scyne ADVISORY

National Evaluation of the Greater Choice for At Home Palliative Care Program

Baseline Report
Department of Health, Disability and Ageing

March 2025

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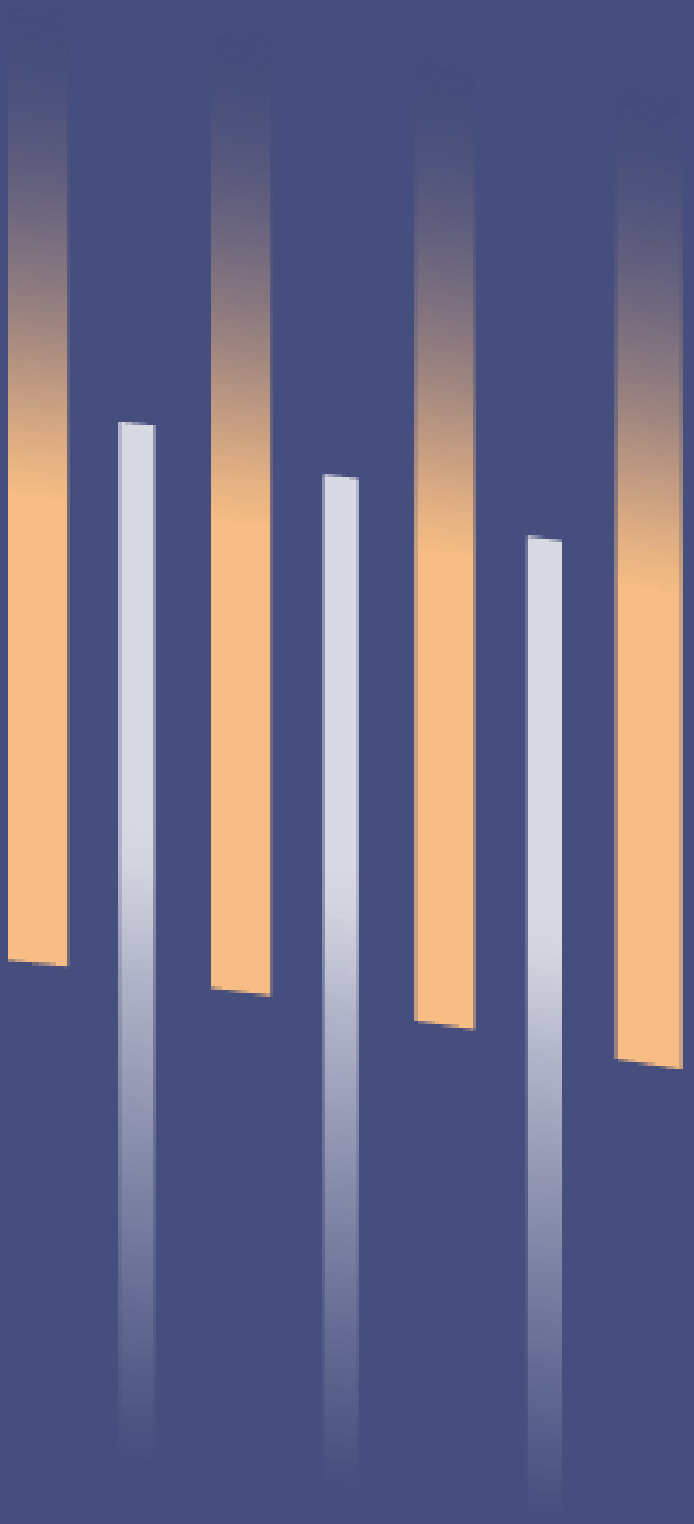


Executive Summary

Greater Choice for At Home Palliative Care Program

Palliative care in Australia refers to the 'treatment, care and support for people with a life limiting illness…to live as fully and as comfortably as possible'.[1]

Demand for palliative care services in Australia will continue to increase as the population ages. Despite 70% of Australians preferring to die at home, only 15% do so, with most palliative care services being delivered in hospital settings.[2]

The Greater Choice for At Home Palliative Care (GCfAHPC) Program (the Program) was launched with 11 Primary Health Networks (PHNs) as a pilot program by the Department of Health, Disability and Ageing (DHDA) in 2017.

The intended outcomes of the Program are to:

- Improve capacity and responsiveness of services to meet local needs and priorities.
- Improve patient access to quality palliative care services available in the home and improved capacity of carers to support people at home.
- Improve coordination of care for patients, across health care providers and integration of palliative care services int their (PHN) region.

The Program funds up to two FTE PHN staff members to design and implement localised palliative care activities that target increased awareness and coordination and facilitate better access to palliative care options available at home and in the community. Program funding is designed to be flexible, empowering PHNs to direct investment to address local needs. The pilot program was evaluated from 2018 to 2020, following which the Program was expanded nationally to include all 31 PHNs from 2021-25.

DHDA commissioned Scyne Advisory to undertake an Evaluation, of the national roll out of the Program, with the aim to:

- Measure and monitor to what extent the Program has led to increased access to, and choice for, palliative care for individuals in their home.
- Inform the future direction of the Program nationally.

When considering the context for the Baseline evaluation, it is important to note that it is taken from the point of national expansion of the GCfAHPC program, with PHNs all commencing from varied points of readiness. This includes PHNs who are continuing to build on activities from the pilot phase as well as new PHNs who may be progressing activities that they commenced prior to joining the program.

National Evaluation of the Greater Choice for At Home Palliative Care Program

The Evaluation covers three key phases or 'tranches' of data collection, analysis and reporting: the Baseline, Midpoint and Endpoint. This iterative data collection approach enables the evaluation to produce comparators and indicators of impact over the course of 3 years.

