



# Summary of findings

Developing a Palliative Care 3-year Action Plan for  
Brisbane South PHN

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***September 2022***



**Beacon  
Strategies** 

# Introduction

The purpose of this desktop review is to scope relevant documentation to develop knowledge and insight of the strategic environment and evidence base. This is an important step in developing a set of meaningful and practical actions for Brisbane South PHNs Palliative Care 3 Year Action Plan.

This version of the desktop review is presented as phase 1 providing the opportunity for the inclusion of further documentation informed through stakeholder engagement activities.

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## Phase 5: Implementation support

Support the Brisbane South PHN team with the practical implementation of the 3 Year Action Plan into existing processes

*August 2022*

[Click here](#) to view our online project schedule



## Phase 4: Develop action plan

The Palliative Care 3 Year Action Plan will be developed and finalised in collaboration with the project steering group.

*August 2022*

## Phase 3: Stakeholder engagement

Develop a stakeholder engagement plan and undertake engagement activities with identified stakeholders

*August 2022*

## Phase 2: Desktop review

Understand previous and existing Palliative Care projects and initiatives through targeted desktop research of key program documents and an environmental scan of other PHNs

*July 2022*

## Phase 1: Project establishment

Define project context and develop key project management documentation, enabling visibility of project deliverables, timelines and accountabilities

*Commence project*

# Project roadmap

# **KEY FINDINGS**

***What are the key strategy  
and policy priorities  
relating to palliative care  
services and what is the  
role of a PHN in delivering  
on this?***

# Summary:

## Strategic priorities (1/3)

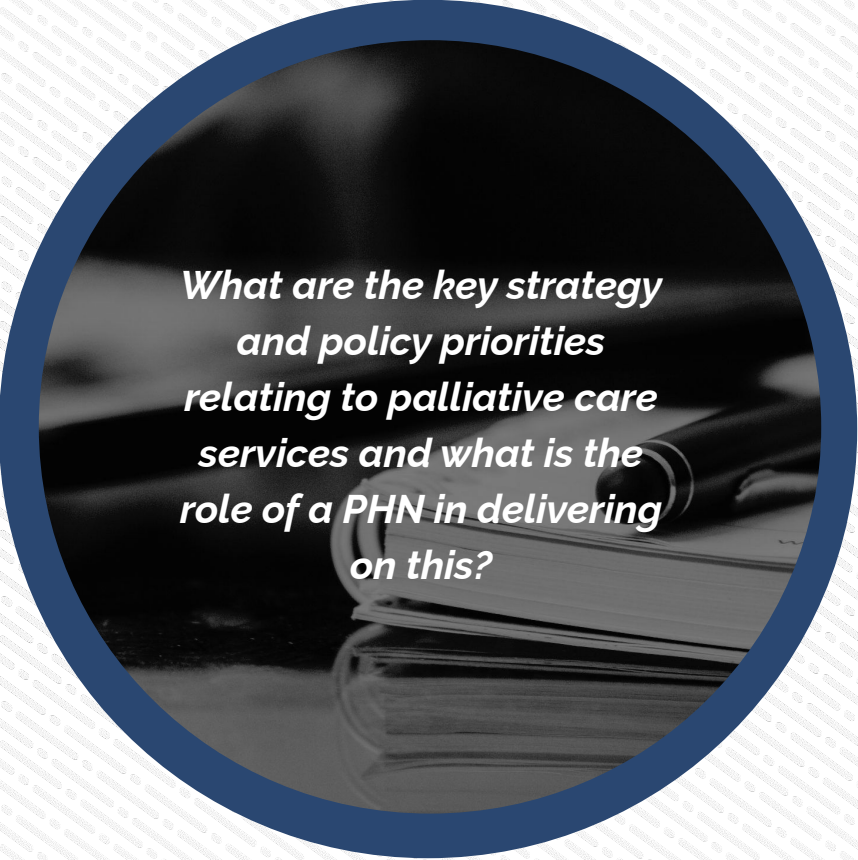
While end-of-life care is a phase of palliative care, the terms are often confused and used interchangeably. Providing a definition of palliative care is an important step to provide context for the development of the Palliative Care 3 Year Action Plan.

The National Strategy, released in 2018, is intended to guide the improvement of palliative care across Australia so that people affected by life-limiting illnesses get the care they need to live well.

The Implementation Plan for the National Palliative Care Strategy 2018 identifies four action areas with specific activities and annual monitoring of progress to achieve the goals of the Strategy.

Four national action areas have been identified in the Implementation Plan to provide direction for collaborative efforts that progress the priorities of the National Strategy over the next five years.

The Palliative Care Australia Roadmap 2022-2027 was developed in response to the growing need for palliative care services across Australia, and guides investments and initiatives to ensure everyone has access to high quality palliative care when they need it.



***What are the key strategy and policy priorities relating to palliative care services and what is the role of a PHN in delivering on this?***

## Summary: Strategic priorities (2/3)

The Palliative Care Australia Roadmap outlines key focus areas, solutions and issues that need addressing in Palliative Care Services.

The Palliative and End-of-Life Care Strategy is being developed in response to the commitment of additional funding from the Queensland Government to lead reform in palliative care for 2021/22-2025/26.

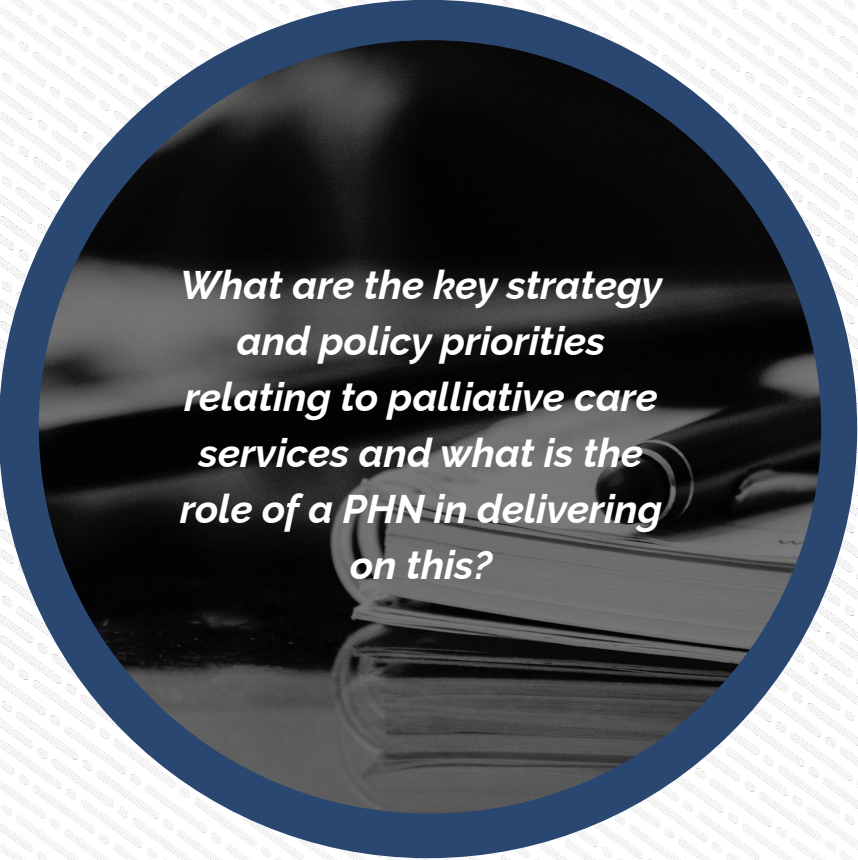
Queensland Health's Specialist Palliative Care Workforce Plan is being developed to support the Palliative and End-of-Life Care Strategy to build the capability and capacity of the frontline specialist palliative care workforce.

Palliative Care in Queensland Priorities outlines six priority strategies and policy actions that provide direction for the transformation of Palliative Care services in Queensland for 2022-23 — focusing on workforce, funding, holistic and inclusive care, accessibility, community engagement and innovation.

Palliative Care Queensland identifies 'Hot Topic Key Improvement Areas' annually based on consultations with key stakeholders. Six Hot Topic Key Improvement Areas were identified for 2022-23 and provide guidance for individuals, organisations and policy makers.

# Summary:

## Strategic priorities (3/3)




*What are the key strategy  
and policy priorities  
relating to palliative care  
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Developed for the DoH, an Exploratory Analysis of Barriers to Palliative Care provides insight into barriers to quality palliative care for consumers and services, enablers for facilitating appropriate palliative care (including workforce, networks, funding and research) and recommendations for the sector.

Following a trial of the GCfAHPC in 11 PHN's, the Commonwealth Department of Health have extended to funding to all Australian PHNs and delivers on the National Palliative Care Strategy.

The Paediatric Palliative Care National Action Plan project aims to enhance the delivery of palliative care to infants, children and young people. Since 2020, the project has delivered a Literature Review and Paediatric Palliative Care Conference.





***What is the operational environment of palliative care in Brisbane South and what palliative care programs and services have Brisbane South PHN commissioned?***

## Summary:

### Operational environment (1/2)

The Current State Report highlights a number of current/previous activities that Brisbane South PHN have led under the Palliative Care portfolio.

The regional older person's strategy highlights joint actions relating to palliative care around strategic planning, (re)designing models of care, uptake of advance care planning, bereavement support, workforce development and compassionate communities.


The Brisbane South Aged Care Workforce Strategy outlines key priorities for developing a capable aged care workforce that delivers services across the ageing journey, including palliative care.

The Aged Care Workforce Baseline Report identified several issues relating to palliative care in Brisbane South, including inadequate knowledge and training for aged care workers, earlier discussions and access to palliative care approaches, and challenges with integration between services.

Brisbane South PHN's Activity Work Plan for holistic palliative care and end of life aims to improve consumer outcomes and experiences and increase efficiency of care provided through place-based approaches and models of care designed with consumers.

Brisbane South PHN's strategy for the Greater Choice for At Home Palliative Centred around supporting communities and health professionals to increase awareness of and deliver high quality and culturally appropriate palliative care.





***What is the operational environment of palliative care in Brisbane South and what palliative care programs and services have Brisbane South PHN commissioned?***

## Summary:

### Operational environment (2/2)

The Department of Health Evaluation of the GCfAHPC concluded that Brisbane South PHNs At Home Palliative Care project achieved positive results for interim outputs and medium-term outcomes of workforce capability and clinical management and identified a number of system level barriers for project delivery.

Metro South Health produced the The GCfAHPC Final Project Report which highlights the successful project outcomes achieved by Brisbane South PHN in improving end-of-life palliative care delivery in participating general practices.

Pallchat Brisbane South Project was delivered from 2020-2022 and achieved positive results against the five expected outcomes identified in the project theory of change.

Pallchat internal activity reflection provides a summary of the lessons learned and recommendations for the future around project establishment, delivery methods and marketing strategies.

The Improving End-of-Life Care for Residential Aged Care Facility Residents Report highlights the outcomes achieved by the Initiative in Residential Aged Care Facilities under phase 3 of the initiative.

Evaluation of the Improving End-of-Life Care for Residential Aged Care Facility Residents Initiative identified a series of recommendations to guide ongoing collaboration between Brisbane South PHN, Metro South Palliative Care Service and RACF's.



*What are the palliative care needs of individuals, families and carers?*

## Summary: Service needs (1/2)

Over 6,200 people die in the Brisbane South region each year, with the majority of these deaths due to chronic, life-limiting conditions where the person would likely have benefited from access to palliative care.

There are generally considered to be 5 phases of palliative care for people with a life-limiting illness, with most of the focus being at the end-of-life rather than starting when the person is 'stable.'

Previous work done by BSPHN highlights the unmet need for people with life-limiting illnesses to access palliative care, and issues relating to the availability, accessibility or effectiveness of services to meet the needs of people and their families/carers.

The palliative care service system in Brisbane South involves both specialist and generalist palliative care services delivering across a range of settings, with leading models of care requiring the involvement and integration of all of these in a way that promotes choice and equity of access.

The Kitchen Table Discussion Report identified knowledge and information on services and access to health professionals as palliative care needs for consumers from Culturally and Linguistically Diverse backgrounds in Brisbane south.



*What are the palliative care needs of individuals, families and carers?*

## Summary: Service needs (2/2)

The Death Literacy Index is a tool that has a means to measure the death literacy of a population or communities and provide insight into the impact of palliative care initiatives.

Implementation of the DLI demonstrates that the death literacy of the Australian population is by learning from experience and talking about death and dying. There is a low knowledge and confidence of the system and information needed to plan for dying, death and caregiving.

The DLI of the Brisbane south population is comparable to the Australian population. Generally across Brisbane south there is a need for activities that aim to increase the knowledge of the population about end-of-life with low scores for knowledge and personal experience the main source of information about death and dying.

In response to the reduced access to bereavement care during to COVID-19, Palliative Care Queensland consulted with stakeholders to identify five recommendations that provide direction for the sector

In response to declining Advance Care Planning activity across Queensland, a statewide survey was conducted and identified confidence and awareness of clinicians and patients as barriers and enablers to Advanced Care Planning.

***What learnings and opportunities can be leveraged from previous or existing Palliative Care services or programs?***

## Summary: Comparable activities

The Greater Choice for At Home Palliative Care Summary Report reviews the activities undertaken by participating PHNs to assess effectiveness, sustainability and future funding.

Evaluation of activities undertaken by PHNs for GCfAHPC identified success in community awareness raising and changing palliative care practices.

