivery of healthcare services.

Clinical handover refers to the exchange of professional responsibility and accountability of an individual and the associated transfer of necessary medical and personal information.

Clinical and non-clinical workforce clinical workforce relates to health professionals delivering clinical components of care, such as doctors, nurses and other professionally registered health practitioners, whereas non-clinical workforce refers to those delivering non-clinical support, such as personal care and disability workers, and aged care support staff.

Death literacy is defined as a set of knowledge and skills that make it possible to gain access to understand and act upon end-of-life and death care options.

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. Settings include general practice, other non-palliative specialties of medicine, aged and community care, community pharmacy and allied health.

Health literacy is the level of which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions.

Health needs as referred to within this regional plan are issues identified through a systematic method of identifying and assessing the unmet health and service needs of people residing in the Gold Coast region.

Palliative care is defined by Palliative Care Australia as person and family-centred care provided for a person with an active, progressive, advanced disease, who has little or no prospect of cure and who is expected to die, and for whom the primary treatment goal is to optimise the quality of life.

Person-centred care is a way of planning and delivering services which sees the person who uses or receives a service as an equal partner in their care journey to ensure it meets their individual needs.

Potentially preventable hospitalisations are defined as hospital transfers and admissions that could have been prevented with earlier access to quality primary care and preventative measures.

Prevalence refers to the proportion of a particular population found to be affected by a medical condition at a given time.

Primary care refers to services provided in the community who are typically the first point of call for individuals seeking health advice or treatment. For example, general practice, allied health providers and community services.

Residential aged care facilities (RACFs) provide a range of care options and accommodation for people who are unable to continue living independently in their own homes. Within the *Regional Plan* RACFs are referred to collectively as the facility, its services, processes and staff.

Service utilisation is data collected that reflects the usage trends of various health services and the demographic information of those individuals accessing them to detect patterns and assist in service improvements.

Specialist palliative care provider is a medical, nursing or allied health professional recognised as a palliative care specialist by an accrediting body or who predominantly works in a specialist palliative care service.

Policy context (part 1)

In 2018, Gold Coast PHN undertook a comprehensive Health Needs Assessment relating to palliative care services. This consisted of a structured approach involving:

- analysing data relating to demographics, population health needs and service use
- mapping the local service provider system
- consulting with key stakeholder groups
- presenting common consumer experiences through patient journey mapping
- identifying evidence-based and emerging models of practice.

For a more comprehensive overview than what's provided here, please refer to the GCPHN's *Palliative Care Health Needs Assessment Report*.

Policy setting

Providing all people with a life-limiting illness with appropriate and effective palliative care is an international, national and state priority area. The policy environment summarised below has guided the development of this regional plan and future activities to be carried out by GCPHN.

National policy

The *National Palliative Care Strategy 2010* 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 Consensus Statement: Essential elements for safe and high-quality end-of-life care identified 10 essential elements for delivering safe and high-quality end-of-life care in Australia. When tailored to the appropriate setting and needs of the population, these elements will strengthen opportunities for delivering best practice end-of-life care. They include:

Processes of Care

Organisational Pre-requisites



1 PATIENT CENTERED CARE

Patients are part of decision making about end-of-life care



6 LEADERSHIP & GOVERNANCE

Policies and systems for end-of-life care



2 TEAMWORK

Clinicians work together to improve end-of-life care



7 EDUCATIONAL & TRAINING

Clinicians have the skills and knowledge to provide end-of-life care



3 GOALS OF CARE

Clear goals improve the quality of end-of-life care



8 SUPERVISION & SUPPORT

Clinicians providing end-of-life care are supported



4 USING TRIGGERS

Triggers identify when patients need end-of-life care



9 EVALUATION & FEEDBACK

The quality of end-of-life care is measured and improved



5 RESPONDING TO CONCERNS

Clinicians get help to rapidly respond to patient suffering



10 SUPPORTING SYSTEMS

Systems align with NSQHSStandards to improve outcomes

The Australian Productivity Commission's report entitled *Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services* sets the scene for the Government's role in funding health systems and the need for health reforms to be supported with greater coordination, more transparency and smoother transitions.

It states that Australia has among the world's best end-of-life care, but services are not available to all who need them. Services and providers alike need to collaborate and coordinate more effectively to enable better palliative care for those who would benefit from services.

State policy

At a state level, palliative care is positioned as a high strategic priority in the broader health system through the Queensland Government's *State-wide strategy for end-of-life care 2015* (the Strategy).

A key aim of the Strategy is to strengthen the capacity of Queensland Health services to respond to the needs of those with a life-limiting illness.