This report presents data covering the Baseline tranche of the Evaluation, with the period of data collection spanning 2022-23. The Baseline report establishes a set of key indicators that will be used as comparators in subsequent phases to determine impact of the Program across its lifecycle. These include core datasets to be accessed via data custodians such as the AIHW or collected by PHNs (e.g. Death Literacy Index data), as well as supplementary sources of data provided by, but not used for standardised comparison, between PHNs. Section 4.2 Key activities in PHN workstreams and Appendix D Baseline indicators and hypotheses discuss these indicators in more detail. Because these datasets are established as comparators for subsequent phases, the Baseline report does not contain conclusive findings or recommendations.

Measuring impact of PHN activities:

As part of the Baseline tranche, a suite of primary data collection methods and tools were co-designed and distributed for PHNs to use in monitoring their activities. As part of Midpoint and Endpoint, it is anticipated that there will be more widespread use and embedding of these tools as part of 'business as usual' practices for GCfAHPC Program activities.

The three primary sources of information for the Baseline tranche included: publicly available national data sets such as those held by the AIHW, data collected locally by PHNs, and case studies of PHN activities. It should be noted that, given the size, scale, and complexity of the palliative care system (including in each PHN region), the funding and duration of the Program, the impact of PHN activities on measurable outcomes will likely be too small to observe using national or even PHN-level health service data. It is more likely that the impact of the Program will be measurable using primary data collection approaches and tools.

Different workstreams will have a varying level of data availability and quality that can be used to measure impact. It is likely that workstreams such as Priority Populations or Awareness in the Community will require more significant input from primary data collection tools and qualitative data.

Baseline activity data on relevant PHN activities is catalogued against four areas of action, as shown in Figure 1.

Figure 1: Overall summary of PHN activity workstreams in palliative care

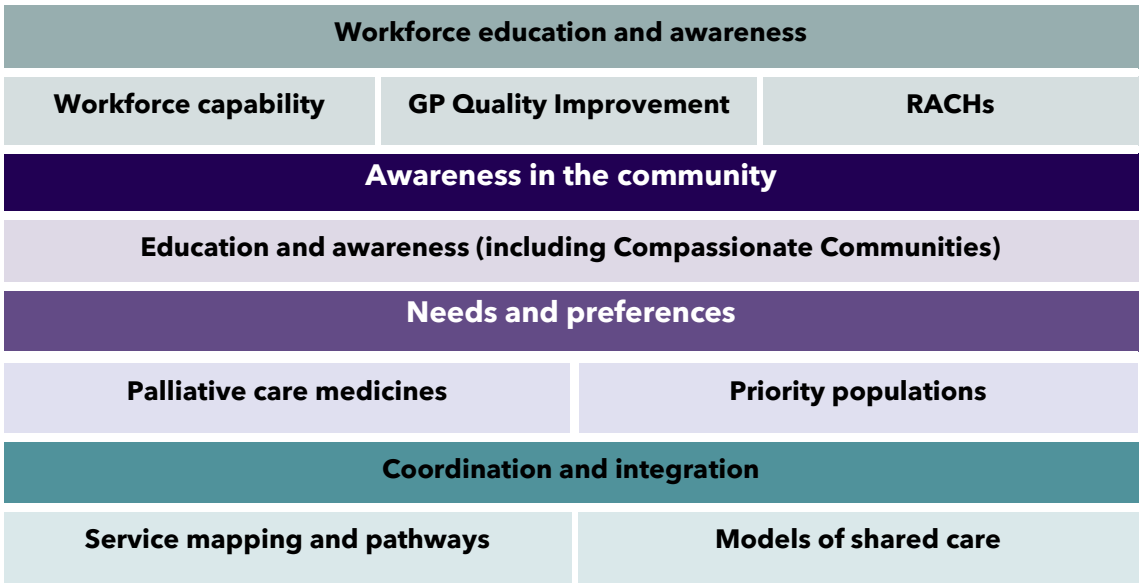
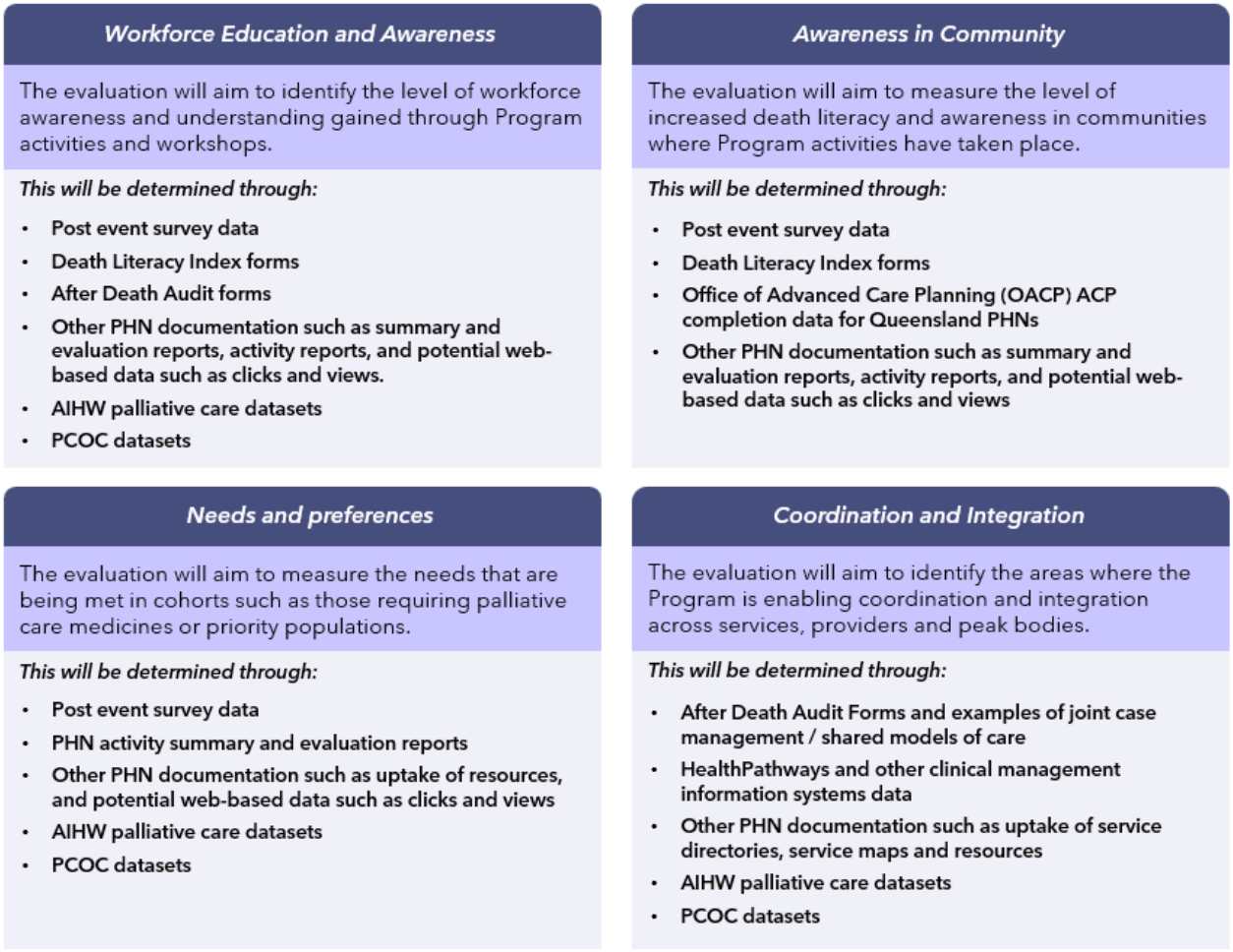