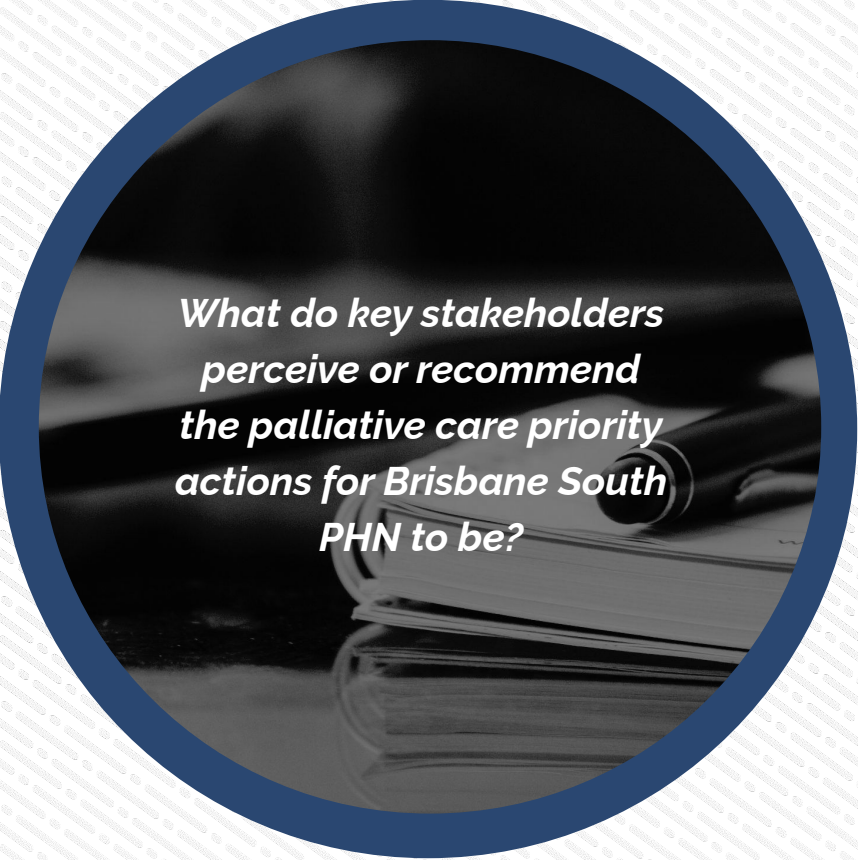
Brisbane South PHN's Current State Report identifies other state and national initiatives that are being implemented. While not every initiative identified is specific to palliative care, it is worth noting these activities as they influenced or interacted with the palliative care landscape in Brisbane South.

The Gold Coast PHN Palliative Care Regional Plan centres around palliative care delivered in primary or community care settings and aims to support an individual's needs to die with dignity and in their place of choice.

The Townsville Area Palliative Care Plan a roadmap to expanding and providing quality palliative care for the communities in the region through the identification of Nine Directions endorsed by key partnering organisations.

The TAPCP identifies Nine Directions for Palliative Care to provide implementation actions and measures to achieve a high quality, equitable and accessible palliative care system that is underpinned by an integration and a skilled workforce.





***What do key stakeholders  
perceive or recommend  
the palliative care priority  
actions for Brisbane South  
PHN to be?***

## Summary: Stakeholder consultation (1/2)

A total of 26 responses to the stakeholder engagement survey were received. The majority of responses were from an Aged Care Services perspective with 14 responses followed closely by Specialist Palliative Care Services with 5 responses.

Survey responses from participants with an Aged Care perspective identified challenges around medication at end-of-life, timely delivery, continuity of care after hours and RN education.

Training and education for RNs and ENs, availability of a skilled workforce and support after hours were common themes identified as challenges and gaps in palliative care services in Brisbane south.

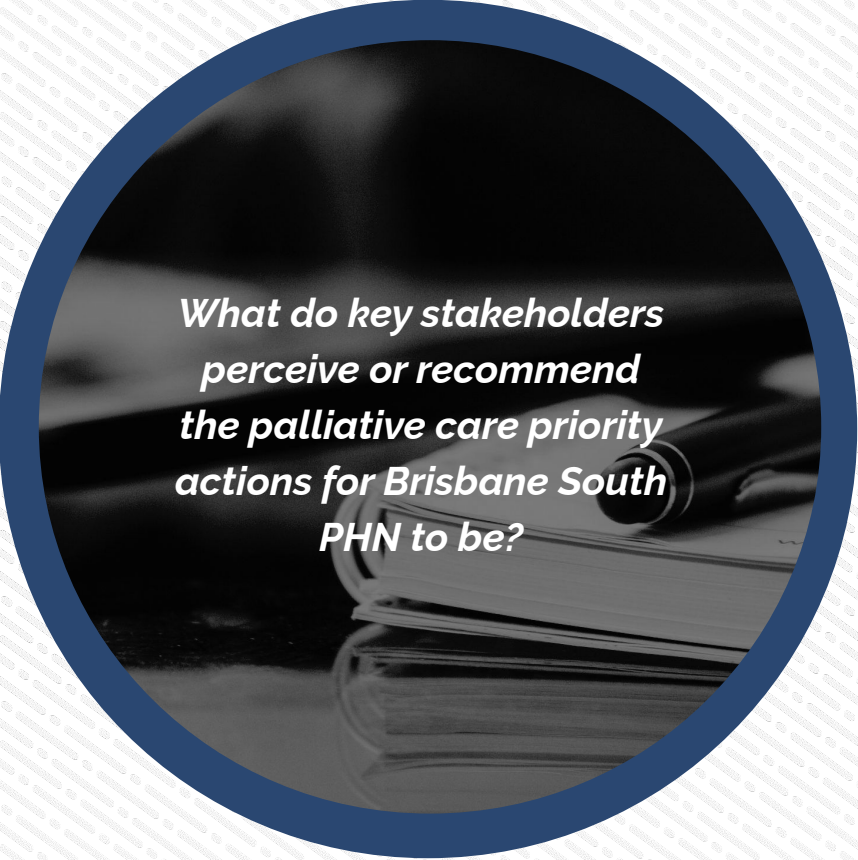
Providing education and training on Advanced Health Directives, Statement of Choices and palliative care at home or RACF for GPs and Nurses featured strongly among responses as a key role of Brisbane South PHN in improving palliative care outcomes for the region.

Among the responses, education featured strongly among the 3 highest priority actions for Brisbane South PHN. This included education for RNs, GPs, staff in RACFs and families to increase skill, capability and awareness of services.

PalliAged, ELDAC, CAREPACT and Mater MACIAE programs have all been identified successful in improving the delivery of person-centred palliative care services .

# Summary:

## Stakeholder consultation (2/2)



***What do key stakeholders  
perceive or recommend  
the palliative care priority  
actions for Brisbane South  
PHN to be?***

The responses from Specialist Palliative Care Service providers were varied and no consistent theme presented as the greeted areas of unmet needs relating to palliative care in Brisbane South.

Advanced Care Planning and availability of a skilled workforce are common themes of gaps that exist in palliative care services in Brisbane South.

Palliative care education, support for the generalist workforce and primary care providers and commissioning services and activities to improve awareness in the community were identified as a role for Brisbane South PHN in improving palliative care outcomes.

Engagement with GPs, education and training and activities to increase the uptake of Advanced Care Plans were identified as some of the highest priority actions and activities for Brisbane South PHN.

Responses from Specialist Palliative Care Services identified a number of sources of information and information to inform Brisbane South PHNs palliative care priorities including PallIPHARM, PallConsult and bereavement support groups.



# **OUR TAKEAWAYS**

# Key takeaways

*Our team has identified the following takeaways from the findings of the desktop review, that will help to inform the development of 'options' to be considered for inclusion in the PHN's 3-year Action Plan.*

There are opportunities to extend the reach of palliative care services to more people with a life-limiting illness — this means increasing both universal accessibility and ensuring equity amongst under-served populations are priorities.

There are opportunities to enable access to palliative care at an earlier phase in a person's journey and in enhancing bereavement support for loved ones — a large focus of palliative care services currently is on end-of-life care specifically (i.e. deteriorating and terminal phases).

Focus on building the capacity of generalist palliative care services to support the majority of palliative care consumers, while advocating for specialist palliative care services to be more integrated and response to people's needs.

Focus of GCfAHPC measure and PHN activities appears to be system-wide coordination and quality improvement activities, rather than direct service commissioning.

Previous palliative care portfolio activities led by Brisbane South PHN show positive outcomes, align with strategic priorities, consistent with activities undertaken by other PHNs — these can be leveraged to increase scale and extend reach under a more coordinated and organised approach with clear objectives and outcomes measurement.

Opportunities for Brisbane South PHN exist across almost all goals in the National Strategy that don't involve direct service commissioning, including:

- build capability of service providers
- ensure palliative care reflects community needs
- supporting accessibility underserved populations
- facilitating cross-sectoral collaboration
- raising awareness and capacity around advanced care planning
- contribute to evidence base
- local workforce and service planning

**DESKTOP  
REVIEW —  
DETAILED  
FINDINGS**

***What are the key strategy  
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# Summary:

## Strategic priorities (1/3)

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The National Strategy, released in 2018, is intended to guide the improvement of palliative care across Australia so that people affected by life-limiting illnesses get the care they need to live well.

The Implementation Plan for the National Palliative Care Strategy 2018 identifies four action areas with specific activities and annual monitoring of progress to achieve the goals of the Strategy.

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The Palliative Care Australia Roadmap 2022-2027 was developed in response to the growing need for palliative care services across Australia, and guides investments and initiatives to ensure everyone has access to high quality palliative care when they need it.

# Summary:

## Strategic priorities (2/3)

***What are the key strategy and policy priorities relating to palliative care services and what is the role of a PHN in delivering on this?***

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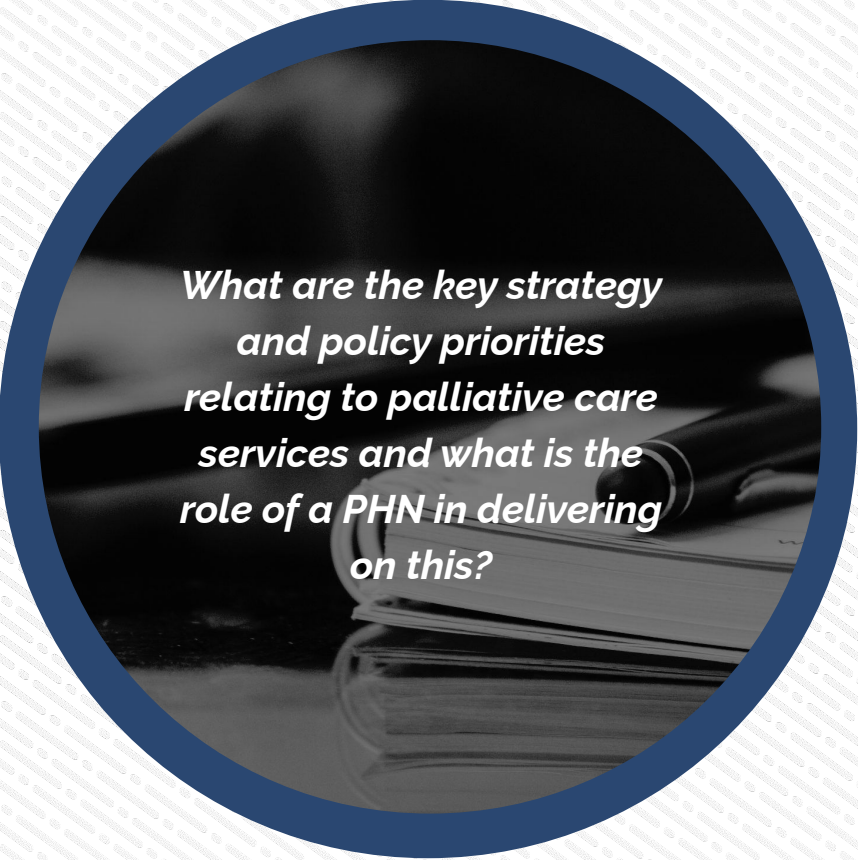
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## Strategic priorities (3/3)



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# What is Palliative Care?

*While end-of-life care is a phase of palliative care, the terms are often confused and used interchangeably. Providing a definition of palliative care is an important step to provide context for the development of the Palliative Care 3 Year Action Plan.*

*"Palliative care is 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 goal is to optimise the quality of life."*

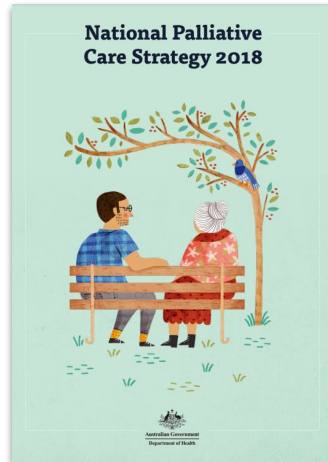
Palliative care takes a holistic approach and provides care for physical, emotional, spiritual or social symptoms. Services provided to individuals are tailored to the needs of an individual.

Palliative care is for people of any age and assists people with illnesses that are serious and cannot be cured such as cancer, motor neurone disease or lung disease.

"End-of-life care is a phase of palliative care and is the last few weeks in which a patient with a life-limiting illness is rapidly approaching death",

# National Palliative Care Strategy

*The National Strategy, released in 2018, is intended to guide the improvement of palliative care across Australia so that people affected by life-limiting illnesses get the care they need to live well.*



Palliative care is appropriate for anyone with a life-limiting illness including chronic conditions, dementia and degenerative diseases.

Many deaths in Australia each year are expected, with estimates of the proportion of people who die who could benefit from palliative care ranging from 50-90%.

Palliative care is provided through a range of healthcare settings, including general practice, neonatal and paediatric services, residential aged care, acute hospitals and generalist community services. It also includes specialist palliative care services in a variety of settings (e.g. inpatient, hospices, community-based services).

Previous focus on expanding palliative care in recent years has focused on improving ability of specialists to provide outreach into community and assisting people to remain at home for longer.

Previous Commonwealth investments in palliative care has included peak bodies, research, clinical education, benchmarking, training and resource development.