The Strategy lays out four service directions for supporting more effective palliative care services within Queensland Health services:

- Improved knowledge and awareness of end-of-life care
- Early initiation of palliative care supported by advance care planning
- Delivery of high-quality end-of-life care practice
- Making best use of the resources available for the projected population

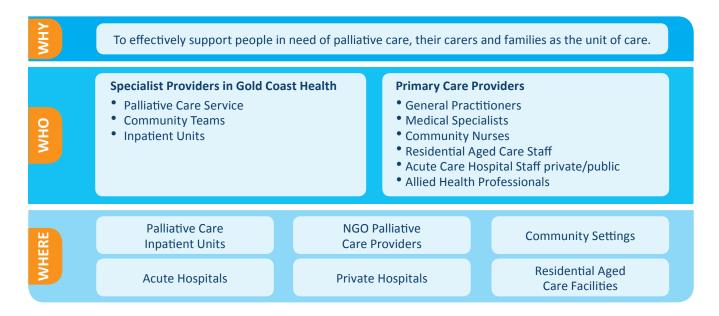
In 2018, a review of Queensland Health's Palliative Care Services (*Queensland Health Palliative Care Services Review*) was announced and commenced to ensure the system is resourced and prepared to effectively respond to the future challenges, such as increased mortality rates and increased demand for services.

Local priorities

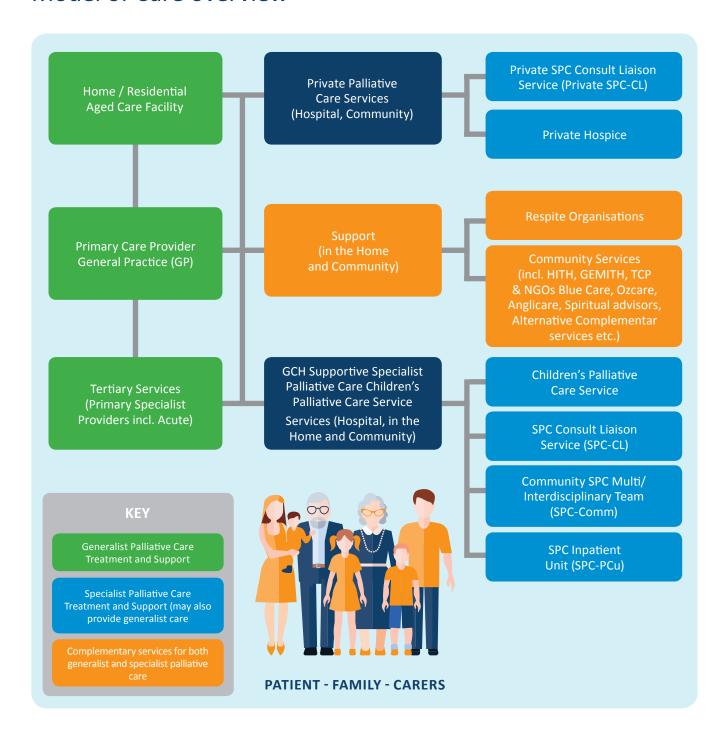
The regional plan aligns with and supports the implementation of relevant recommendations from Gold Coast Health and Gold Coast PHN's *Integrated Care Alliance Model of Palliative Care*, which has a shared aim of reducing potentially preventable hospitalisations and supporting greater choice for athome palliative care.

The Integrated Care Alliance has shaped an agreed model of care below which focuses on enhancing existing care systems and pathways, rather than developing a new model of care. The implementation of the model is based on a set of local recommendations across home and residential aged care, primary care and tertiary services.

Integrated Palliative Care Framework



Gold Coast Integrated Care Alliance Palliative Care Model of Care overview



VOLUNTEER COMMUNITY

Knowledge and Information Sharing Platform (KISP)

Specialist Palliative Care Treatment and Support (may also provide generalist care)

Health literacy; knowledge sharing, awareness, appreciation, public conversation around death and palliative care terminology, acknowledgment of process of dying, re-educate community about scope of general practive, de-institutionalise dying IT; iEMR, shared records, access across sectors, easy cancellation function once patient has passes away specialist knowledge; specialist research, publish but allow translate to support health literacy facilitation for volunteer community, links to bereavement counsellors (short and long term), links to Lions groups and support groups such as Heart Foundation.

Facts and figures relating to palliative care

The number of recorded deaths in the Gold Coast region continues to increase.

In 2016, there were 3,512 deaths in the region, which increased by 24 per cent over the last decade.

The five leading causes of death for the Gold Coast region over the period 2012-2016 were:

- · Coronary heart disease
- Cerebrovascular disease
- Dementia and Alzheimer's disease
- Lung cancer
- · Chronic obstructive pulmonary disease

Given the large number of deaths recorded within the region that are related to a chronic condition, many of these deaths are likely to have a distinguishable phase where there is an opportunity for the provision of appropriate and effective palliative care.

Data from 2017 shows that there are over 850 annual admissions to public hospitals in the Gold Coast region for palliative care. These admissions accounted for a total of 5,989 occupied bed days at an average length of stay of around seven days.