Figure 2 categorises the data sources that will be used to capture PHN achievements. This methodology will be further developed over the course of the Midpoint and Endpoint evaluation.

Figure 2: Measurement of impact summary



Overview of PHN activity

The data provided in the Baseline report is synthesised from a rapid review of relevant policies, existing national and State and Territory funded initiatives and Australian palliative care services, publicly available palliative care data, and primary data collection, including semi-structured interviews with all 31 PHNs, an online PHN survey, an online palliative care service provider survey, and materials submitted from PHNs relating to Program activities. The

At the time of data collection several PHNs were already undertaking palliative care initiatives activities. This is in part due to the pilot program conducted with 11 PHNs and existing projects self-initiated by PHNs due to identified community needs.

The range of PHN activities being delivered at baseline is explored in detail in Chapter 4.

Examples include:

Workforce Education and Awareness:

- A curated 2-day symposium during Palliative Care Week to raise awareness of palliative care services and skills-based education for service providers in the Darling Downs and West Moreton region.
- A Regional Victorian Palliative Care Collaborative consisting of Murray PHN, Gippsland PHN, and Western Victoria PHN to drive a Palliative Care Quality Improvement in General Practice toolkit that has enabled greater primary palliative care data collection.

Awareness in the community:

- Conversation skills workshops for personal care workers and carers to support greater confidence in having conversations surrounding planning for palliative care, death and dying, undertaken in unique ways by multiple PHNs.

Needs and preferences:

- The collaboration of Metro Melbourne PHNs (Eastern Melbourne, North Western Melbourne and South Eastern Melbourne) to create a metropolitan-wide interactive map of community pharmacies that stock palliative care medicines.
- Brisbane North PHN working with Palliative Care Australia to list 'palliative friendly pharmacies' in the region that stock the five core categories of end-of-life care medicines on the National Palliative Care Services Directory.
- Training and education developed by the Western Australia Primary Health Alliance targeting health professionals in ACCHOs to provide palliative care to Aboriginal and Torres Strait Islander people.

Coordination and Integration:

- The development of a multidisciplinary approach to care planning by Murrumbidgee PHN, where general practices host monthly multidisciplinary team meetings to collaboratively plan appropriate care and referrals.

The baseline data provided in this report should be considered in the context of the following limitations:

- The development of a multidisciplinary approach to care planning by Murrumbidgee PHN, where general practices host monthly multidisciplinary team meetings to collaboratively plan appropriate care and referrals.
- Limited data availability – This Evaluation has been challenged by a paucity of data. There is limited nationally relevant data examining palliative care in Australia and PHNs have described gathering data from local service providers as challenging.
- Low response rates – Stakeholder surveys and data collection tools received low response rates likely due to the time constraints and competing priorities for health sector stakeholders and service providers. The Baseline report has taken care to triangulate findings from a range of sources to improve the reliability of conclusions.

Next steps of the evaluation include:

- Midpoint (due in 2024) – to further explore PHN activities, processes, implementation, key enablers and barriers, and any early evidence of impact.
- Endpoint (due in 2025) – focused on impact on the Program in achieving intended outcomes, and key insights to inform the future direction of the Program, and other palliative care policies and initiative.