## Key principles of National Strategy:

Palliative care is person-centred care

Death is a part of life

Carers are valued and receive the care they need

Everyone has a role to play in palliative care

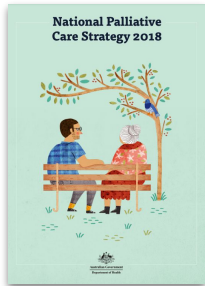
Care is high quality and evidence-based

Care is accessible — this includes number of 'under-served' population groups:

- Aboriginal and Torres Strait Islander
- culturally and linguistically diverse, particularly new migrants
- lesbian, gay, bisexual, transgender and intersex
- living with disability, including cognitive impairment such as dementia
- experiencing homelessness
- in long-term institutional care (including prison)
- ageing and frail
- living in rural and remote areas

# National Palliative Care Strategy (cont.)

*The National Strategy provides clear guidance around a set of national priority areas, such as capability, access, collaboration and investment, where regional action could lead to better palliative care outcomes.*



## Goal 1: Understanding

- service awareness and system literacy
- access to information
- advance care planning
- carer-focused information and support
- consideration of cultural beliefs and practices in palliative care

## Goal 2: Capability

- role of specialist services
- screening, assessment and early referral
- recognising clinical deterioration + dying
- evidence-based information for providers and carers
- end of life planning
- cultural capability

## Goal 3: Access and choice

- access to care in right place at right time
- person-centred approach to palliative care planning
- Access for priority populations
- use of technology
- support for carers (in-home, respite, bereavement)

## Goal 4: Collaboration

- technology and agreed pathways
- networking and communication across system
- involving people with life-limiting illnesses in services
- funding mechanisms
- collaboration with First Nations communities

## Goal 5: Investment

- responsive service delivery models
- workforce planning, development and support
- enabling technology
- expanding primary, community-based and tertiary services

## Goal 6: Data and evidence

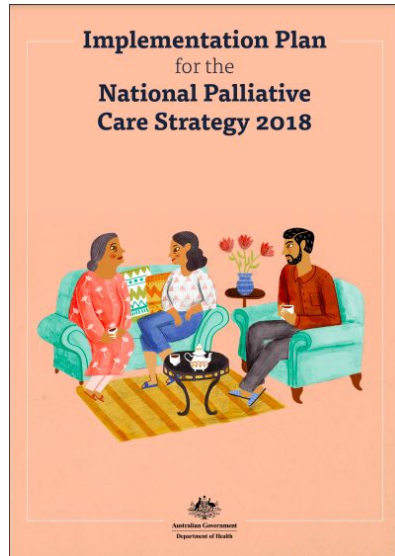
- consistent collection of data
- monitoring and reporting of activities
- continuous quality improvement
- inclusive research and evaluation activities

## Goal 7: Accountability

- governance mechanisms
- regular reporting
- consultation with consumers, carers and providers
- integration with other sectors
- including palliative care indicators within accreditation processes

# Implementation Plan for the National Palliative Care Strategy 2018

*The Implementation Plan for the National Palliative Care Strategy 2018 identifies four action areas with specific activities and annual monitoring of progress to achieve the goals of the Strategy*



The Implementation Plan has been developed to guide the National Palliative Care Strategy 2018. The implementation plan is a critical step in creating a link between the vision and priorities identified in the Strategy and activities funded to achieve the goals of the Strategy. Implementation of the Strategy is the responsibility of Commonwealth, state and territory governments.

Four national action areas have been identified to address the goals and priorities within the National Strategy. The plan provides direction for the next five years.

The Implementation Plan was developed in consultation with key jurisdictional stakeholders. Ongoing monitoring of progress will be undertaken through the completion of annual report from each jurisdiction and key data indicators are being developed for evaluation.

# Implementation Plan for the National Palliative Care Strategy 2018 (Cont.)

*Four national action areas have been identified in the Implementation Plan to provide direction for collaborative efforts that progress the priorities of the National Strategy over the next five years*

## Action area 1 -

***Access to palliative care is increased, particularly for underserved populations***

- Build understanding and capability of service providers
- Delivery of palliative care aligned with community needs
- Supporting underserved populations to access care when and where it is needed

## Action area 3

***Advance care plans are being prepared by people affected by life-limiting illness and used to facilitate shared decision-making across care settings***

- Awareness raising of advanced care plans that will involve people in decisions about their care
- Capacity and capability building for the sector and service providers

## Action area 2

***The collaboration and coordination of palliative care is improved***

- Improving cross-sectoral collaboration through
  - Service models
  - Patient data sharing across care settings
  - Building capacity of service providers with support of specialist palliative care services

## Action area 4

***Nationally consistent data collection mechanisms are implemented and national public reporting is underway***

- Improve the quality of the national evidence base
- Inform national research by identifying gaps in evidence and data
- Inform workforce and service planning

# Palliative Care Australia Roadmap 2022-2027

*The Palliative Care Australia Roadmap 2022-2027 was developed in response to the growing need for palliative care services across Australia, and guides investments and initiatives to ensure everyone has access to high quality palliative care when they need it*

The Palliative Care Australia Roadmap 2022-2027 sets the direction to ensure access to high quality palliative care for all who need it. The Roadmap sets out guidance of investment and initiatives needed in palliative care over the next 5 years. Palliative Care Australia have developed the Roadmap in response to the increasing need for palliative care in Australia.



## The Roadmap addresses key areas for prioritisation:

1. Investment to grow the sector through government funding
2. Increasing capability and capacity of the workforce
3. Making palliative care core business for aged care facilities
4. Building an evidence base through data and research
5. Supporting carers in their role
6. Fully funding the Paediatric Palliative Care Action Plan
7. Strategies to raise awareness about palliative care



# Palliative Care Australia Roadmap 2022-2027 (Cont.)

*The Palliative Care Australia Roadmap outlines key focus areas, solutions and issues that need addressing in Palliative Care Services*

Roadmap	Solution	Issues to address
<b>Investment</b>	Government funding to increase capability, capacity and evidence base of the palliative care sector	<ul style="list-style-type: none"> <li>• Access to high quality palliative care with a skilled workforce</li> <li>• Carers providing care for those with life-limiting illness</li> <li>• Understanding/comfort talking about death and dying</li> <li>• Data and research about palliative care</li> </ul>
<b>Aged Care</b>	Delivering quality palliative care in aged care facilities	<ul style="list-style-type: none"> <li>• Access to palliative care in aged care</li> <li>• Training and skills of workforce and funding of services</li> </ul>
<b>Medicines</b>	Increased investment of pharmacology in palliative care	<ul style="list-style-type: none"> <li>• Access to palliative care medication</li> <li>• Training of workforce in palliative care medicine</li> </ul>
<b>Grief and Bereavement</b>	Establish suitable and appropriate standards for grief and bereavement	<ul style="list-style-type: none"> <li>• Access to appropriate grief and bereavement support</li> <li>• Workforce not required to provide grief and bereavement support</li> </ul>
<b>Aboriginal and Torres Strait Islander Palliative Care</b>	Culturally appropriate models of care for Aboriginal and Torres Strait Islander People	<ul style="list-style-type: none"> <li>• Access to culturally appropriate and trauma informed palliative care</li> <li>• Appropriate training of workforce</li> </ul>

# Palliative and End-of-Life Care Strategy

*The Palliative and End-of-Life Care Strategy is being developed in response to the commitment of additional funding from the Queensland Government to lead reform in palliative care for 2021/22-2025/26*

## Palliative and End-of-Life Care Strategy



The Strategy builds on previous reform and guides the delivery of compassionate high quality palliative care that meets individuals needs, preferences and goals at the end of life. The Strategy is supported by the development of a Queensland Health Specialist Palliative Care Workforce Plan to increase capacity and capability of frontline workers.

Developed through a co-design process with stakeholders, seven key principles guide and are reflected in program and policy design and the delivery of palliative care in Queensland.

1. Person-centred, compassionate, culturally/spiritually safe care
2. High-quality and evidence-based care
3. Equitable and accessible
4. Individuals and their families are supported through to grief and bereavement
5. Holistic and integrated care
6. Individuals receive support for informed-decision making
7. Life-limiting illness, dying, death, grief and bereavement care are recognised as a normal part of life

The final Strategy is due for release mid-2022

### Goals

Seven goals have been identified as ideal outcomes of the Strategy:

1. Governance
2. Access to quality services
3. Information about care
4. Individual needs and preferences
5. Support for families and carers
6. Skilled workforce
7. Data and research

Action areas will support the goals allowing the measuring, monitoring and tracking of progress of the Strategy.

# Specialist Palliative Care Workforce Plan

*Queensland Health's Specialist Palliative Care Workforce Plan is being developed to support the Palliative and End-of-Life Care Strategy to build the capability and capacity of the frontline specialist palliative care workforce.*

Additional reform funding from Queensland Government includes investment in the growth of the specialist palliative care workforce. The Queensland Health Specialist Palliative Care Workforce Plan is a supporting document of the Palliative and End-of-Life Care Strategy (2021/22-2025/26). The plan outlines the sustainable approach to increasing the capability and capacity of the specialist palliative care workforce. The final Workforce Plan is due for release mid-2022

Four focus areas will be form part of the Specialist Palliative Care Workforce Plan.

**1** **Designing the workforce**  
The workforce is designed to respond to current and future workforce models

**2** **Enabling the workforce**  
Sustainability of the workforce is achieved through increased training, practice and integrated services

**3** **Strengthening the workforce**  
Deliver pathways for education and clinical practice

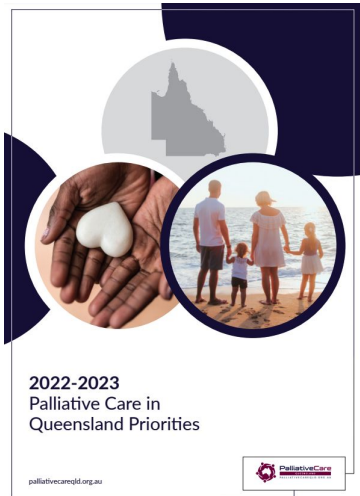
**4** **Keeping the workforce connected**  
Increase cross-sector collaboration



# 2022-23 Palliative Care in Queensland Priorities

*Palliative Care in Queensland Priorities outlines six priority strategies and policy actions that provide direction for the transformation of Palliative Care services in Queensland for 2022-23 – focusing on workforce, funding, holistic and inclusive care, accessibility, community engagement and innovation.*

Through an annual summit, Palliative Care Queensland bring together stakeholders that hold an interest and expertise in Palliative Care. Collaboration amongst stakeholders contributes to the development of a tool to identify sector priorities, strategies, policies and actions for Palliative Care in Queensland in the following year. The priorities 2022-23 include:



**Priority 1 - Workforce**  
Sustainability and capacity of the workforce

**Priority 2 - Sector Funding**  
Increase investment in palliative care to support equitable access

**Priority 3 - Holistic and Inclusive Care**  
Enhance capability and capacity of sector to provide holistic care and meets the needs of underserved populations

**Priority 4 - Remote, Rural and Regional Access**  
Implement strategies such as models of care and integration to increase access and equity

**Priority 5 - Community Engagement**  
Increase community awareness

**Priority 6 - Innovation and Research**  
Improve data and evidence-base of the palliative care sector

# 2022-23 Palliative Care In Queensland Priorities (cont.)

*Palliative Care Queensland identifies 'Hot Topic Key Improvement Areas' annually based on consultations with key stakeholders. Six Hot Topic Key Improvement Areas were identified for 2022-23 and provide guidance for individuals, organisations and policy makers*



Through consultations conducted during 2021-22 with Palliative Care Queensland Members and the Palliative Care sector more broadly, key areas of interests were identified and formed as Hot Topic Key Improvement Areas.

The Key Improvement Areas provide guidance for individuals, organisations and policy makers working in the relevant areas.

## **The 2022-23 Hot Topic Key Improvement Areas**

1. Specialist Palliative Care
2. Generalist Palliative Care
3. Public Health Palliative Care
4. Palliative Care for First Nations people
5. Palliative Care for people living in regional, rural and remote areas
6. Palliative Care for people experiencing homelessness

# Exploratory Analysis of Barriers to Palliative Care

*Developed for the DoH, an Exploratory Analysis of Barriers to Palliative Care provides insight into barriers to quality palliative care for consumers and services, enablers for facilitating appropriate palliative care (including workforce, networks, funding and research) and recommendations for the sector.*

The exploratory analysis identifies the barriers and enablers to accessing quality palliative care and recommendations for the palliative care sector people for people from underserved populations or people with complex needs. Nine under-served populations were identified and are characterised by significant diversity.

## Four key enablers for facilitating appropriate palliative care

1. Networks, partnerships and collaborations
2. Workforce development
3. Financial support and resourcing
4. Research, evaluation and monitoring

## Recommendations

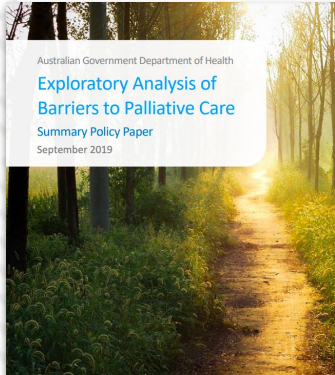
- Raise awareness and normalise conversations in communities about palliative care and end-of-life
- Implement strategies to initiate of palliative care early
- Improve understanding of under-served population and deliver person-centred care
- Provide individuals and families with information to support informed decision making
- Further embed Advanced Care Planning into the sector

## Barriers to accessing quality palliative care - consumer

- Discomfort discussing death and dying
- End-of-life literacy and awareness
- Mistrust and fear in healthcare services
- History of trauma
- social/family breakdown
- Delayed diagnosis/presentation
- Language, communication and cultural misalignment

## Barriers to accessing quality palliative care - service

- Cultural awareness/competency
- Workforce capability
- Service availability to meet the needs of individuals
- Referral process
- Language, communication and cultural misalignment
- Funding



# Greater Choices for At Home Palliative Care Measure

*Following a trial of the GCfAHPC in 11 PHNs, the Commonwealth Department of Health have extended to funding to all Australian PHNs to coordinate and improve palliative care and delivers on the National Palliative Care Strategy.*

From 1st July 2021, all Australian PHNs received funding from the Commonwealth Department of Health to implement the Greater Choices for At Home Palliative Care Measure.

The aim of the initiative is to coordinate and improve palliative care through PHNs and supporting people's preference to be cared for and dying at home.

Funding PHNs to deliver the GCfAHPC Measure aligns with the National Palliative Care Strategy which identifies PHNs as having a role in implementing the strategy to provide care at home and locally.