By 2027, Gold Coast Health projects that the number of palliative care-related admissions will double to over 1,700.

There is limited regional data available relating to palliative care services delivered in the community by general practitioners (GPs), non-palliative medicine specialists and allied health and ancillary practitioners.

It is estimated that the proportion of GP consultations that are palliative care-related may be as high as one in every 100 consultations.

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.

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 (GCUH), the privately-operated Hopewell Hospice and one non-government organisation who provides community palliative care services for Gold Coast Health.

It shows that performance benchmarks are typically being met or exceeded by inpatient or hospice services, but not for community-based services, due to the limited availability of 24-hour support for patients in the community setting.

The Gold Coast service system

The need for palliative care in Australia is increasing

150K+

Expected deaths per year



Australians are living longer but chronic diseases and co-morbidity increase with age 87%

of death are due to chronic conditions



1 in 4 Australians had 2 or more chronic conditions





250 people are diagnosed with demetia each day

138K+

people are diagnosed with cancer each year



28% increase in palliative care related hospitalisation between 2011-2012 & 2015-2016

Source:

 $www.aihw.gov.au/reports/life-expectancy-death/deaths-in-australia/contents/age-at-death\\ www.aihw.gov.au/getmedia/6bc8a4f7-c251-4ac4-9c05-140a473efd7b/aihw-aus-221-chapter-3-3.pdf.aspx\\ canceraustralia.gov.au/affected-cancer/what-cancer/cancer-australia-statistics$

www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/contents/admitted-patient-palliative-care/profile-of-palliative-care-related-hospitalisations

Accessibility and appropriate utilisation of highquality 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, however around half of all deaths occur in hospital.

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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.

Gold Coast Primary Health Network (GCPHN) shares an aim with the Gold Coast Health (GCH) to enhance, integrate and collaborate community and primary palliative care services. Both organisations categorise palliative care providers as either:

- Generalist palliative care: providing care 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.
- Specialist palliative care: 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.

The most recent data available (2017) for the number of palliative care-related separations in Gold Coast Health facilities demonstrates the age demographics of those accessing public palliative care services.

Age	Number of hospital separations
0 – 14	0
15 – 44	57
45 - 69	299
70 - 84	335
85+	163

Not all people approaching the end of life need specialist palliative care.

Generalist palliative care is provided in the community by a broad range of providers, including:

- GPs and nurses
- Other medical specialists (e.g. oncology)
- Non-government organisations
- Allied health practitioners
- · Aged care services
- Private providers
- Hospice

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. 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.

Hopewell Hospice is an eight bed, (minimum one 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.

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.

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.

The majority of specialist palliative care services on the Gold Coast are situated in the Robina Hospital with the 16-20 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.

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.

National PCOC data (2017) shows the following statistics relating to performance of specialist palliative care services:

- 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 SES 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 lifelimiting conditions such as heart failure, Chronic Obstructive Pulmonary Disease or dementia with 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.

Health needs and service issues (part 2)



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.



A lack of specific MBS items for palliative care-related attendances by GPs means regional data on the delivery of primary care palliative care services is limited.



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. This often results in an avoidable emergency presentation or hospital admission.



Effectiveness of local palliative care services in an inpatient setting typically exceeds patient outcome benchmarks, but achieving similar outcomes in the community setting is challenging due to limited resourcing.



MBS-funded specialist palliative services, such as public outpatient models or privately-delivered services, are utilised much less in the Gold Coast compared to the national rate but have reportedly increased in the last two years.



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.



Families report difficulty with understanding and navigating the palliative journey of loved ones including equipment requirements.



Fatigue and burnout for families supporting loved ones at home is a significant issue, particularly those with limited practical and social support.



Care coordination involving a person's different care providers and family is seen as important but can be difficult due to a lack of dedicated resources to operationally support and limited uptake of telehealth models.



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.



Limited funding is available to support community services to provide afterhours in-home care, offer respite nursing support or purchase appropriate equipment to enable palliative care to be provide in a patient's home (including residents of RACFs).



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.

Introduction to Regional Plan

Rationale

The demand on palliative care services is projected to increase in the Gold Coast due to the ageing population and higher proportion of older people in the region.

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 availability and use of palliative care services is increasing, the proportion of people who die receiving palliative care services is still relatively low.

There are over 3,500 deaths on the Gold Coast each year. Most of the leading causes of death are chronic conditions, which are likely to have a distinguishable phase where palliative care is appropriate.

Currently, most of the demand for palliative care services in the Gold Coast region falls on specialist public inpatient and community teams at Robina Hospital and Gold Coast University Hospital. But not all people approaching the end of life need specialist palliative care.