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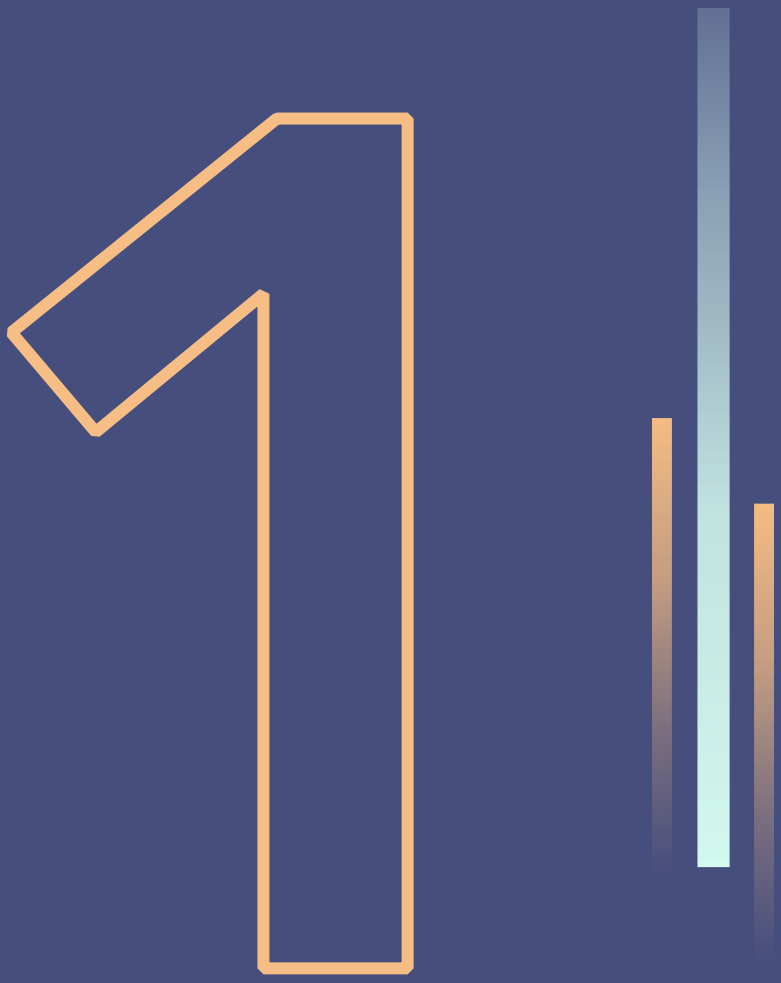


Baseline Report

Background and Objectives

1 Background and Objectives

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'.[1] The aim of palliative care is to optimise quality of life.[2] End-of-life care (EOLC) is care and services for people and their families who are facing the end of their life. EOLC is an important part of palliative care and is provided for people of any age. The focus of EOLC is to help a person live out their life as comfortably as possible[3]

1.1 The Greater Choice for At Home Palliative Care Program

Launched in May 2017 by the Department of Health, Disability and Ageing (DHDA), the GCfAHPC program was introduced to drive palliative care coordination through the Primary Health Networks (PHNs). The Program aims to enable people's preference for palliative and EOLC at home and in the community. The National Palliative Care Strategy states that 'palliative care received at home and in-community-based settings can be provided in different ways including care and support from families and friends, social networks, faith communities, private or not-for-profit nursing and allied health agencies or services, residential aged care facilities, general practitioners, public, private or not-for-profit social services, and specialist outreach services.[4]

PHNs are enabled to undertake activities to meet the following four objectives:

Improve access to safe, quality palliative care at home and support EOLC systems and services in primary health care and community care.

Enable the right care, at the right time and in the right place, to reduce preventable hospitalisations.

Generate and use data to support continuous improvement of services across sectors.

Use available technologies to provide flexible and responsive care, including care after usual business hours.

The 11 PHN trial sites were evaluated from July 2018 to December 2020. The evaluation of the pilot program found that there was merit to expand the Program beyond the 11 PHN pilot sites, with recommendations to improve clarity and guidance on the flexible use of funding, and shared learnings from existing activities.[5] In 2021-22, the Australian Government

[1] Palliative Care Australia (2018). Background Report to the Palliative Care Service Development Guidelines. Available at: https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/02/PalliativeCare-Background-to-Service-Delivery-2018_ v3.pdf

[2] DHDA. (2019). What is Palliative Care? Available at: www.health.gov.au/topics/palliative-care/about-palliative-care/what-is- palliative-care#what-is-endoflife-care

[3] Ibid.

[4] DHDA (2018) National Palliative Care Strategy 2018. Available at: www.safetyandquality.gov.au/sites/default/files/2019-06/national_palliative_care_strategy_2018.pdf

[5] Deloitte (2021). Greater Choice for at Home Palliative Care Final Report.

committed further funds to expand the Program to all PHNs, nationally, for four years to 2024-25.

PHNs are funded to employ up to two Full-Time Equivalent (FTE) staff members to implement activities that are designed at "increasing awareness, facilitating and coordinating access to safe, quality palliative and EOLC at home."[6]

The Program is intended to lead to the following key outcomes:[7]

- Improved capacity and responsiveness of services to meet local needs and priorities.
- Improved patient access to quality palliative care services at home; and
- Improved coordination of care for patients, across health care providers and integration of palliative care services in their region.

1.2 Evaluation of the GCfAHPC Program

As part of the expanded rollout, a national evaluation of the GCfAHPC measure has been commissioned (the Evaluation). The Evaluation commenced in September 2022 and is due for completion in 2025. The Evaluation is intended to assess the impact of the Program on access to palliative care at home and in the community, and to inform the future direction of the Program and palliative care policies.

The scope of the Evaluation includes three tranches of data collection, analysis and reporting:

1 Baseline – to identify PHN activities as part of the Program, and to establish a baseline of key local and system-wide indicators that will be used as a comparator at Midpoint, and Endpoint to determine the impact of the Program in achieving outcomes. These local and system-wide indicators are discussed in section 4.2 Key activities in PHN workstreams and Appendix D: Baseline indicators and .

2 Midpoint – to further explore PHN activities, processes, implementation, key enablers and barriers, and any early evidence of impact.

3 Endpoint – focused on impact of the Program in achieving intended outcomes, and key insights to inform the future direction of the Program, and other palliative care policies and initiatives.

Figure 3 shows the key stages of the evaluation:

Figure 3: GCfAHPC Evaluation timelines

[6] DHDA (2021). PHN Program Expansion of the GCfAHPC Measure Grant Opportunity Guidelines.

[7] Ibid.

Baseline Report

Current State

2 Current State

2.1 Palliative care in Australia

In Australia, palliative care is 'treatment, care and support for people with a life-limiting illness.' It 'helps people live as fully and as comfortably as possible' with the aim to ease 'the suffering of patients and families.'[8] Assisting people to have a good quality of life through palliative care may involve:[9]

- Managing physical symptoms such as pain
- Emotional, spiritual and psychological support
- Social care, including help with things like washing, dressing or eating
- Help for families to come together to talk about sensitive issues
- Support for people to meet cultural obligations
- Counselling and grief support
- Referrals to respite care services.