Goal of the GCfAHPC Measure:

- Improve access to in home palliative care
- Support palliative care in primary and community care settings
- Reducing unnecessary hospital presentations
- Collect and use data to inform service design and delivery
- Provide flexible and responsive care through technology



# Paediatric Palliative Care National Action Plan Project

*The Paediatric Palliative Care National Action Plan project aims to enhance the delivery of palliative care to infants, children and young people. Since 2020, the project has delivered a Literature Review and Paediatric Palliative Care Conference.*

Palliative Care Australia is working with Paediatric Palliative Care Australia and New Zealand to deliver the Paediatric Palliative Care National Action Plan project. The project has been funded by the Australian Government and is a three year project that commenced in 2020.


The project will support parents, carers and health professionals who are supporting the specialist needs of children that are living with life limiting conditions.

The project objectives are:

- Increase knowledge of gaps in paediatric palliative care services
- Identify areas where paediatric palliative care services are needed
- Improve information and support for parents and children
- Coordinating a national approach to enhance practical assistance to children

The project addresses key activities including:

- Develop the National Paediatric Palliative Care Action Plan
- Developing paediatric palliative care data
- Education including webinars for parents and health professionals
- Developing a paediatric palliative care website to host resources for parents and health professionals



***What is the operational environment of palliative care in Brisbane South and what palliative care programs and services have Brisbane South PHN commissioned?***

## Summary:

### Operational environment (1/2)

The Current State Report highlights a number of current/previous activities that Brisbane South PHN have led under the Palliative Care portfolio.


The regional older person's strategy highlights joint actions relating to palliative care around strategic planning, (re)designing models of care, uptake of advance care planning, bereavement support, workforce development and compassionate communities.

The Brisbane South Aged Care Workforce Strategy outlines key priorities for developing a capable aged care workforce that delivers services across the ageing journey, including palliative care.

The Aged Care Workforce Baseline Report identified several issues relating to palliative care in Brisbane South, including inadequate knowledge and training for aged care workers, earlier discussions and access to palliative care approaches, and challenges with integration between services.

Brisbane South PHN's Activity Work Plan for holistic palliative care and end of life aims to improve consumer outcomes and experiences and increase efficiency of care provided through place-based approaches and models of care designed with consumers.

Brisbane South PHN's strategy for the Greater Choice for At Home Palliative Centred around supporting communities and health professionals to increase awareness of and deliver high quality and culturally appropriate palliative care.



***What is the operational environment of palliative care in Brisbane South and what palliative care programs and services have Brisbane South PHN commissioned?***

## Summary:

### Operational environment (2/2)

The Department of Health Evaluation of the GCfAHPC concluded that Brisbane South PHNs At Home Palliative Care project achieved positive results for interim outputs and medium-term outcomes of workforce capability and clinical management and identified a number of system level barriers for project delivery.

Metro South Health produced the The GCfAHPC Final Project Report which highlights the successful project outcomes achieved by Brisbane South PHN in improving end-of-life palliative care delivery in participating general practices.

Pallchat Brisbane South Project was delivered from 2020-2022 and achieved positive results against the five expected outcomes identified in the project theory of change.

Pallchat internal activity reflection provides a summary of the lessons learned and recommendations for the future around project establishment, delivery methods and marketing strategies.

The Improving End-of-Life Care for Residential Aged Care Facility Residents Report highlights the outcomes achieved by the Initiative in Residential Aged Care Facilities under phase 3 of the initiative.

Evaluation of the Improving End-of-Life Care for Residential Aged Care Facility Residents Initiative identified a series of recommendations to guide ongoing collaboration between Brisbane South PHN, Metro South Palliative Care Service and RACF's.

# Current State Report: Palliative care in Brisbane South

*The Current State Report highlights a number of current/previous activities that Brisbane South PHN have led under the Palliative Care portfolio*



[initially 2017 to mid-2021; since extended for additional 4 years]

- Practice Nurse Enhancement Program
- Capacity Building Calendar

# Older People's Health and Wellness Strategy

*The regional older person's strategy highlights joint actions relating to palliative care around strategic planning, (re)designing models of care, uptake of advance care planning, bereavement support, workforce development and compassionate communities.*



The *Brisbane South Older People's Health and Wellness Strategy 2019-2024* aims for 'older people in the Brisbane south region to experience a greater quality of life through safe connected and coordinated person centred health care in an age friendly community'.

Older people represent a significant proportion of the target population for access to palliative care and end-of-life care specifically in Brisbane South.

Health service challenges for older people that relate to palliative care include:

- system fragmentation
- complexity of older people's health and social needs
- health / aged care workforce capability & capacity
- societal considerations (e.g. ageism, elder abuse/control, equity and vulnerability)
- service pressures & increasing demand for care

Enablers of the Strategy include technology, workforce, governance and partnerships, clinical leadership, financial sustainability and change management

## Relevant 'high impact' actions outlined in the Strategy:

Engage and ensure **strategic alignment** across existing End of Life service plans [1.1.4]

Increase **choices for consumers** as to where they die [1.2.2]

Working with GPs to embed **ACP conversations** during health checks particularly on diagnosis of a chronic or life limiting illness [1.3.3]

Address gaps in the provision of older people's services and explore **better value models** for palliative care [2.1.3]

Include **palliative care representation** in a cross-sectoral older people's health and wellbeing leadership group [2.1.4]

Enhance family and carer education, information and support for their own **bereavement** requirements [2.1.6]

Increase the capacity and confidence of the primary care **workforce** to deliver high quality end-of-life services (including better use of relevant Medicare items) [2.3.2]

Explore the utility and application of **compassionate communities** for palliative and end-of-life consumers [4.1.2]

# Aged Care Workforce Strategy

*The Brisbane South Aged Care Workforce Strategy outlines key priorities for developing a capable aged care workforce that delivers services across the ageing journey, including palliative care.*



- The *Aged Care Workforce Strategy* aims to develop a regional approach to creating a capable aged care workforce in the region.
- Workforce development is a combination of efforts to attract and retain the right people, support people to work top of scope, and implementation of models that best utilise the current workforce across care settings to meet people's diverse needs
- The aged care workforce includes all touch points across a consumers ageing journey.

## Identified priorities:

1. Increasing the capacity and capability of primary care
2. Improving the interface between care settings
3. Upskilling RACF and in-home care workforce
4. Attracting and rewarding GPs
5. Improving gerontic content in clinical training pathways
6. Attracting skilled clinicians in geriatric medicine in both hospital and community settings

**Action 1.2:** *Develop training and support materials for staff working in the primary care setting to deliver palliative and end-of-life care that supports people to die at their place of choosing and support loved ones with grief, loss and bereavement.*

## Identified workforce challenges and opportunities:

- Demand for services exceeds workforce growth
- Anticipated increase in demand for end-of-life services in primary care. High quality end of life services in the primary care setting and with well defined, coordinated pathways and integration between community and hospital settings considered critical.
- Fragmented service delivery across settings prevents people from receiving the right care, in the right place and at the right time



# Aged Care Workforce Baseline Report 2020

*The Aged Care Workforce Baseline Report identified several issues relating to palliative care in Brisbane South, including inadequate knowledge and training for aged care workers, earlier discussions and access to palliative care approaches, and challenges with integration between services.*



Brisbane South PHN's Aged Care Workforce Baseline report describes the baseline of the Aged Care Workforce Strategy objectives and provide a current state overview of the workforce in Brisbane south.

The report is designed to guide the monitoring and evaluation of the objectives outlined in the Aged Care Workforce Strategy and provide performance indicators that will monitor output and outcomes of activities.

## **Objective 1 - A workforce with a mix of skills, competencies, backgrounds and with reach across the region**

- Growth and sustainability of workforce
- Delivery of professional development and training
- Demand and need based workforce distribution
- Workforce skill meets the needs of older people

*"Concerns have been raised with industry entrants lacking skills and inadequate theoretical and practical training courses in areas such as palliative care".*

## **Objective 2 - A workforce of people who are passionate, confident and rewarded in providing care for older people**

- Provider experience of aged care sector
- Patient reported experience measures
- Integrated models of care



# Aged Care Workforce Baseline Report 2020 (cont.)

*The Aged Care Workforce Baseline Report identified several issues relating to palliative care in Brisbane South, including inadequate knowledge and training for aged care workers, earlier discussions and access to palliative care approaches, and challenges with integration between services.*

## **Objective 3 - A workforce that provides the right care, in the right place, at the right time, for older people**

- Care delivered by a capable aged care and primary care workforce keeping people well and out of hospital
- Uptake in models of care that are multidisciplinary and coordinated

*“There is a need to re-orientate services towards more ‘upstream’ models of care that focus on...early conversations about palliative and end-of-life approaches to care when appropriate.”*

## **Objective 4 - A workforce that is underpinned by a culture of cross-sectoral, collaborative partnership**

- Integration of care to deliver efficient and effective services and increase patient experience
- Increased use of technology and digital health initiatives as a driver of communication and coordination of care

*“Interactions between services, including palliative care services reported challenges in mixed workforce roles and setting, process inconsistencies and cross sector funding.”*

# BSPHN - Activity Work Plan

*Brisbane South PHN's Activity Work Plan for holistic palliative care and end of life aims to improve consumer outcomes and experiences and increase efficiency of care provided through place-based approaches and models of care designed with consumers.*

Sets out priorities and describes activities relating to holistic palliative and end of life care options. Aims of the activity include:

- improving QOL for older people and other identified priority groups (50 years and older and vulnerable groups) during end of life and increase their choice of place to die.
- supporting carers/families to provide high quality end of life care
- increasing Advance Care Planning adoption
- contributing to the evidence base to support cost effectiveness of supporting at home palliative care

## Identified needs

- improved awareness, provision and uptake of palliative care in Brisbane South
- palliative care that reflects individual needs and choices
- managing care in community settings
- access to respite and carer support
- enhanced service navigation of health and social services

## How it will be delivered

- partnerships and a placed based commissioning process
- commissioning new or modified services to increase options for people in (or close to) their homes. This includes social, emotional, functional, respite and clinical options
- innovative models of care informed by older people, carers and their families

# Brisbane South PHN Greater Choice for At Home Palliative Care - Activity Work Plan

*Brisbane South PHN's strategy for the Greater Choice for At Home Palliative Centred around supporting communities and health professionals to increase awareness of and deliver high quality and culturally appropriate palliative care*

The Department of Health funded 11 PHNs across Australia for The Greater Choice for At Home Palliative Care initiative (GCfAHPC). GCfAHPC aims to support an increase in the delivery of high quality and safe palliative care at home and support of end-of-life services to reduce hospitalisations and provide care in the place of choice.

Brisbane South PHN was funded to deliver the GCfAHPC and centred their strategies around culturally and linguistically diverse and refugee communities. Brisbane South PHNs approach aimed to achieve the following outcomes:

- Increase the knowledge of and access to palliative care services and support for culturally and linguistically diverse communities
- Increase health professional competency to deliver culturally appropriate evidence-based palliative and end-of-life care
- Develop care pathways to support connection and coordination across the health system

# Greater Choice for At Home Palliative Care Summary report

*Under the GCfAHPC Measure, Brisbane South PHN had initially proposed a GP Shared Care model, the Department of Health Evaluation identified that this model was redesigned to a General Practice Nurse Enhancement model of care following consultation*

The Department of Health launched The Greater Choice for At Home Palliative Care Measure in 2017 to support an individual's preference to die at home. Funding was provided to 11 PHNs across Australia, Brisbane South PHN was successful in their expression of interest to participate in the pilot.

Brisbane South PHN commissioned Metro South Palliative Care Service to develop a model of care and tool for general practices that supported the delivery of best-practice and person-centred palliative care. Two part-time Palliative Care Clinical Nurse Consultants were recruited to deliver mentoring activities to 9 practices in Brisbane south. A project steering group was established to provide guidance throughout the project.

## Activities delivered by Brisbane South PHN included:



### Mentoring

Mentoring for practice nurses including coaching, face to face education and linkage to relevant resources on topics such as advanced care planning.



### QI Toolkit

Development of a general practice palliative care Quality Improvement Toolkit to implement and enhance practice processes around referrals, MBS items and practice data cleansing.



### Education

Education sessions delivered by health professionals across the region who are experienced in palliative care to increase general knowledge across the region.

# Brisbane South - At Home Palliative Care (Cont.)

*The Department of Health Evaluation of the GCfAHPC concluded that Brisbane South PHN's At Home Palliative Care project achieved positive results for interim outputs and medium-term outcomes of workforce capability and clinical management and identified a number of system level barriers for project delivery*

Outcomes of Brisbane South PHN At Home Palliative Care project include:



## **Project enablers**

- Establishing and managing productive relationships with participating general practices

## **Project barriers**

- System level factors including disparity between clinical time required and MBS item remuneration
- COVID-19

## **Considerations for broader roll-out**

- Embedding advanced care planning discussions into 75+ year health checks and chronic disease management plans identified as a sustainable change
- General practice participation the pilot project was based on interest in palliative care and should be considered for scalability
- General practices with high a population of culturally and linguistically diverse patients may require a tailored approach

# Final Report - Greater Choice for At Home Palliative Care Project Phase 2

*Metro South Health produced the The GCfAHPC Final Project Report which highlights the successful project outcomes achieved by Brisbane South PHN in improving end-of-life palliative care delivery in participating general practices*

A series of evaluation activities were conducted for Brisbane South PHNs GCfAHPC project activities. The methods of evaluation included a review of after death audits, post project surveys, practice data collection, ACP document data, Metro South Palliative Care Service referral data and education session data.

## Reported Project Outcomes

Evaluation of Phase 2 of the GCfAHPC project demonstrated the following outcomes:

- 9 general practices were recruited to participate in the project and 8 practice successfully completed their participation
- Increase in skill of general practices to recognise deterioration and dying in patients
- Increase in knowledge, skills and confidence in providing end-of-life care of participating practice staff
- 8 out of 9 participating practices were supported by a palliative care support pharmacy within their geographical area
- Increase in ACP conversations completed in participating practices
- An upward trend in completion and upload of ACP documents
- Decrease in discussions around medicals goals of treatment as a result of COVID-19 impacting practice nurse staffing
- ACP discussions linked in with the delivery of all primary health care by all participating staff

## Project limitations

- Not all practices who participated were suitable for the project as they do not offer home visits
- The population base of one participating practice did not meet the target population of the project
- Data governance, software limitations and data cleansing/coding for practices



# Pallichat Brisbane South Project Report 2020-2022

*Pallichat Brisbane South Project was delivered from 2020-2022 and achieved positive results against the five expected outcomes identified in the project theory of change*



Pallichat Brisbane South was commissioned by Brisbane South PHN from April 2020 until March 2022.