Inpatient specialist palliative care is labour and cost-intensive, and greater efforts to palliative care in the primary care and community settings (i.e. generalist palliative care) could deliver positive outcomes for the majority of patients who don't present with complex symptoms or needs.

Consultation with local stakeholders has identified a range of issues that may be impacting the effectiveness of generalist palliative care services to meet the needs of people in the Gold Coast region.

The *Regional Plan* aims to improve choice and flexibility to support people to die at home in comfort and with dignity. This requires the right services to be delivered in the right place at the right time.

A shared commitment to engagement, collaboration and innovation is required across the sector to achieve the vision of people living well and dying well in the Gold Coast.

There are a wide range of stakeholders who can contribute, including general practitioners (GPs) and other primary care providers, aged care and community care services, public and private hospitals, volunteering organisations, and consumer and carer representatives.

The *Regional Plan* and its priorities are supported by the *Palliative Care Health Needs Assessment,* which outlines the findings of data analysis, service mapping, patient journey mapping, targeted consultation and co-design workshops. The report is available on the GCPHN website.

Methodology

The *Palliative Care Regional Plan* was developed collaboratively with palliative care services across the region and is supported by findings from the *Palliative Care Health Needs Assessment*.

The five priorities identified in this regional plan have been developed in response to the local health needs, service issues and opportunities identified through a structured needs assessment and co-design process undertaken by GCPHN using the methodology below:

Data analysis	Service mapping	Patient journey mapping	Consultation	Co-design workshops
Relevant data indicators enable analysis of the drivers of service demand and levels of existing service utilisations.	Service mapping identifies and profiles existing services, broken down by service type, location, target population and provider type.	Patient journey mapping is an engagement tool to understand service issues and enablers from the perspective of health consumers.	Multifaceted consultation was undertaken to capture the opinions and priorities of diverse stakeholders, including: • Gold Coast Health • GPs • service providers • consumer/ carer representatives	Potential service responses were designed collaboratively with the wider sector and community in a participatory workshop format.

The outcomes from the co-design workshops were summarised and presented back to Gold Coast PHN's existing advisory mechanisms for prioritisation. The advisory groups involved in the prioritisation of regional plan activities include:

- Palliative Care Leadership Group
- Clinical Council
- Community Advisory Council
- Primary Care Partnership Council

Scope of the Regional Plan

The scope of the regional plan includes services that can be categorised as either generalist or specialist palliative care. It focuses predominantly on palliative care delivered in the primary care or community settings, and how these services interface with palliative care provided within the hospital setting.

Specific focus areas arising from GCPHN's strategic objectives relating to palliative care include:

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

Recognising the need for a collaborative approach, the plan involves primary health care providers, residential and in-home aged care providers, public and private hospitals, hospice facilities and other community-based organisations.

What do we hope to achieve?

The regional plan aims to contribute to GCPHN's overarching vision to build one world class health system for the Gold Coast.

Across all its program areas and priorities, GCPHN's strategic goals include:

- Improve coordination of care to ensure people receive the right care at the right place at the right time, by the right person
- Increase efficiency and effectiveness of health services for people particularly those at risk of poor outcomes
- Engage and support general practice and other stakeholders to facilitate improvements in our local health system
- Be a high performing, efficient and accountable organisation

In the context of palliative care services this three-year plan is working towards the following strategic goals:

CREATING TRULY PERSON-CENTRED CARE

Putting people with palliative care needs in the centre of all that we do in order to meet their needs and support them and their family/carers through their journey to enable a good death in their place of choice.

FOCUSING ON AN INTEGRATED AND COORDINATED APPROACH

Helping guide navigation, communication and consistent processes between services to support people with palliative care needs to continue to live and die in their place of choice.

ENSURING EFFECTIVE, EFFICIENT AND BEST PRACTICE HEALTH CARE

Building relationships across the service system to ensure better outcomes for people with palliative care needs and their carers and families, and more efficient delivery of care for service commissioners.

ENSURING THE WORKFORCE HAS ONGOING EDUCATION AND SUPPORT

Providing opportunities for ongoing education to ensure a high level of capability and confidence within the workforce providing generalist palliative care services.

Implementation and governance

This plan reflects the diversity of providers delivering palliative care services within the Gold Coast region. It focuses on how these providers interact with state-funded public hospital and health facilities, and how better integration and coordination can be achieved.

The overarching implementation of the *Palliative Care Regional Plan* will be led by GCPHN, with oversight and governance to be provided by GCPHN's existing advisory mechanisms including:

- Palliative Care Leadership Group
- Clinical Council
- Community Advisory Council
- Primary Care Partnership Council

The priorities and accompanying activities will guide activities across the sector and these will be monitored and reviewed in an ongoing manner as a commitment to meeting demand and improving services within a changing environment for people accessing palliative care services.

Each priority has identified measures of success. GCPHN will use these measures to progressively evaluate the delivery and impact of the regional plan.