The settings where people receive palliative care depends on their needs and preferences, and may be:[10]

- At home
- In hospital
- In a hospice
- In a Residential Aged Care Home (RACH).

While most people indicate a preference to die at home, palliative care continues to primarily be delivered within hospital settings. Some of the contributing factors are:

- The perception that palliative care options apply only in the final stages of life, or at the 'end-of-life'.
- Limited understanding and awareness, of the palliative care services available at home and in the community.

Limited workforce capacity and capability to deliver palliative care at home and in the community.

[8] DHDA. (2019). What is Palliative Care? Available at: www.health.gov.au/topics/palliative-care/about-palliative-care/what-is- palliative-care.

[9] Ibid.

[10] Ibid.

2.1.1 Palliative care services and providers

Australia's palliative care system is a network of stakeholders, providers, sectors and policies which can be difficult to navigate (Figure 4). People may experience changing needs and preferences throughout their palliative care journey that are influenced by social, psychological, and personal factors, as well as the complexity of their health conditions, symptoms, and phases of care.

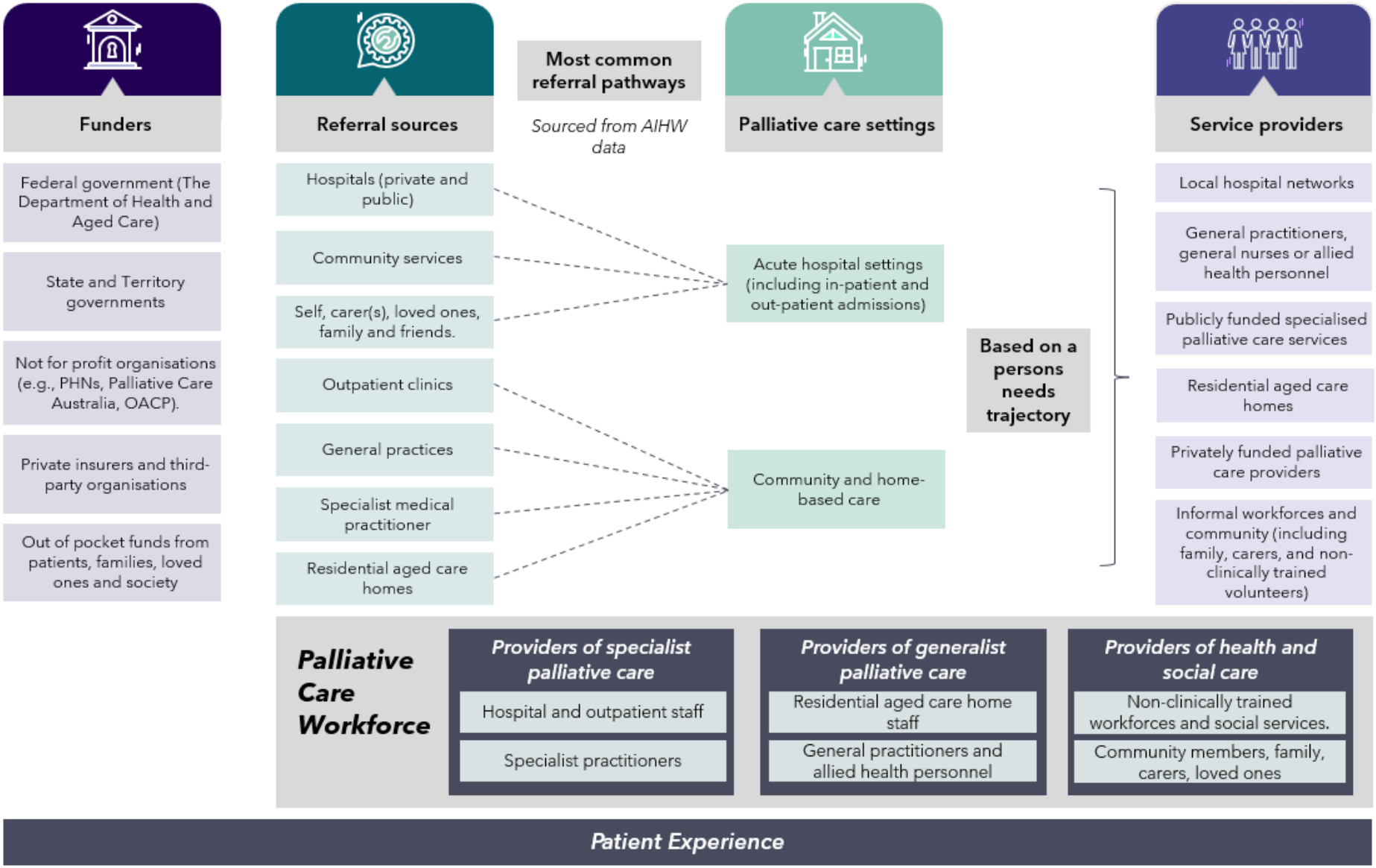
For those requiring palliative or end of life care, there are three broad population cohorts, each of which may require differing level of generalist (delivered by community nurses or general practitioners) or specialist care support:[11]

- 'People with straightforward and predictable needs', which are generally able to be managed in the community through their own resources and support systems, possibly in conjunction with social (such as aged care services) and generalist health care.
- 'People with intermediate and fluctuating needs', who experience intermittent and fluctuating symptoms that may result in unplanned use of hospital and/or specialist palliative care services.
- 'People with complex and persistent needs', who may have complex physical, psychological, social, and spiritual needs that require dedicated specialist palliative care and shared care models of delivery.

There are several potential entry points into the palliative care system depending on a person's location, and the services available in their region. The most common referral sources into palliative care services include public and private hospitals, outpatient clinics, GPs, specialist palliative care services, RACHs and community services.