The project delivered a series of activities that aimed to create compassionate communities through facilitating group and individual support conversations, community education and increasing connections through networking and community events.

The Pallichat project used a theory of change model to identify five expected outcomes which were monitored and measured throughout the delivery of the project. These include:

1. Awareness of support and services available
2. Confidence to discuss illness, dying, death or grief
3. Ability of community members to help others at end-of-life
4. Awareness and understanding of palliative care
5. Knowledge that reality of death is an important part of life

Data collection throughout the project was supported by a project feedback framework underpinned by the Healthy End of Life Program tools. Program feedback and measures demonstrated an increase across all five identified outcomes.

# Pallichat - PCQ Internal Activity Reflection

*Pallichat internal activity reflection provides a summary of the lessons learned and recommendations for the future around project establishment, delivery methods and marketing strategies*

PalliChat Brisbane South was commissioned by Brisbane South PHN, launched in July 2020 and ended in March 2022. The project achieved an increase across the five expected outcomes with particular success through networking, group engagement and kitchen table discussions.

All staff involved in the project were invited to share their reflections of the project, provide feedback throughout the project and participate in survey evaluation of different aspects of the project. The internal review identified what worked and didn't work across phases of the project and provides recommendations for the future.

## What worked?

- Kitchen table discussions
- Stakeholder interviews for project establishment
- Theory of change model to inform evaluation
- Group Circles of Care Mapping
- Face to face activities
- Hosting in community venues
- Last Aid, PalliNavigator and sector webinars
- Branding, social media marketing and E-News
- Consumer advocates for marketing

## What didn't work?

- Complex and high level evaluation framework
- Phone support line
- Virtual chats and online networks
- Expectations of success measures
- Misunderstanding of project by aged care
- Designated project website
- Promotional flyers
- Staff changes and role challenges
- COVID

## Key recommendations

- Use Stakeholder interviews and kitchen table discussions for project development
- Theory of change model for evaluation
- Key search terms for local database for service mapping
- Success measure of quality rather than quantity
- Deliver sessions through face to face methods and in groups
- PalliLearn Basic and Intensives are good flexible models
- Include education and keynote speakers at network activities
- Share network member contacts
- Promote the project through consumers
- Adapt project to community need
- Adequate staffing and plan for new staff induction
- Plan for COVID interruptions
- Collect project feedback through mixed methods

# Improving End-of-Life Care for Residential Aged Care Facility Residents Initiative

*The Improving End-of-Life Care for Residential Aged Care Facility Residents Report highlights the outcomes achieved by the Initiative in Residential Aged Care Facilities under phase 3 of the initiative*

Brisbane South PHN and Metro South Palliative Care Service (MSPCS) have been collaborating with RACFs in Brisbane south through a series of initiatives aimed to improve end-of-life care. Phase 3 is a third collaborative initiative delivered by Brisbane South PHN commissioning MSPCS to implement the activities over an 18 month period. The initiative supported participating RACFs to embed best practice end-of-life care and increase capacity to provide quality end-of-life care.

Activities delivered through phase 3 of the initiative included:

- **Facility Managers** - resources with reference to the New Aged Care Quality standard and academic detailing for facility managers were developed
- **Clinical provider** - conferences and online education on quality end of life care and ACP and a mentorship

## Outcomes

### Improved capacity of RACF to provide quality end of life care

- All RACFs implemented aspects of the quality of end-of-life model

### Improved outcomes of RACF nurses to provide quality end-of-life care

- Subjective improvements in capacity and perceived skills in providing end-of-life care
- Increase in knowledge of the MSH Framework for End-of-Life Care and areas of ACP, symptom management and criteria to commence an end-of-life care pathway
- No impact on RACF nurses confidence in end-of-life communications

### Improved resident end-of-life care outcomes

- Increase in the number of residents who were able to be cared for and die in their place of choice - an indicator of best-practice palliative care
- Decreased request for hospital transfer indicating an increase in confidence and experience provided by RACF




# Improving End-of-Life Care for Residential Aged Care Facility Residents Initiative (Cont.)

*Evaluation of the Improving End-of-Life Care for Residential Aged Care Facility Residents Initiative identified a series of recommendations to guide ongoing collaboration between Brisbane South PHN, Metro South Palliative Care Service and RACFs*

## **Recommendations**

Recommendations based on the findings from phase 3 of the initiative include:

- BSPHN and MSPCS structure interventions that enhance the translation of best end-of-life practice into clinical care to promote sustainable high quality end-of-life care for residents of RACFs
- Exploration of funding for Specialist Palliative Care Clinical Nurse Consultants to embed the nurse mentorship programme into all RACFs in Brisbane south
- Explore RACF resident-preferred outcomes at end of life and increase documentation of advanced care plans
- BSPHN commission an in-depth study across RACFs to:
  - Implement palliative care case conferencing
  - Increase utilisation of terminal care plans
- Continue growth of [www.pallConsult.com.au](http://www.pallConsult.com.au) website



***What are the palliative care needs of individuals, families and carers?***

## Summary: Service needs (1/2)

Over 6,200 people die in the Brisbane South region each year, with the majority of these deaths due to chronic, life-limiting conditions where the person would likely have benefited from access to palliative care.

There are generally considered to be 5 phases of palliative care for people with a life-limiting illness, with most of the focus being at the end-of-life rather than starting when the person is 'stable.'

Previous work done by BSPHN highlights the unmet need for people with life-limiting illnesses to access palliative care, and issues relating to the availability, accessibility or effectiveness of services to meet the needs of people and their families/carers.

The palliative care service system in Brisbane South involves both specialist and generalist palliative care services delivering across a range of settings, with leading models of care requiring the involvement and integration of all of these in a way that promotes choice and equity of access.

The Kitchen Table Discussion Report identified knowledge and information on services and access to health professionals as palliative care needs for consumers from Culturally and Linguistically Diverse backgrounds in Brisbane south.



***What are the palliative care needs of individuals, families and carers?***

## Summary: Service needs (2/2)

The Death Literacy Index is a tool that has a means to measure the death literacy of a population or communities and provide insight into the impact of palliative care initiatives.

Implementation of the DLI demonstrates that the death literacy of the Australian population is by learning from experience and talking about death and dying. There is a low knowledge and confidence of the system and information needed to plan for dying, death and caregiving.

The DLI of the Brisbane south population is comparable to the Australian population. Generally across Brisbane south there is a need for activities that aim to increase the knowledge of the population about end-of-life with low scores for knowledge and personal experience the main source of information about death and dying.

In response to the reduced access to bereavement care during to COVID-19, Palliative Care Queensland consulted with stakeholders to identify five recommendations that provide direction for the sector.

In response to declining Advance Care Planning activity across Queensland, a statewide survey was conducted and identified confidence and awareness of clinicians and patients as barriers and enablers to Advanced Care Planning.

# Mortality in Brisbane South

*Over 6,200 people die in the Brisbane South region each year, with the majority of these deaths due to chronic, life-limiting conditions where the person would likely have benefited from access to palliative care.*

**6,285**

average annual number of total deaths in BSPHN region over 5-year period 2016-2020

**80.6**

years is the median age at death for people in BSPHN region (2020)

**17**

of top 20 causes of death in BSPHN region relate to chronic conditions such as cancer, dementia, heart disease, diabetes (about 60% of all deaths)

Top 10 causes of death	No. of deaths	% of all causes
Coronary heart disease	4,049	12.9
Dementia including Alzheimer's disease	2,791	8.9
Cerebrovascular disease	2,050	6.5
Lung cancer	1,754	5.6
Chronic obstructive pulmonary disease (COPD)	1,280	4.1
Colorectal cancer	1,089	3.5
Diabetes	926	2.9
Suicide	774	2.5
Prostate cancer	714	2.3
Breast cancer	632	2.0



# Phases of palliative care

*There are generally considered to be 5 phases of palliative care for people with a life-limiting illness, with most of the focus being at the end-of-life rather than starting when the person is 'stable.'*

## Stable

Patient problems and symptoms are adequately controlled by an established plan of care

AND

further interventions to maintain symptom control and quality of life have been planned

AND

Family & carer situation is relatively stable, and no new issues are apparent

## Unstable

An urgent change in the plan of care or emergency treatment is required as

- the patient experiences a new problem that was not anticipated
- the patient experiences a rapid increase in the severity of a current problem
- the circumstances of the patient's family/carer(s) change suddenly, impacting on patient care

## Deteriorating

The care plan is addressing anticipated needs but requires periodic review because

- the patient's overall functional status is declining
- the patient has a gradual worsening of existing problem and/or a new but anticipated problem
- the carer(s)/family undergo(es) gradually worsening distress that impacts on the patient's care

## Terminal

Death is likely within days.

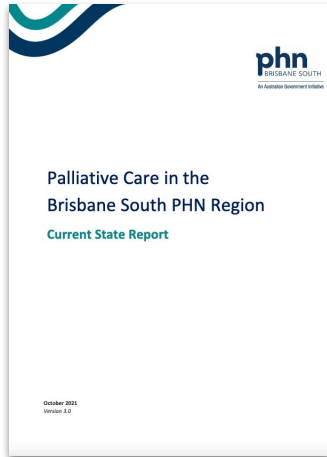
Change in focus of plan of care to ensure physical, psychological and spiritual comfort care, with provision of anticipatory end of life medications.

## Bereavement

The patient has died  
Bereavement support provided to family/carers.

# Current state report: Palliative care in Brisbane South

*Previous work done by BSPHN highlights the unmet need for people with life-limiting illnesses to access palliative care, and issues relating to the availability, accessibility or effectiveness of services to meet the needs of people and their families/carers.*



## Community needs

There is evidence of much unmet need in Brisbane South with demand for palliative care rising due to ageing population and more people dying after prolonged periods with chronic disease than short trajectory or unexpected deaths.

Challenges to estimate demand for palliative care services but the following provides an indication:

- prevalence of chronic and life-limiting conditions
- incidence of mortality to selected causes such as chronic disease cancer, dementia

While 7 in 10 Australians indicate they would prefer to die, most won't — about 50% die in hospital, 30% in RACFs and only 15% at home.

Death Literacy Index research suggests Brisbane South requires significant improvement in all areas, although results are generally better than the national average.

## Service delivery issues

Palliative care has been shown to be well provided in some regions of Brisbane South but on a small scale.

Despite many workforce capability-building opportunities being freely available, awareness, confidence and knowledge relating to palliative care remains low.

Statewide and local consultation suggests people's palliative care needs are not being met consistently or in a holistic way.

Issues relating to accessibility and availability include:

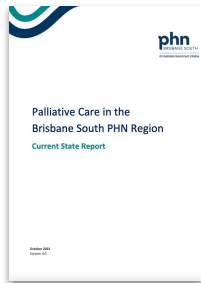
- services not being available and limited places
- patients not being identified and referred to available services early or at all
- services driving urgent, reactive care rather than coordinated, proactive care
- having to wait and be delayed to access service
- having to access services in a setting not of their choice

Issues with coordination, integration and quality include:

- awareness and navigation
- poor communication with patient, family and providers
- limited information-sharing between settings
- breakdown in transitioning care between settings
- lack of shared care planning.

# Current state report: Palliative care in Brisbane South

*The palliative care service system in Brisbane South involves both specialist and generalist palliative care services delivering across a range of settings, with leading models of care requiring the involvement and integration of all of these in a way that promotes choice and equity of access.*



## Current service system

Palliative care services are delivered by a mix of:

- Specialist palliative care providers — physicians and nurses with postgrad quals in palliative care and clinical experience *[there are two specialist providers in the region (Metro South & St Vincent's Private)]*
- Non-specialist or generalist providers — GPs, other specialists, nursing, allied health, support workers, carers and volunteers

Palliative care is delivered in a mix of settings — at home, in hospital, hospice, RACF or institutional setting — with varying models of care.

Palliative care incorporates advice, care coordination, nursing and personal care, respite, emotional support, equipment access and carer/support

Specialist services are intended to focus on patients with complex issues. Hospitalisation is often the only option due to a lack of community-based options in Brisbane South.

Palliative services in Brisbane South are guided by HealthPathways and the Metro South Health End of Life framework.

Uptake of advance care planning is an important aspect of palliative care outcomes.

## Leading / emerging models of care

- Upskill community personal care workers to empower local communities
- Local older persons activist group-community support
- Nurse-led clinic for symptom management with community health workers for support
- Mobile clinic with local support workers helping to connect remote patients to get access to care
- Specialist hospital with outpatient clinic
- Hospice with both inpatient and community services
- Palliative program integrated into primary care covered within universal health coverage.