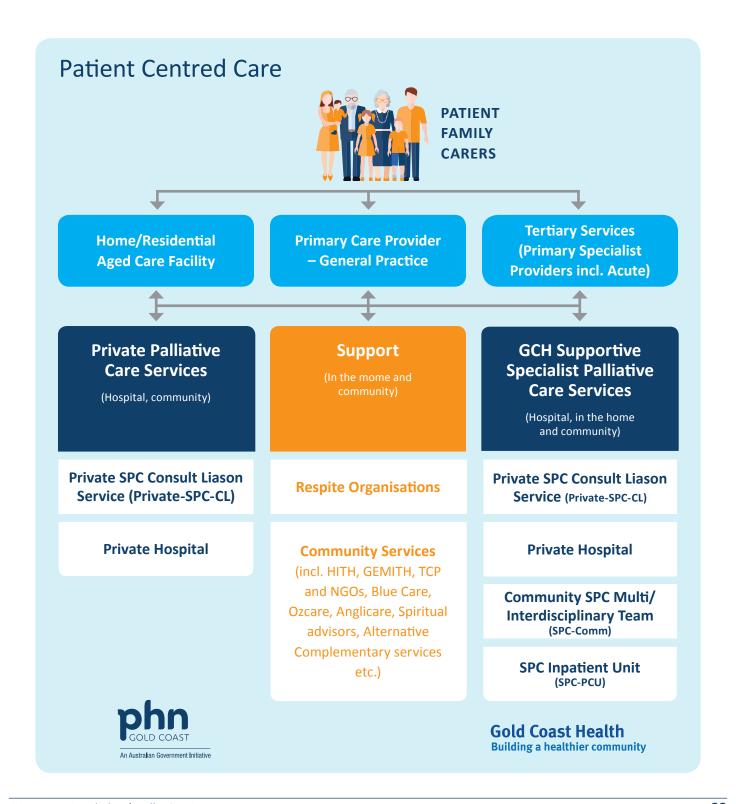
The next step for the plan is to further engage with key stakeholders, such as Gold Coast Health (GCH) to establish an agreed and formalised governance structure which will enable the plans to reflect wider partner collaborative planning, joint investment and performance monitoring against the regional plan.

GCPHN and GCH recognise the importance of primary healthcare providers and hospitals working together to ensure services are best tailored to meet the needs of local communities. This commitment is reaffirmed and strengthened through the Primary Health Care Improvement Committee and the Integrated Care Alliance as each of these collaborative partners has a significant and shared interest in the health of the Gold Coast region.

We have reaffirmed that GCPHN and GCH will prioritise and plan for services to best meet local health care needs as a collaborative. Our organisations have a shared commitment to strengthening existing joint partnerships and governance structures, driving continual innovation to address systemic gaps and strengthen the interface between acute and primary care. We are jointly committed to integrated models of care which support delivery in the appropriate settings and strengthen the effectiveness, efficiency, and health outcomes for all those who live in the Gold Coast region.

We recognise that working together puts us in the best position to improve patient care, outcomes and pathways, by moving care, where appropriate, into the primary care setting. There is no 'one size fits all' approach – instead, jointly, GCPHN and GCH will promote flexible approaches to meet the communities' specific needs. Driven by consumer needs, collectively we aim to:

- Ensure a coordinated approach to service planning and delivery across the Gold Coast, prioritising service gaps and challenges.
- Develop agreed common, seamless and complementary pathways.
- Work collaboratively to deliver more care in the primary care setting.
- Develop new ways of working together in partnership to improve patient care, access, outcomes and pathways.
- Create opportunities for our people to share resources, ideas, knowledge and experience to improve care through partnerships at the frontline.



Strategic priorities (part 3)

The following five priorities have been developed in response to the local health needs, service issues and opportunities identified through a structured needs assessment and co-design process undertaken by Gold Coast Primary Health Network (GCPHN).



The priorities will guide the planning and delivery of generalist palliative care services over the next three years within the Gold Coast region.

Some activities may be undertaken within existing resources, programs and activities, while others will require additional investment and resourcing subject to availability through GCPHN, its local partner organisations including Gold Coast Health and the Commonwealth Government.

Activities have been prioritised by Gold Coast PHN advisory mechanisms based on identified health needs and service issues within the region.