[11] https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/02/PalliativeCare-Background-to-Service- Delivery-2018_v3.pdf

Figure 4: Australian palliative care service system



As outlined in Table 1 in general terms there are three groups of palliative care providers.

Table 1: Summary of palliative and end-of-life services and providers in Australia

Care type	Providers	Core competencies
Providers of health and social care	Likely to be non-clinically trained workforces or volunteers (e.g. with Cert IV, V, etc.), members of the community, or part of related facilities and social services.	Social, psychological, and spiritual support. Community, disability, aged and social service care. Grief and bereavement care and support.
Providers of generalist palliative care	Likely to be health professionals with primary or initial responsibilities for health needs of a person. This may include GPs, practice and home care nurses, geriatricians, and allied health personnel.	Basic management of pain and symptoms. Basic management of psychological support. Basic discussions about prognosis, goals of treatment, suffering, code status.
Providers of specialist palliative care	Likely to be health professionals that have been referred people with more complex and persistent symptoms which can only be managed by secondary care. This may include oncologists or specialised and trained palliative care nurses and doctors.	Management of pain that cannot be readily controlled or other symptoms. Management of more complex psychological support, including grief and existential distress. Assistance with conflict resolution regarding goals or methods of treatment. Assistance in addressing cases near futility.

Source: https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/02/PalliativeCare- Background-to-Service-Delivery-2018_v3.pdf

2.1.2 Palliative care service use and demand

According to the Australian Institute of Health and Welfare (AIHW):[12]

- The average age of patients was 74 years old, with 50% of palliative care related hospitalisations ending with the patient dying in hospital.

[12] AIHW (2023). Palliative Care Services in Australia. Available at: www.aihw.gov.au/reports/palliative-care-services/palliative- care-services-in-australia/contents/about

- In 2021-22, only 4,800 people were assessed (via an Aged Care Funding Instrument appraisal) as requiring palliative care in their permanent RACH setting, against the 245,000 people aged 65 and over entering residential care and home care that year.
- Total expenditure on specialist palliative care under MBS was $5.6 million in 2021-22. There were 1.3 million palliative care-related prescriptions provided to 453,300 people, with 89% of these prescribed by GPs.

Demand for palliative care services in Australia is expected to grow in coming years. Australia's population is expected to grow to 30 million by 2030 and people aged over 85 will comprise around 2.8 % of the population. More people will live with multiple and complex chronic diseases, with high symptom burden, and for longer duration.[13]

Despite demand for palliative care, in 2020 there were only 300 palliative medicine physicians, and 3,800 palliative care nurses employed in Australia (compared to over 25,000 GPs).[14] The data demonstrates inequity of access by geographic setting; most of the employed palliative physicians (80 %) work in major cities and 75 % work in a hospital setting. Similarly, three-quarters of nurses work in major cities with 56 % working in hospital settings.[15]

To meet growing demand for palliative care, Australia must maintain and strengthen its palliative care sector, creating more opportunities for integration and provision of multi-disciplinary care. This will require ongoing investment and clear employment pathways to reach the benchmark set by Palliative Care Australia (PCA) of two FTE specialist palliative medicine physicians and 3 palliative care nurses per 100,000 population.[16]

2.2 Palliative care policy and reform in Australia

There are several national policies, strategies and frameworks for Australia's palliative care system. Prominent among these are The 2013 National Palliative Care Standards and The 2018 National Palliative Care Strategy.

The 2018 National Palliative Care Strategy represents a commitment from the Commonwealth, state, and territory governments to ensure quality palliative care. This vision is stated as a commitment that "people affected by life-limiting illnesses get the care they need to live well."[17] It cements the understanding that palliative care should be a holistic process including physical, psychological, social, emotional, and spiritual care. It also acknowledges that palliative care is not equally available to all people because of geography, awareness, economics, workforce, and accessibility, particularly for people from underserved communities.

[13] PCA (2019). Palliative Care 2030. Available at: https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2019/02/ Palliative-Care-2030-public.pdf

[14] Ibid.

[15] PCA (2019). Palliative Care 2030. Available at: https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2019/02/ Palliative-Care-2030-public.pdf

[16] Ibid.

[17] www.health.gov.au/sites/default/files/the-national-palliative-care-strategy-2018-national-palliative-care-strategy-2018.pdf

The 5th edition of the National Palliative Care Standards outlines an 'ideal' palliative care experience in Australia including initial and ongoing holistic assessment, partnership driving communication, informed decisions, family, and carer inclusion, integrated person-centred care, and qualified workforces who are supported in their roles.[18]

There are also several other intersecting and relevant national policies, referencing palliative and end of life care as part of its priorities and actions. This includes palliative care being a key consideration in several recent sector reforms, such as Aged Care. Several initiatives in existing National Palliative Care Projects funded by DHDA intersect with the GCfAHPC Program.

Similarly, state and territory governments have a role in the palliative care system, as do peak bodies and advocacy groups.

2.3 'Dying well' and best practice palliative care

'Dying well' is defined as "a death that is free from avoidable distress and suffering, for people, family, and caregivers; in general accord with the person's and families" wishes.[19] In 2015, the Australian Commission into Safety and Quality in Health Care released a National Consensus statement, outlining the 10 key features of best practice EOLC:[20]

4 Patients are part of decision making about EOLC.
5 Clinicians work together to provide EOLC.
6 Clear goals improve the quality of EOLC.
7 Triggers identify when patients need EOLC.
8 Clinicians get help to rapidly respond to patient suffering.
9 There are policies and systems in place for EOLC.
10 Clinicians have the skills and knowledge to provide EOLC.
11 Clinicians are supported.
12 The quality of EOLC is measured and improved.
13 Systems align with National standards to improve outcomes.