# Kitchen Table Discussion Report - Palliative Care in Brisbane South

*The Kitchen Table Discussion Report identified knowledge and information on services and access to health professionals as palliative care needs for consumers from Culturally and Linguistically Diverse backgrounds in Brisbane south.*

A series of consumer consultation was conducted by Health Consumers Queensland on behalf of Palliative Care Queensland. Kitchen Table Discussions were hosted with consumers from CALD backgrounds with consultation questions designed to understand Palliative Care knowledge and needs of the community. Consultation themes included:

## Knowledge and gaps of services and supports

- Limited knowledge of and information about services and support options
- A centralised intake service
- More culturally appropriate and respectful services including interpreters and rituals around end of life care
- Limited workforce of social workers to deliver care

## Promotion of services

- GPs are a 'go to' for information
- Promotion of holistic support and services in libraries, RACFs, retirement villages, community centres
- Online educational videos and audio for older people who are unable to read
- Targeted media campaign on social media and in newspapers

## Availability of information

- Preference for information to be provided as a toolkit and tailored to the individual situation
- Post toolkit, further support should be offered, especially for the CALD community
- Information is best received in hard copy format due to limited digital literacy

## Availability of a health professional

- Health professionals identified as the 'go to person' for information
- Clear guidance from health professionals on what to do is valued
- Training and mentoring for care givers is essential and could be provided by phone or face to face



Health Consumers Queensland  
Kitchen Table Discussions Report  
Palliative Care in Brisbane South PHN region  
Prepared for  
Palliative Care Queensland

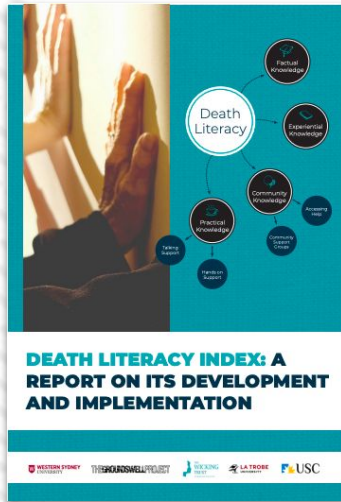
Date: 17 June 2020  
Prepared by Anne Curtis, Engagement Consultant, Health Consumers Queensland

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PALLIATIVE CARE QUEENSLAND | Kitchen Table Discussion Report

# Death Literacy Index: A Report on its Development and Implementation

*The Death Literacy Index is a tool that has a means to measure the death literacy of a population or communities and provide insight into the impact of palliative care initiatives.*



The Death Literacy Index (DLI) was designed as a tool to measure the levels of death literacy across the whole population or a local level and as a means to measure the impact of initiatives designed to increase death literacy.

*"Death Literacy is the knowledge and skills that people need to make it possible to gain access to, understand, and make informed choices about end-of-life and death care options."*

DLI contains 29 questions across 4 subscales:

## Practical Knowledge

An individual's perception of how well they can talk about dying, death and loss and contribute to the care of others

- Talking support
- Hands-on Support

## Experiential Knowledge

Knowledge and skills an individual has learnt as a result of education about death or experience caring for others

## Factual knowledge

Knowledge about the system and what is needed to plan well for dying, death and caregiving.

## Community Knowledge

Knowledge and awareness of supports and services that are available in the community.

- Community support groups
- Accessing help

# Death Literacy Index: A Report on its Development and Implementation (Cont.)

*Implementation of the DLI demonstrates that the death literacy of the Australian population is by learning from experience and talking about death and dying. There is a low knowledge and confidence of the system and information needed to plan for dying, death and caregiving.*

A national survey was conducted in 2019 to assess the death literacy of the Australian population using the DLI and additional demographic questions.

DLI results showed the following results:

- Experiential knowledge was scored the highest demonstrating that the populations death literacy is learnt from experience
- Practical knowledge - talking support scored second highest which indicates that there is a comfort among the participants to talk about death and dying.
- Factual knowledge received the lowest score highlighting a low level of knowledge and confidence of participants about the death system and the information they need to plan for dying, death and caregiving.
- Personal experience was rated as the highest source of information about death and dying among individuals
- Older Australians demonstrated a higher level of death literacy index score along with people who were widowed and were lowest among people who did not have religious or spiritual beliefs.

# Building Death Literacy in Brisbane South

*The DLI of the Brisbane south population is comparable to the Australian population. Generally across Brisbane south there is a need for activities that aim to increase the knowledge of the population about end-of-life with low scores for knowledge and personal experience the main source of information about death and dying.*

Brisbane South PHN commissioned the GroundSwell Project to assess the Death Literacy Index (DLI) of the Brisbane south region. Brisbane South PHN aim to use the outcomes of the Building Death Literacy project to provide strategic and operational guidance and investment into solutions that incorporate an approach to end-of-life care.

The project involved administering an online survey using the Death Literacy Index along with the delivery of workshops to setup the survey and communicates the results. An analysis of the results and a comparison against a national sample was undertaken as part of the project.

The samples collected included a population sample of the region (N=1200) and community sample of community groups from the BSPHN network including seniors, groups and Aboriginal and Torres Strait Islander Communities (N=101).

Findings of the DLI in Brisbane south include:

- The population in Brisbane south has a comparable DLI than the Australian population
- Factual knowledge of the population scored the lowest in the general Brisbane south population which was in line with Australian results and demonstrates a need for activities to increase the knowledge of the population about end-of-life
- Experiential knowledge scored the highest which demonstrates that personal experience is the main source of information for the population about death and dying
- Talking support received a higher score than hands on support which demonstrates a higher level of comfort to discuss death and dying and providing support through conversation than practical support
- Death literacy Index increased with age
- Individuals with a spiritual or religious belief has higher levels of DLI
- Education level was not related to DLI





# Palliative Care in Queensland 2021: Bereavement Care

*In response to the reduced access to bereavement care during to COVID-19, Palliative Care Queensland consulted with stakeholders to identify five recommendations that provide direction for the sector*



Bereavement is the state of loss and grief and is profoundly personal. Bereavement care forms an essential aspect of palliative care. In 2021 Palliative Care Queensland facilitated consultation on the topic of bereavement care with key stakeholders to inform policy development and organisational strategy and operations.

The consultation process aimed to gain an understanding of the needs, what is happening and what are the opportunities and priorities for improvement in relation to bereavement care.

Based on consultation findings, 5 recommendations and focus areas were identified.

**Recommendation 1:** Undertake a service audit and gap analysis to support the development of a resource that can provide a central hub for bereavement service and supports, information and referrals

**Recommendation 3:** Support health professionals and services providing bereavement care in Queensland to have greater access to the latest research, training and information about contemporary models of bereavement and bereavement care

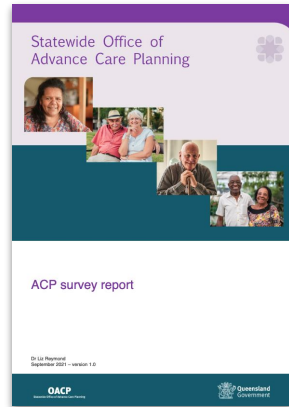
**Recommendation 2:** Review the processes used to identify people who need specialist bereavement care

**Recommendation 4:** Support policy and service development in relation to bereavement care for disaster and pandemic management, conduct a Statewide survey of the general public to understand more about the experience of grieving during COVID-19

**Recommendation 5:** Provide ongoing public education and awareness in relation to bereavement care

# Advanced Care Planning Survey Report (2021)

*In response to declining Advance Care Planning activity across Queensland, a statewide survey was conducted and identified confidence and awareness of clinicians and patients as barriers and enablers to Advanced Care Planning.*



It was identified that Advanced Care Planning (ACP) activity across Queensland had been declining despite known advantages. A survey was disseminated to explore local barriers and enablers of ACP activities to inform future plans to increase ACP uptake. There were 751 responses from health professionals across both the hospital and primary care sector.

## Barriers to ACP

1. Lack of knowledge/confidence discuss
2. Patient unwilling to discuss ACP
3. Focus of healthcare on living longer
4. Lack of support to implement ACP including required time

## Responses to most appropriate person to conduct ACP discussions:

1. GPs
2. Skilled ACP facilitators
3. All members of the team
4. Social workers/counsellors
5. Hospital doctors

## Enablers of ACP

1. Awareness raising of ACP
2. Confidence of health professionals to talk about ACP
3. Clinicians that are skilled and dedication in ACP
4. Having time available to discuss ACP
5. Increased understanding of clinicians around the benefits of ACP

***What learnings and opportunities can be leveraged from previous or existing Palliative Care services or programs?***

## Summary: Comparable activities

The Greater Choice for At Home Palliative Care Summary Report reviews the activities undertaken by participating PHNs to assess effectiveness, sustainability and future funding.

Evaluation of activities undertaken by PHNs for GCfAHPC identified success in community awareness raising and changing palliative care practices.

Brisbane South PHN's Current State Report identifies other state and national initiatives that are being implemented. While not every initiative identified is specific to palliative care, it is worth noting these activities as they influenced or interacted with the palliative care landscape in Brisbane South.

The Gold Coast PHN Palliative Care Regional Plan centres around palliative care delivered in primary or community care settings and aims to support an individuals needs to die with dignity and in their place of choice.

The Townsville Area Palliative Care Plan a roadmap to expanding and providing quality palliative care for the communities in the region through the identification of Nine Directions endorsed by key partnering organisations.

The TAPCP identifies Nine Directions for Palliative Care to provide implementation actions and measures to achieve a high quality, equitable and accessible palliative care system that is underpinned by a integration and a skilled workforce.

# Greater Choice for At Home Palliative Care Summary Report

*The Greater Choice for At Home Palliative Care Summary Report reviews the activities undertaken by participating PHNs to assess effectiveness, sustainability and future funding*



The Greater Choice for At Home Palliative Care Measure was implemented in 2017 and evaluated from 2018-2020. The evaluation aimed to assess implementation, effectiveness, sustainability and barriers and enablers of the CHfAHPC Measure.

The GCfAHPC Measure was piloted in 11 PHNs across Australia. Activities implemented by PHNs included:

- Building palliative care capability of RACF, Aged Care and primary care workforce
- Developing a model of care that supports general practices and RACFs
- Raising awareness in communities of palliative care
- Community knowledge awareness of palliative care options and local support options
- Establishing palliative care service pathways improvements

# Greater Choice for At Home Palliative Care Summary Report (cont.)

*Evaluation of activities undertaken by PHNs for GCfAHPC identified success in community awareness raising and changing palliative care practices*

## Key findings and learnings

Evaluation of the GCfAHPC Measure identified the following:

- There were varying levels of readiness of PHNs to commence the project
- Activities implemented by the 11 PHNs were tailored to meet the needs of their regions and were varied in approach
- A number of PHNs undertook community consultation to establish their approach contributing to suitability for the PHN region
- Participating PHNs reported positive update of activities centred around capability building of health professionals
- Participating PHNs implementing awareness raising activities reported an increase in knowledge of palliative care and local support services
- PHNs were able to demonstrate changes in palliative care practices
- Project governance structures such as steering groups were reported by PHNs as valuable supports for successful implementation of project activities

Due to the varied approach taken by each PHN, the short duration of project implementation and an absence of agreed metrics for data collection an overall cost-effectiveness analysis could not be assessed.

### Project enablers

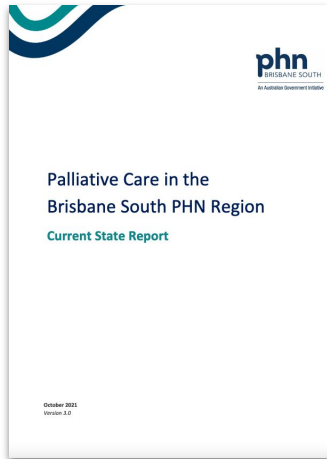
- Dedicated funding stream

### Project barriers

- Staff retention
- COVID-19
- Absence of a agreed metrics among participating PHNs resulting in inconsistent data
- Insufficient lead time from funding announcement to commencement

# Current state report: Palliative care in Brisbane South

*Brisbane South PHN's Current State Report identifies other state and national initiatives that are being implemented. While not every initiative identified is specific to palliative care, it is worth noting these activities as they influenced or interacted with the palliative care landscape in Brisbane South.*



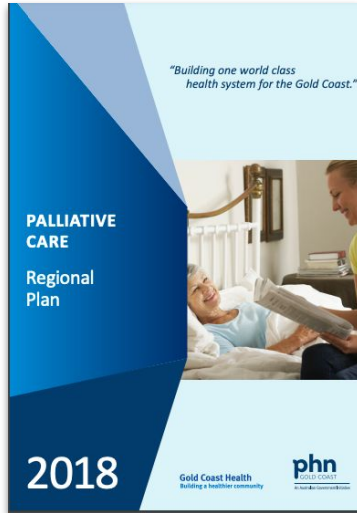
## External related projects

Projects delivered within the last 2 years at a state or national level:

- Caring@Home
- Care in the Right Setting (CaRS)
  - MASS Palliative Syringe Driver Program (MASS PSDP) and MASS Palliative Care Equipment Program - Delivered under Car
  - Specialist Palliative Care Rural Telehealth (SPaRTa)
- Comprehensive Palliative Care in Aged Care Measure
- Specialist Palliative Care in Aged Care Project (SPACE)
- Pallipharm
- What matters to Bill and Betty

# Gold Coast PHN - Palliative Care Regional Plan

*The Gold Coast PHN Palliative Care Regional Plan centres around palliative care delivered in primary or community care settings and aims to support an individuals needs to die with dignity and in their place of choice.*



The Gold Coast PHN Palliative Care Regional Plan was developed to support access to high quality palliative care that are responsive to an individual's needs. The Regional Plan was developed with palliative care services across the region and is supported by findings from the Palliative Care Health Needs Assessment. The implementation of the Palliative Care Regional Plan will be led by GCPHN and supported by advisory mechanisms such as the Palliative Care Leadership Group.

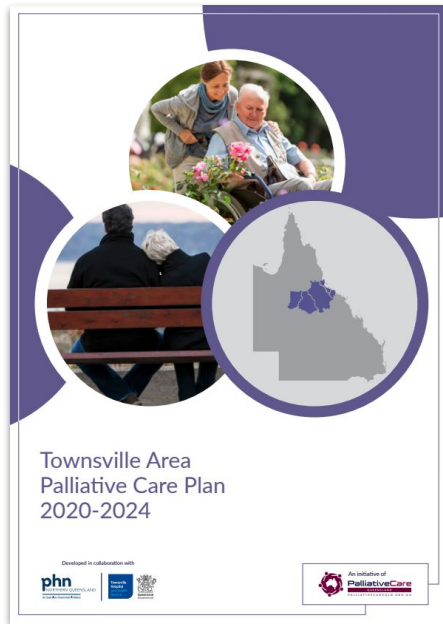
The action plan identified 5 priority areas:

1. Workforce capacity building - people have access to a well-informed, skilled and confident workforce
2. Volunteer availability - people have access to a valued, supported and recognised network of palliative care volunteers
3. Sector collaboration - palliative care services are collaborative and work together to support the needs of people accessing services
4. Community awareness and education - people are supported to obtain high health, death and compassion literacy and service knowledge
5. Service navigation and coordination - people have appropriate support to navigate and access services for their health and social needs



# Townsville Area Palliative Care Plan 2020-2024

*The Townsville Area Palliative Care Plan a roadmap to expanding and providing quality palliative care for the communities in the region through the identification of Nine Directions endorsed by key partnering organisations.*



The Townsville Area Palliative Care Plan (TAPCP) provides a set of coordinated and intended actions that inform strategy, priorities, funding and policy relating to the delivery of palliative care in the region. The focus of the TAPCP is on the person with palliative care needs, their family or carer, health providers, clinical services and the broader community.