1 Workforce Capacity Building

People have access to a palliative care workforce that is well-informed, highly skilled and confident in their ability to provide palliative care

People on the Gold Coast told us they value:

- Competence
- Diversity
- Availability
- Holistic care
- Understanding
- Responsiveness



What success looks like

ACTIONS

- 1 Support the availability and uptake of existing government funded workforce training and education initiatives available to support the palliative care workforce, such as:
 - **a.** The Palliative Care Education and Training Collaborative (consisting of Palliative Care Curriculum for Undergraduates (PCC4U), and Program of Experience in the Palliative Approach or PEPA).
 - **b.** Palliative care online training portal for staff, carers and volunteers who provide palliative care in the community.
 - c. Centre for Palliative Care Research and Education (CPCRE)
 - **d.** Advance Care Planning Australia online learning space for health professionals, care workers and community members
 - **e.** The Advance Project, an accredited online training activity and evidence-based toolkit for GPs and general practice nurses to support advance care planning and palliative care.
 - f. CareSearch, an online portal with database of palliative care related evidence and guidance.
 - **g.** PalliAGED apps for GPs and nurses working in residential aged care, community care and general practice and providing end-of-life care.
 - **h.** Caring@home, educational resources for community service providers, health professionals and carers in helping manage breakthrough symptoms using subcutaneous medication.
- 2 Support the uptake of an appropriate existing resources to assist the generalist palliative care workforce to develop confidence in approaching end of life conversations as part of routine patient care such as the 'Dying to Talk' discussion starter resource.
- 3 Explore opportunities with Palliative Care Queensland to facilitate an annual palliative care forum for Gold Coast service providers to showcase local services and programs, facilitate networking opportunities and share information and resources.

- 4 Support the implementation of the Integrated Care Alliance recommendation to support the role of GPs in coordinating palliative care for their patients, particularly in patient's homes (including RACFs), through a business model, which may include:
 - a. MBS item number advice, including services for private patients
 - b. information on case-conferencing using telehealth
 - c. advice and support for available Practice Incentive Programs
 - d. adoption of My Health Record
 - **e.** early identification and referral into supportive and palliative care services and advance care planning.
- 5 Raise awareness of the availability of Gold Coast Health Specialist Palliative Care Service to provide telephone support to GPs and RACF nursing staff, and explore extension of support into after-hours period.
- 6 Support mechanisms to increase cultural awareness in palliative care services, such as:
 - a. Palliative Care Australia's Dying to Talk Aboriginal and Torres Strait Islander Discussion Starter.
 - **b.** palliAGED, resources for Aboriginal and Torres Strait Islander Peoples and their carers.
 - **c.** Department of Health's *Providing Culturally Appropriate Palliative Care to Aboriginal and Torres Strait Islander Peoples: Resource Kit.*
 - **d.** End of Life Directions for Aged Care (ELDAC) provides toolkits for providers working in home care, primary care, RACF, legal and working together, a business hour helpline, and access to evidence-based information and service information.
 - **e.** Queensland Health's Sad News, Sorry Business: Guidelines for caring for Aboriginal and Torres Strait Islander people through death and dying.
 - **f.** Support cultural awareness training in mainstream services, including through the Commonwealth-funded Partners in Culturally Appropriate Care (PICAC) initiative.
 - **g.** ACPTalk, a national advance care planning resource for health professionals conducting advance care planning with people from different religious and cultural backgrounds.
 - **h.** Uptake of the Translating and Interpreting Service (TIS National).
 - i. Advance Care Planning Australia resources translated in 13 languages.
- 7 Explore opportunities to develop and implement programs to increase the availability of after-hours clinical support for individuals and carers in their homes (including RACFs).
- 8 Support the uptake and visibility of palliative care data collection across the Gold Coast region through the Palliative Care Outcomes Collaboration (PCOC), including a support tool to assist general practice to participate in PCOC.
- 9 Leverage opportunities to share information on palliative and end of life care resources and training opportunities within existing professional development events held locally.
- 10 Inform and influence State and Commonwealth Government policies, strategies and processes to continually advocate for reforms that enhance palliative care outcomes.

Possible measures of success

- Increased number of Program of Experience in the Palliative Approach (PEPA) placements across the Gold Coast region.
- Increased attendance at palliative care-related educational events and workshops across the region.
- Increased uptake of advance care planning.
- Increased confidence reported by local GPs to deliver palliative care for their patients.
- Reduction in preventable emergency department presentations and hospital admissions, particularly patients transferred from their homes in the after-hours period.
- Increase in palliative care-related attendances by GPs into patient's homes and RACFs.
- Increased uptake of palliative care services from vulnerable and under-serviced populations.

OUR VISION FOR THE GOLD COAST

"People on the Gold Coast will live well and die well"

2 Volunteer Availability

People have access to a valued, supported and recognised network of palliative care volunteers

People on the Gold Coast told us they value:

- Compassionate communities
- Social connection
- Practical support for carers
- Bereavement support



What success looks like

ACTIONS

- 1 Develop a Gold Coast Regional Palliative Care Volunteer Network that coordinates and expands on existing volunteer programs, to provide consistent, best practice palliative care volunteering across Gold Coast. The program could include:
 - **a.** Appropriate promotion and messaging mechanisms to reach and engage suitable volunteers.
 - **b.** Education, training and support for volunteers.
 - **c.** Development of clear volunteering guidelines to set clear expectations and manage risks.
 - **d.** Appropriate client and task matching to provide meaningful support to people with palliative needs and their families.
- **2** Explore opportunities to collaborate with local universities to promote volunteering and appropriate placements in palliative care settings by students across all disciplines.
- **3** Empower and build the skills of palliative care volunteers to deliver carer and family respite and bereavement support, and promote death literacy in the community.
- 4 Create and sustain a strong palliative care volunteering presence in the Gold Coast region by promoting volunteering as an important and valued part of the delivery of all services providing palliative care in the region.