[18] https://palliativecare.org.au/publication/standards

[19] Institute of Medicine, Washington

[20] www.safetyandquality.gov.au/sites/default/files/migrated/National-Consensus-Statement-Essential-Elements-forsafe-high- quality-end-of-life-care.pdf

Baseline Report

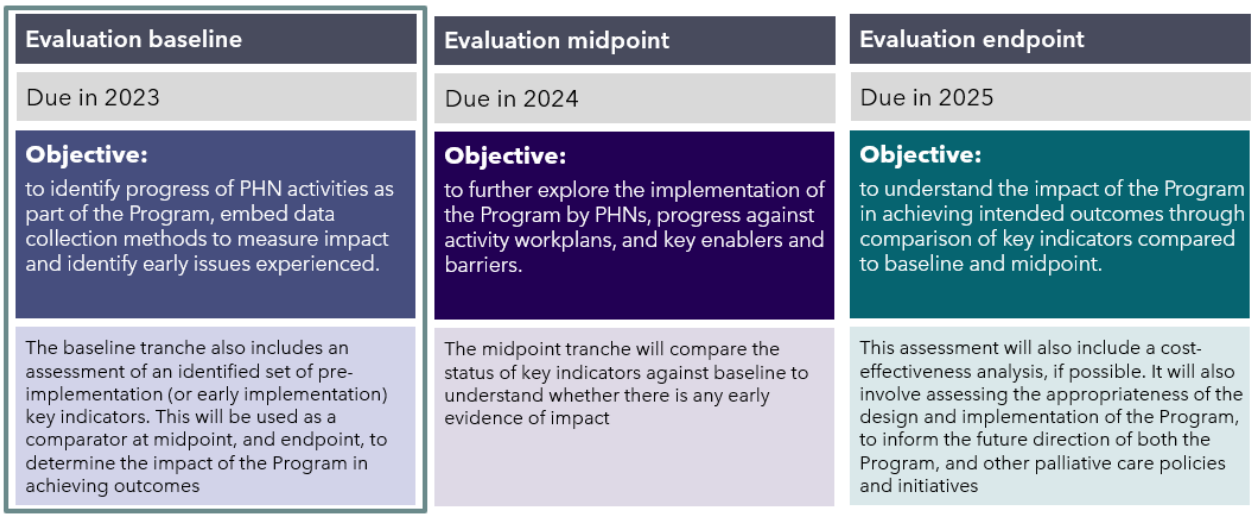
Approach to the Evaluation

3 Approach to the Evaluation

3.1 Evaluation phases

The Evaluation of the GCfAHPC national Program has been designed as a core component of the Program. It is a three-year, prospective evaluation including three key phases of data collection and analysis; Baseline, Midpoint and Endpoint. Key features of each evaluation phase are described below.

Figure 5: Evaluation phases: Baseline, Midpoint and Endpoint



3.2 Program Logic

A Program Logic has been developed to capture the objectives, inputs, activities, outputs, and outcomes of the Program. It has been iteratively developed in partnership with DHDA and has been refined over the course of a series of workshops and consultations with all 31 PHNs. The Program Logic comprises four key elements:

- Objectives – what the program is intended to deliver
- Inputs and activities – the resources, investments, actions and processes needed to deliver the Program
- Outputs – the tangible products and processes generated as a result of the Program
- Outcomes – the changes to knowledge, beliefs, behaviours, and to the system because of the Program. Outcomes are grouped into short, medium and long term. Subject to data quality and scope, outcomes can be assessed by population groups if applicable to the relevant activity (e.g., Aboriginal and Torres Strait Islander Australians or individuals from culturally and linguistically diverse background)

Figure 6: GCfAHPC Evaluation Program Logic

Evaluation Objectives	Inputs	Activities	Outputs	Outcomes		
				Short-term (<1 year)	Medium-term (1-3yrs)	Long-term (3+yrs)
Improve access to palliative care at home and support end-of-life systems and services in primary care, community care, and after hours	Pilot evaluation and findings	Understand needs and preferences of consumers, families, and carers through consultations	Needs assessments	Increased person/carer awareness of palliative care options (including ACP) and choices	Improved person/carer access and uptake of at-home and community based palliative care options and services	Greater community awareness that palliative and end-of-life care includes shared community responsibilities
		Collated existing data and identify insights, gaps and duplication	Service/system maps			
	Commonwealth funding for PHN FTE resources			Increased workforce knowledge of services and choices available for people	Increased access to services (including culturally appropriate services)	
Enable right care, at the right time, at the right place to reduce unnecessary hospitalisations		Identify and map areas for development in end-of-life care and palliative care	Activity Work Plans			People/carers palliative care choices and needs increasingly being met
	Community stakeholder consultations (individuals, carers, clinical/non-clinical providers)				Increased completion of Advance Care Plans	
		Build community capability/capacity and/or awareness about end-of-life and palliative care and embed community engagement	Education, training and awareness campaigns/resources	Increased workforce confidence and skills for people (including culturally appropriate services)		
Use available technologies to support flexible and responsive palliative care at home, including in the after hours period	Existing strategies, guidelines and frameworks	Deliver education and training to meet the needs of the workforce and to build capacity	Documented referral pathways (existing/newly designed)		Increased and consistent use of streamlined services and appropriate referral pathways	Family and carers have a greater knowledge of what to expect and are better prepared for the death of a family member (including bereavement)
		Develop Continuous Quality Improvement processes to improve the quality of palliative and end-of-life care		Increase in flexible and responsive palliative care supported through use of available technologies		
	Existing evidence, tools, training and resources		Mechanisms for collaboration and integration between PHNs, service providers and the community		Increased collaborative coordination and integration across and between service providers	
Generate and use data to support continuous improvement of services across sectors	Existing data sets and data collections tools	Develop and implement models of care coordination that meet objectives	New Models of Care, tools and resources	Increased awareness and acceptance of new approaches to data collection, sharing, reporting and use	Improved collection, monitoring and reporting of palliative care data	Acceptance and uptake of a core palliative care dataset supported by key partners

3.3 Evaluation Framework

To guide the Evaluation, 16 lines of enquiry (LoEs) were developed in consultation with DHDA and all 31 PHNs to assess the design, implementation, appropriateness, effectiveness and value for money of the Program. The LoEs are designed to support and structure the Evaluation and are mapped against the Quintuple Aim Framework domains,[21] which are widely used by PHNs to determine the impact of projects and commissioned services.