Development of the TAPCP was guided by a situational analysis providing a comprehensive overview of palliative care and the the current and future palliative care needs of the Townsville Area. The situational analysis identified the need for an action plan to address the gaps between services that are currently available and the services that are needed.

The TAPCP identified the Nine Directions which detail the relevant actions and measures for success. The TAPCP including the Nine Directions are endorsed by NQPHN, Townsville HHS, Townsville Aboriginal and Islander Health Service and all seven LGA's. Endorsement of the TAPCP included commitment to participation as a working group member, implementation activities and monitoring and review.

# Townsville Area Palliative Care Plan 2020-2024 (Cont).

*The TAPCP identifies Nine Directions for Palliative Care to provide implementation actions and measures to achieve a high quality, equitable and accessible palliative care system that is underpinned by a integration and a skilled workforce.*

## Direction 1

### **Raise awareness and build community capacity**

Increase awareness of the community about palliative care services and comfort talking about dying, death and grief

## Direction 2

### **Care navigation**

Support for patients from palliative care providers to navigate the system and deliver person-centred care

## Direction 3

### **Rural and remote areas**

Increase options for palliative care services to those living in rural and remote locations

## Direction 4

### **Aboriginal and Torres Strait Islanders**

Culturally appropriate palliative care services and supports are available for all Aboriginal and Torres Strait Islander residents

## Direction 5

### **Advanced Care Planning**

Individuals are supported to complete ACP through initiation and continuation of conversations

### **Integration of care**

Integration across the sector will be strengthened to improve care continuity and access

## Direction 6

### **Workforce**

Growth, sustainability and training of the workforce to deliver high quality palliative care

## Direction 7

### **Monitoring, evaluation and research**

Establishing methods of data collection, monitoring and evaluation in palliative care and contributing to the development of research to establish and evidence base

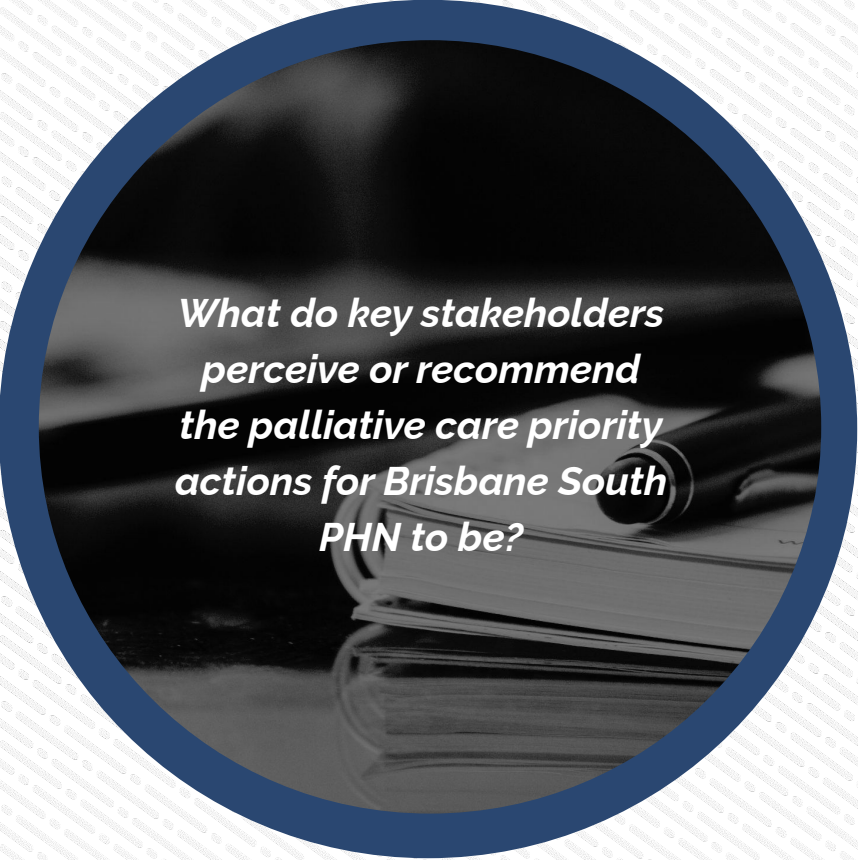
## Direction 8

### **Disaster planning, response and recovery**

Enhancing disaster management to ensure continuity of safe and high quality care

## Direction 9

**STAKEHOLDER  
CONSULTATION  
FINDINGS  
[INITIAL]**



***What do key stakeholders  
perceive or recommend  
the palliative care priority  
actions for Brisbane South  
PHN to be?***

## Summary: Stakeholder consultation (1/2)

A total of 26 responses to the stakeholder engagement survey were received. The majority of responses were from an Aged Care Services perspective with 14 responses followed closely by Specialist Palliative Care Services with 5 responses.

Survey responses from participants with an Aged Care perspective identified challenges around medication at end-of-life, timely delivery, continuity of care after hours and RN education.

Training and education for RNs and ENs, availability of a skilled workforce and support after hours were common themes identified as challenges and gaps in palliative care services in Brisbane south.

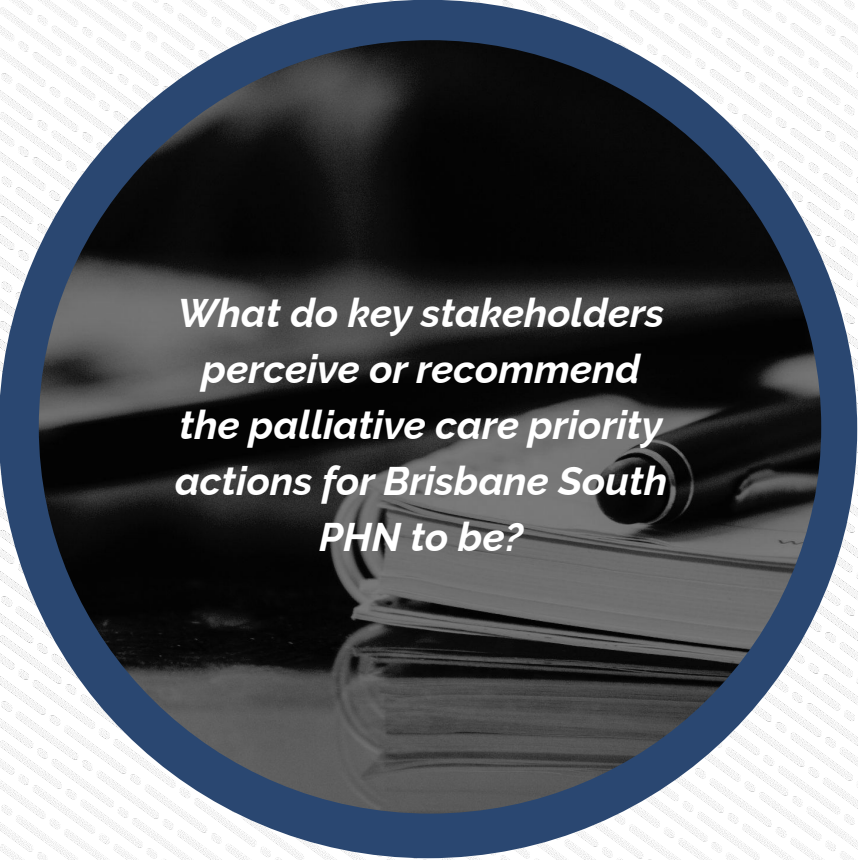
Providing education and training on Advanced Health Directives, Statement of Choices and palliative care at home or RACF for GPs and Nurses featured strongly among responses as a key role of Brisbane South PHN in improving palliative care outcomes for the region.

Among the responses, education featured strongly among the 3 highest priority actions for Brisbane South PHN. This included education for RNs, GPs, staff in RACFs and families to increase skill, capability and awareness of services.

PalliAged, ELDAC, CAREPACT and Mater MACIAE programs have all been identified successful in improving the delivery of person-centred palliative care services .

# Summary:

## Stakeholder consultation (2/2)



***What do key stakeholders  
perceive or recommend  
the palliative care priority  
actions for Brisbane South  
PHN to be?***

The responses from Specialist Palliative Care Service providers were varied and no consistent theme presented as the greeted areas of unmet needs relating to palliative care in Brisbane South.

Advanced Care Planning and availability of a skilled workforce are common themes of gaps that exist in palliative care services in Brisbane South.

Palliative care education, support for the generalist workforce and primary care providers and commissioning services and activities to improve awareness in the community were identified as a role for Brisbane South PHN in improving palliative care outcomes.

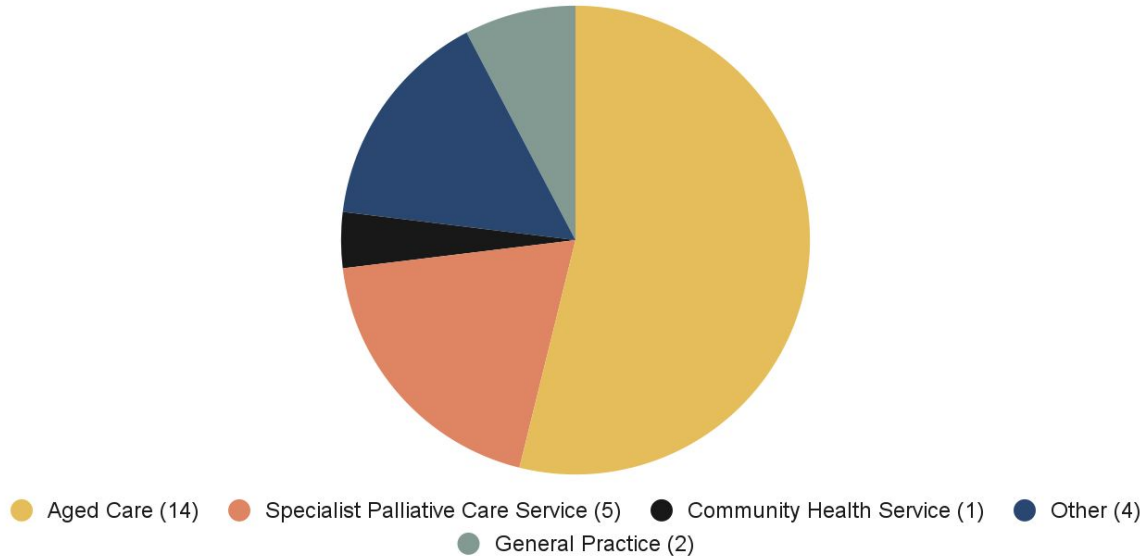
Engagement with GPs, education and training and activities to increase the uptake of Advanced Care Plans were identified as some of the highest priority actions and activities for Brisbane South PHN.

Responses from Specialist Palliative Care Services identified a number of sources of information and information to inform Brisbane South PHNs palliative care priorities including PalliPHARM, PallConsult and bereavement support groups.

# Stakeholder Engagement Survey

*A total of 2 responses to the stakeholder engagement survey were received. The majority of responses were from an Aged Care Services perspective with 14 responses, followed by Specialist Palliative Care Services with 5 responses.*

**Stakeholder Perspective**



# Engagement Survey - Aged Care Perspective

*Survey responses from participants with an Aged Care perspective identified challenges around medication at end-of-life, timely delivery, continuity of care after hours and RN education.*

## **Q1. What are the greatest areas of unmet need relating to palliative care in Brisbane south?**

Participant responses include:

- Dedicated staff to be able to facilitate care to those in need
- Accessing palliative care assessment in a timely manner that is relevant and appropriate
- Accessing appropriate medications that are not in imprest stock in RACF
- Accessing education for RNs/ENs on an ongoing basis.
- Lack of communication
- Information on services that can be accessed not only for the patient but their carer as well
- I think it has dramatically improved in the last 5 years.
- Care for RACF who have specifically identified in the AHD or SOC that they would prefer to die in hospital. Residents and patients that would be suitable to start on a palliative pathway while an acute inpatient are dismissed and sent back to RACF with no pathway started or even prescriptions for EOL medications
- Access to palliative care professionals outside of business hours.
- GP knowledge of medication management
- aged care staff lack of training and knowledge of palliative care, Locum often refused to chart end of life drugs as they don't know the patient well
- Access after hours for RACF for resident changes with complex needs
- Timely delivery of palliative medicine provided by GP
- Identify stages of a palliative plan
- Education to families on pathways

*"When a resident, who is in the late unstable palliative stage, whose regular GP is on Leave, it can be very difficult to obtain end of life prescriptions to manage palliative pain and other end of life symptoms. After Hours GP are very reluctant to do this - understandably".*



# Engagement Survey - Aged Care Perspective

*Training and education for RNs and ENs, availability of a skilled workforce and support after hours were common themes identified as challenges and gaps in palliative care services in Brisbane south.*

## **Q2. What are the challenges/gaps that exist in palliative care services in Brisbane South to meet these needs?**

- Access to resources in a short time frame. Residents sometimes are only palliating over a short time period, (within a week) and access to a Nurse practitioner or palliative care nurse is not easy.
- Limited time and funding for RNs/ENs to attend education/training during work hours.
- Residents discharged from hospital who are palliative not having SOC completed or AHD completed-responsibility left on RACF to complete this-contributes to delay in implementing palliative/EoL care
- Accessing unavailable medications.
- Workforce education and training is needed to address limitations in palliative care background, knowledge and qualifications
- Further training to be provided to staff in the industry, especially in aged care by Brisbane South, more visibility in Aged Care Industry.
- I think the service is excellent
- Hospital nursing staff do not have the knowledge and experience when dealing with holistic care of the older person and the end of life requirements.
- There is often poor communication between the hospital and the patients families
- Lack of appropriately skilled staff who are able to spend time with the resident's EPOA/family to discuss the options when a resident does not have an AHD or SOC and is for CPR and life prolonging treatment when the resident is entering the terminal phase of their life.
- Whilst Opal has Palliative Champions Education of Aged Care Nurse in their role and responsibilities with EOL care for them to gain confidence and clinical skills needed especially with symptom control
- After hours and weekend access to doctors prepared to initiate palliative medications. Education to RNS and families