Possible measures of success

- Increased number of palliative care volunteers in the Gold Coast region.
- Less fatigue and burnout reported by carers of people with palliative needs.
- Increased number of volunteers accessing palliative care education and training activities.
- Increased number of generalist palliative care services engaging volunteers in their model of practice.

3 Sector Collaboration

Palliative care services on the Gold Coast are collaborative and work together to support the individual needs of people accessing their services

People on the Gold Coast told us they value:

- Continuity of care
- Accessibility
- Being informed and involved
- Early planning and decision-making



What success looks like

ACTIONS

- 1 Support the implementation of the Integrated Care Alliance recommendation to develop a regional Palliative Care Advisory Group to provide palliative care advice and support to health professionals within the region.
- 2 Explore opportunities to develop and implement a resource that supports effective clinical handover and reduces communication errors between hospitals, residential aged care facilities, GPs and community organisations.
- 3 Explore opportunities and potential service models to provide access to 24-hour support for carers and families of people with palliative needs who choose to die at home.
- 4 Enhance the role of community pharmacists in supporting palliative care within the region by:
 - **a.** Education and awareness around common medications to assist in maintaining adequate stock levels.
 - **b.** Promoting the use of My Health Record in pharmacies.
 - **c.** Promoting community pharmacists as a necessary representative on multidisciplinary care teams.
 - **d.** Support community pharmacists to enhance medication management to support at-home palliative care.
- 5 Support the implementation and awareness of the Integrated Care Alliance recommendation to design, implement and evaluate a GP palliative care mentorship program across the region, where select GPs receive specialist palliative care advice, support and resources to support them to provide best-practice palliative care to their patients.

- 6 Support the implementation of the Integrated Care Alliance recommendation to design and implement a coordinated discharge referral process which empowers the individual and their family/carer to integrate back into primary care, including at-home palliative care. This may include:
 - **a.** Collaborative case conferencing involving GPs, family and carers.
 - **b.** Advance care planning.
 - **c.** Providing information to enable access to community-based programs and resources.
 - d. Effective clinical handovers.
- 7 Support existing businesses and services within the region to foster a 'whole of community approach to dying', which may promote local opportunities that:
 - a. increase informal respite opportunities.
 - **b.** reduce isolation and loneliness.
 - c. reduce stigma around death and dying.

Possible measures of success

- Increased effectiveness of clinical handovers of palliative patients reported by hospital clinicians, GPs and RACF staff.
- Increased confidence reported by GPs in the region to deliver palliative care.
- Increased number of carers and family members reporting feeling involved and confident to support in the care of a loved one with palliative needs.
- Increased after-hours support for families and carers.
- Increased number of people dying at home within the region.
- Increased number of families and carers reporting that they feel well supported after the death of a loved one.
- Increased uptake of advance care planning.
- Increased palliative care-related attendances by GPs into patient's homes and RACFs.

4 Community Awareness and Education

People are supported to obtain a high level of health, death and compassion literacy and service knowledge

People on the Gold Coast told us they value:

- Community connections
- Family and carer engagement
- Being informed and involved
- Compassionate communities



What success looks like

ACTIONS

- 1 Develop and implement a multifaceted community facing communication strategy to increase understanding of palliative care in the community, with possible topics to include:
 - a. how to approach end-of-life conversations
 - b. improving health, death and compassion literacy in the community
 - c. preparing for death
 - d. advance care planning, particularly from a young age
 - e. information on available services and supports.
- 2 Coordinate and disseminate existing resources that are able to better inform and support people who are accessing palliative care services and their family and carers, such as:
 - a. Queensland Health's care at the end of life resources
 - b. Office of Advance Care Planning
 - **c.** Peak Bodies (e.g. Council on The Ageing Queensland, Palliative Care Queensland and Carers Queensland).
- 3 Work with the Community Advisory Council to undertake a review of GCPHN's existing resources and information platform, including the HealthyGC website, to ensure consumer-facing resources are contemporary and developed with clear and simple language and messaging.
- 4 Support local community organisations to create opportunities to deliver information to people, start conversations and reduce isolation and loneliness through support groups, 'death cafes' and by having a presence at existing seniors and community events.

- 5 Utilise existing resources within the region to disseminate information:
 - a. Newsletters of like-minded organisations
 - b. Seniors groups, RSLs and sporting clubs
 - c. Existing online forums and social media.
- 6 Explore opportunities within the region to develop and implement intergenerational programs to reduce stigma around death and dying, such as partnerships between child care centres and residential aged care facilities.

Possible measures of success

- Increased uptake of advance care planning.
- Increased health, death and compassion literacy reported within the Gold Coast community.
- Increased number of people accessing palliative care services and their carers and families reporting that they feel better connected to information and supports.
- Increased number of linkages and partnerships with non-health related community organisations relating to raising awareness about palliative care and death and dying.

5 Service Navigation and Coordination

People have appropriate support to navigate and access services to meet their health and social needs

People on the Gold Coast told us they value:

- Ease of navigation
- Support to remain at home
- Support for carers
- Holistic care



What success looks like

ACTIONS

- Support the implementation of the Integrated Care Alliance recommendation to invest in the inclusion of a care navigator role to support individuals to navigate and access relevant health and social services.
- 2 Enhance HealthyGC website to include a consumer-friendly service directory relating to local palliative care services and established, credible palliative care helplines to support individuals, families and their carers to access information on palliative care and available services, such as:
 - **a.** PalAssist, a free Queensland 24 hour telephone and online service for palliative care patients, carers, family and friends seeking practical and emotional support
 - **b.** End of Life Directions for Aged Care (ELDAC) helpline runs in business hours to provide information to people caring for people with a palliative need
 - c. Advance Care Planning Australia advisory service.
- 3 Support the role of My Health Record as an effective information platform across all services delivering specialist and generalist palliative care to support service providers in making informed and appropriate referral decisions.
- 4 Explore opportunities to support general practice nurses to provide the care navigation function for patients with palliative needs being managed in the primary care setting.
- 5 Work with Gold Coast Health to support the investment of in an emergency department telephone triage line for RACFs, community service providers and general practice, that aims to offer specialist advice and support to prevent unnecessary hospital transfers.

Possible measures of success

- Reduction in preventable emergency department presentations and hospital admissions.
- Increased number of people with palliative needs and their carers reporting that they feel better informed of their service options.
- Increased confidence reported by people with palliative needs and their carers to find and access the services they need.
- Increased number of visits and length of time on palliative care section of the HealthyGC website.

Reference List

Australian Commission on Safety and Quality in Health Care, 2015 National Consensus Statement: Essential elements for safe and high-quality end-of-life care. Available at: https://www.safetyandquality.gov.au/wp-content/uploads/2015/05/National-Consensus-Statement-Essential-Elements-forsafe-high-quality-end-of-life-care.pdf

Australian Commission on Safety and Quality in Health Care (ACSQHC), 2015 The First Australian Atlas of Healthcare Variation. Available at: https://www.safetyandquality.gov.au/atlas/atlas-2015/

Australian Government Department of Health, 2010 National Palliative Care Strategy. Available at: http://www.health.gov.au/internet/main/publishing.nsf/content/EF57056BDB047E2FCA257BF000206168/\$File/NationalPalliativeCareStrategy.pdf

Australian Government Productivity Commission, 2018 Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services. Available at: https://www.pc.gov.au/inquiries/completed/human-services/reforms/report

Australian Institute of Health and Welfare (AIHW), 2012-2016 Mortality Over Regions and Time (MORT) books. Available at: https://www.aihw.gov.au/reports/life-expectancy-death/mort-books/contents/mort-books

AIHW, 2018. Palliative care services in Australia. Available at: https://www.aihw.gov.au/reports/palliative-care-services-in-australia/contents/summary

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

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

Gold Coast Health, palliative care data (supplied by Gold Coast Health Strategy and Health Service Planning Branch)

Grattan Institute, 2014. Dying Well. Available at: https://grattan.edu.au/wp-content/uploads/2014/09/815-dying-well.pdf

Palliative Care Outcomes Collaboration, 2018 Palliative care services at a glance, 2017 data tables. Available at: https://ahsri.uow.edu.au/pcoc/services-at-a-glance/index.html

Queensland Health, 2018 Queensland Health Palliative Care Services Review. Available at: https://www.qld.gov.au/ data/assets/pdf file/0016/14272/consultation-paper.pdf

Queensland Health, 2015 State-wide strategy for end-of-life care. Available at: https://www.health.gld.gov.au/_data/assets/pdf_file/0022/441616/end-of-life-strategy-full.pdf

University of Sydney, 2016 Bettering the Evaluation and Care of Health (BEACH) survey 2015-16. Available at: http://sydney.edu.au/medicine/fmrc/beach/

University of Wollongong, 2018 Palliative Care Outcomes Collaboration (PCOC). Available at: https://ahsri.uow.edu.au/pcoc/index.html

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

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