*"The challenge is to link with Metro South Palliative Care Team in a timely manner that can provide a seamless connection between the palliating resident and end of life medications. There can be a delay with getting prescriptions made by the MSPCS to the pharmacy so the pharmacy will accept such prescriptions and dispense them. Although there is some EoL medications in Imprest there may not be enough for the current needs in the Care Community (Care Home). All while the regular GP is on Leave. MSPCS do a wonderful job and this comment in no way reflects negatively on that."*

# Engagement Survey - Aged Care Perspective

*Providing education and training on Advanced Health Directives, Statement of Choices and palliative care at home or RACF for GPs and Nurses featured strongly among responses as a key role of Brisbane South PHN in improving palliative care outcomes for the region.*

**Q3. What do you see the role of Brisbane South PHN is in improving palliative care outcomes for the Brisbane South region?**

- Education/training:
  - onsite in facilities to offer upskilling for RNs & ENs
  - completion of AHD and/or SOC in the community/retirement living communities etc.
  - Educating RACF teams to minimise the need for services at RACF's as this is our core business
  - Education to gps on palliative care at home or facility
- Providing timely services to residents in RACF before and after discharge from hospitals.
- Liaising with the RAC and easy access to services when needed
- Information source
- I think PHN be able to support those difficult cases is needed but RACF are now able to manage pall care for majority of cases now.
- Would it be possible for a prescribing doctor working through/from MSPCS to make prescriptions on BestMed rather than rely on paper medication charts, backed by prescriptions that had then to be sent to appropriate pharmacy before the medication changes would be accepted?
- Supporting residents and families in complex cases
- Supporting GPs who do not care for large numbers of RACF residents or have limited experience in palliative care
- Supporting RNs with limited education/experience in palliative care.
- Assisting RACFs in working with GPs & families to enable the residents to have a 'good' death.
- Ensuring that GP's area aware of best practice and support symptom management
- Wonderful, used the metro south palliative care service many times to support difficulty patient and family
- Improving gps understanding of death certificate need, after hours. A contact point for facility!!! Update information on medication especially PRNs

# Engagement Survey - Aged Care Perspective

*Among the responses, education featured strongly among the 3 highest priority actions for Brisbane South PHN. This included education for RNs, GPs, staff in RACFs and families to increase skill, capability and awareness of services.*

## Q4. What would be the 3 highest priority actions/activities for Brisbane South PHN to improve palliative care outcomes over the next 3 years?

### Priority 1:

- Upskilling staff in residential facilities
- Education and training as older RNs retire and newer/younger inexperienced are entering the workforce.
- More visibility
- funding access
- Education for RACF staff
- Ensure through education, that aged care nurses know how to access your palliative services
- Community GP education
- More Palliative Care Nurse Practitioners
- More staff to access without feeling like a nuisance
- provide education to aged care staff
- Education, More PEPA Placements
- GP responsibilities and education

### Priority 2:

- Access to Palliative care nurses remotely
- Review of imprest stock medications to include medications such as hydromorphones.
- Improved communication
- information on available supports
- Education for hospital staff
- Continue to link with grieving families as this is most supportive
- RN education and support
- After hours palliative team support for RACFs
- Family sessions to educate and prepare
- provide education to Locum
- After hours assistance to RAC

### Priority 3:

- Support for Facilities to complete Statement of Choices with families so there is no confusion or unnecessary hospital admissions
- Collaboration with AHGP for implementation of baseline palliative medications in the RACF.
- Assisting with training to RAC staff support to carers and patients
- Further liaison between the hospital and RACF
- Provide leaflets about your services we could give to residents and their loved one.
- More funding for palliative care services to RACFs
- Education \*\*\*\*
- make more people aware of the service
- Family education

# Engagement Survey - Aged Care Perspective

*PalliAged, ELDAC, CAREPACT and Mater MACIAE programs have all been identified successful in improving the delivery of person-centred palliative care services*

## **Q5. Are there any key sources of information or inspiration that you would identify that could inform Brisbane South PHN's palliative care priorities for the next 3 years?**

- I believe there is an Aged care facility northside of Brisbane that has implemented nursing inline with hospital practices (nurses can cannulate and administer IV fluids/medications as required. This is something we would be interested in accessing resources and support in implementing at our facility, so even residents on a longer term palliation plan can return to the facility without the need or stress of having to return to hospital for treatments or pain management.
- Working with RAC management team, reviewing their process and taking some inspirational ideas and implementing into current framework.
- RAC's are limited by GP engagement. Research around providing an individual environment for patient palliative
- I was involved in a project over ten years ago in Townsville funded by then medicare local and led by an experienced and very senior CN to run a palliative care project. Project involved several RACFs from different organisations nominating person(s) RNs/ENs/CNs to collaborate on implementing the pathway. Was a very successful project with adaptation of the Liverpool pathway into several RACF and many education sessions organised monthly. Education on pall. medications, complementary medicine, bridging gaps in RACF, forums with pall.care specialists. This was effective in significantly increasing the knowledge base in RACF about palliative care, creation of pall. care teams within RACF.

*"I find the work done and training offered by PalliAGED really helpful for all team members. The ELDAC project is also changing the way the Organisation now approaches palliative care in a positive person-centred way".*

*"Best thing that ever happened to Residential Aged care was the Palliative Approach Toolkit from and subsequent training that went through the industry including CAREPACT and Mater MACIAE programs".*

# Engagement Survey -Specialist Palliative Care Perspective

*The responses from Specialist Palliative Care Service providers were varied and no consistent theme presented as the greeted areas of unmet needs relating to palliative care in Brisbane South.*

## **Q1. What are the greatest areas of unmet need relating to palliative care in Brisbane south?**

Stakeholder responses include:

- Community awareness
- ACP and Palliative Care in the Primary Care setting including Residential Aged Care Facilities (RACF)
- Bereavement support
- Pharmacy support
- Early intervention
- under 65 funding
- Lack of resources and funding for palliative care patients
- Palliative care competent community nurses available 24/7
- RACF palliative care competent nursing staff GPS who will provide palliative care for their patients

# Engagement Survey -Specialist Palliative Care Perspective

*Advanced Care Planning and availability of a skilled workforce are common themes of gaps that exist in palliative care services in Brisbane South*

## **Q2. What are the challenges/gaps that exist in palliative care services in Brisbane South to meet these needs?**

Stakeholder responses include:

- ACP Facilitators
- Funding for overnight nursing respite, domiciliary nursing support esp. in the under 65 yr old age group
- GP involvement including the afterhours space esp in the RACF setting
- ACP in the primary care space
- Lack of bereavement services
- Limited specialist palliative care resourcing
- Limited scope for generalist clinicians to provide palliative care support
- Limited access to end of life medicines
- Communication we need more regular meetings between services we often don't seem to have a voice
- Basically workforce shortages, but also specialist palliative educators to upskill the workforce that is available

# Engagement Survey -Specialist Palliative Care Perspective

*Palliative care education, support for the generalist workforce and primary care providers and commissioning services and activities to improve awareness in the community were identified as a role for Brisbane South PHN in improving palliative care outcomes.*

## **Q3. What do you see the role of Brisbane South PHN is in improving palliative care outcomes for the Brisbane South region?**

Stakeholder responses include:

- Support education in Primary Health Care
- Working with specialist palliative care services, primary care and the community through linkage, engagement and commissioning/ supporting evidence based models
- Maximising opportunities to upskill the generalist workforce
- Offering more bereavement support services & making this known amongst consumers
- Engaging with community pharmacists to stock end of life medicines and encouraging them through financial incentives
- Collaboration, sharing ideas and resources, being united
- Commissioning advance care planning activities both in community and residential aged care facilities
- Partnering to provide on-going palliative care education



# Engagement Survey -Specialist Palliative Care Perspective

*Engagement with GPs, education and training and activities to increase the uptake of Advanced Care Plans were identified as some of the highest priority actions and activities for Brisbane South PHN*

**Q4. What would be the 3 highest priority actions/activities for Brisbane South PHN to improve palliative care outcomes over the next 3 years?**

## **Priority 1:**

- GP Engagement
- Increase ACP in primary care including RACF
- Increase bereavement support under 65 funding
- Encouraging advance care planning activities

## **Priority 2:**

- Support Practice Nurse ACP education
- Increase GP involvement in Palliative Care ?shared care arrangements
- Support community pharmacies to stock end of life medicines
- increased resources/funding
- Supporting palliative care education in aged care

## **Priority 3:**

- Interprofessional collaboration with MSPCS and GPs
- Maximise education to the generalist workforce to provide palliative care support
- Education
- Working with GPs to identify local barriers to provision of palliative care

# Engagement Survey -Specialist Palliative Care Perspective

*Responses from Specialist Palliative Care Services identified a number of sources of information and information to inform Brisbane South PHNs palliative care priorities including PalliPHARM, PallConsult and bereavement support groups*

**Q5. Are there any key sources of information or inspiration that you would identify that could inform Brisbane South PHN's palliative care priorities for the next 3 years?**

Stakeholder responses include:

- Brisbane South Palliative Care Collaborative
- palliPHARM initiative and the work done on incentivising community pharmacists to stock end of life medicines through a reimbursement funding model
- PallConsult education to generalist clinicians - perhaps utilising pallconsult and pepa to provide regular education?
- Bereavement support groups
- Recent Australian Health Review authored by Scott, Reymond, Sansome and Miller



# Methodology

# Phase 2

## *Desktop review*

### Tasklist:

- Develop a **proposed approach** document that outlines framing questions and scope of documents for analysis
- Obtain **relevant source documents** from Brisbane South PHN
- Conduct **desktop review and analysis** of supplied documents
- Undertake **environmental scan** of PHNs for other existing initiatives
- Document **key findings and considerations** and present back to Brisbane South PHN via PMT

### Notes on resourcing:

- Delivered over 8 consulting days
- We will commence following agreement from BSPHN on the research questions and sources



Understanding the strategic environment and evidence base is a crucial step in developing a set of meaningful and practical actions. Our approach to this desktop review involves identifying and obtaining key source documents from Brisbane South PHN and undertaking a targeted scan of the strategic environment and evidence base.

We will review and analyse documented findings and insights sourced from national/state policies and plans, Department of Health guidance, sector-generated research and position statements, and review/evaluation of previous palliative care initiatives delivered by Brisbane South PHN. A scan of a sample of peer PHNs will identify other existing projects and initiatives.

The desktop review will inform the identification of future strategic investment opportunities for the development of the Palliative Care 3 Year Action Plan. We will present a brief overview of the findings and considerations to the project working group to check the accuracy of interpretation and capture internal direction to inform subsequent steps.

# Research questions

*Research questions help us to identify source material that is relevant and to frame our analysis and reporting of the information we will review.*

1

*What are the key strategy and policy priorities relating to palliative care services and what is the role of a PHN in delivering on this?*

2

*What is the operational environment of palliative care in Brisbane South and what palliative care programs and services have Brisbane South PHN commissioned?*

3

*What are the palliative care needs of individuals, families and carers?*

4

*What learnings and opportunities can be leveraged from previous or existing Palliative Care services or programs?*

# Phase 3

## *Stakeholder engagement*

### Tasklist:

- Draft an **engagement plan** that outlines an agreed approach for engagement activities
- Undertake **stakeholder engagement** activities as outlined in engagement plan
- Present **stakeholder engagement findings** in a staged report to allow Brisbane South PHN time to read and digest.

### Notes on resourcing:

- Delivered over 6 consulting days
- Support is required from Brisbane South PHN for identification and invitation of stakeholders to participate in engagement



We will develop a stakeholder engagement plan that provides a structured approach to capturing the input and insights of key stakeholders to inform the Palliative Care 3 Year Action Plan.

In collaboration with the PMT, we will seek guidance to shape the engagement approach then develop an engagement plan that outlines:

- key stakeholders to be involved
- agreed recruitment strategies
- appropriate engagement methods (and scope of activities)
- areas of inquiry
- logistics and timeframes.

Our findings from the engagement activities will be collated and presented to Brisbane South PHN in a staged report to allow time for the team to review and absorb the information. This will be followed by a meeting to discuss the outcomes of the engagement activities.

# Engagement approach

*To ensure that engagement is meaningful and captures the right people at the right time, our engagement activities will occur in two phases.*

## Phase 1 - Stakeholder Survey

A brief stakeholder engagement survey will be developed to ask 4-5 short questions. The responses to the engagement survey will be collated to form themes which will provide the basis for focus group discussions. The stakeholder survey is scheduled to be delivered in July 2022.

The aim of the survey is to:

- Understand the perception of stakeholders on the role of Brisbane South PHN in improving Palliative Care Outcomes
- Identifying the priority activities for Brisbane South PHN in improving palliative care outcomes
- Identifying sources of information for further insights and ideas to inform Brisbane South PHNs priorities for the next 3 years

## Phase 2 Stakeholder engagement - Focus groups/interviews

Using the survey findings, Beacon Strategies will facilitate a small number (5-10) of focus groups/interviews with key stakeholders. The stakeholder focus groups and interviews are scheduled to occur in August 2022.

The aim of the stakeholder engagement focus groups/ interviews is to:

- Speak with key stakeholders to understand their needs for palliative care services in Brisbane South
- Discuss key themes that were identified through the stakeholder survey
- Identify opportunities for Palliative Care in Brisbane South



# Beacon Strategies

The logo for Beacon Strategies features the word "Beacon" on the top line and "Strategies" on the bottom line, both in a white, sans-serif font. A stylized yellow sunburst icon, consisting of a central dot and several radiating lines, is positioned between the two words, partially overlapping the end of "Beacon" and the beginning of "Strategies".