Table 2: GCfAHPC Evaluation Lines of Enquiry

Lines of Enquiry (LoE)	
Population Health	
1	To what extent has the Program reduced preventable hospitalisations?
2	Is the design of the Program appropriate and effective in achieving the Program objectives?
3	How appropriate is the current funding and resourcing model to enable PHNs to meet the Program objectives? Is this consistent across PHNs?
4	How effective have governance arrangements been for implementing and achieving the objectives of the Program?
5	To what extent do activities/initiatives implemented by PHNs align with Program objectives?
6	How appropriate are PHN activities and initiatives in meeting the preferences and needs of individuals/carers/workforce?
7	Has the Program been implemented as planned (within PHNs, as well as nationally)?
8	To what extent are services coordinated, integrated, and are able to provide continuity of palliative care?
9	To what extent has the Program generated and used data to support continuous improvement of services across sectors?
Patient Experience	
10	To what extent has awareness of palliative care in the community (including family and carers) increased?
11	To what extent has the Program increased individual awareness of palliative care options and choices (including ACP completion and end-of-life planning)
Value for Money	

[21] DHDA (2018). PHN Program and Performance Quality Framework

Lines of Enquiry (LoE)	
12	How cost-effective is the Program?
Provider Experience	
13	To what extent has the Program increased workforce knowledge and awareness of palliative care options and services available for individuals?
14	To what extent has the Program increased workforce confidence and skills in providing palliative care services available for individuals?
Equity	
15	To what extent has the Program improved access to palliative care at home and in the community?
16	How appropriate is the Program at meeting the needs and preferences of families, individuals and carers?

The Evaluation Framework captures process and outcome-based LoEs. Process LoEs assess the type of Program activities chosen, and the implementation of the Program. Outcome-based LoEs assesses how successful GCfAHPC is in delivering its intended outcomes and objectives through the measurement of impact.

3.4 Data collection approach and tools for the Evaluation

The data collection approach and tools for the Evaluation were co-designed with PHNs, DHDA, and other key stakeholders. A desktop scan was conducted to identify palliative and EOLC datasets and tools that could be used as part of the national GCfAHPC Evaluation. This included:

- Review of documents and materials relating to the pilot evaluation.
- Datasets and tools identified through consultation with PHNs.
- Rapid, targeted scan of available literature on palliative care data collection in Australia.

While the datasets and tools already in use, planned for, or being considered by PHNs is extensive, the assessment focused on those with the potential for broad, if not national use, across PHNs. The datasets and tools identified were then assessed based on:

- Relevance
- Reliability
- Availability (i.e., ease of data access / collection)
- Ease of implementation / uptake (i.e., is, or could be, used nationally, or for a subset of PHNs)

Based on this assessment, a set of datasets and tools were selected for use across the multi-stage Evaluation. Chapter 5 outlines a detailed explanation of those, as well as the intended outcomes.

3.5 Baseline data collection and analysis

Baseline data collection for the Evaluation was conducted between June and August 2023. As part of this tranche the following data was collected and analysed:

- Semi-structured interviews with all 31 PHNs on processes, and implementation, of activities as part of the Program.
- Online PHN survey (58 responses received representing 30 PHNs).
- Online palliative care service provider survey (233 responses received across 29 PHN regions).
- Materials submitted from PHNs including, but not limited to, program documentation, progress reports, post-event survey results, event attendance / participation data, etc, relating to activities.
- Australian Institute of Health and Welfare (AIHW) Palliative Care Services in Australia dataset.

Data has been analysed and synthesised to determine scale and type of PHN activities as part of the Program, which has assisted to identify challenges experienced by PHNs, and opportunities to improve implementation of activities.

Baseline data has also been used to establish a set of key local and system-wide indicators that will be used as a comparator at Midpoint, and Endpoint, to determine the impact of the Program in achieving outcomes. These indicators are discussed in section 4.2 Key activities in PHN workstreams and Appendix D: Baseline indicators and .

3.6 Limitations and considerations

Baseline tranche findings should be considered in the context of the following caveats:

- Causality – While it may be possible to identify overall trends across PHNs, and PHNs that share similar characteristics, any findings derived will be associative rather than causal in nature. We will identify and report on other programs and variables that may influence outcomes and findings of the evaluation.
- Limited data availability – This Evaluation has been challenged by a paucity of data. There is limited nationally relevant data examining palliative care in Australia and PHNs have described gathering data from local service providers as challenging.
- Low response rates – Stakeholder surveys have received generally low response rates. This impacts the reliability of conclusions that can be drawn from such small datasets.

Cognisant of this limitation, the Baseline report has taken care to triangulate findings from a range of sources to improve the reliability of conclusions.

Methodological limitations that are specific to certain data points or sources analysed within this report are provided in line with the associated analysis.

Baseline Report

PHN Activity Summary

4 Overview of PHN Activities at Baseline

Each PHN is implementing activities to variable extents. In particular, the 11 Pilot PHN sites have made significant progress as they have been able to build on prior work and knowledge.

PHN activities at Baseline were identified through a combination of Activity Work Plans (AWPs), and consultations. It is evident that, enabled by the flexibility of the Program guidelines, a broad range of activities are being implemented across PHNs to meet the needs of local communities. PHN activities are summarised in the Baseline PHN Activity Catalogue, which provides a point-in-time reference of activities undertaken.

PHNs activities can be categorised into four workstreams: workforce education and awareness; awareness in the community; meeting palliative care needs and preferences; and coordination and integration of services.

4.1 PHN workstreams

At the beginning of the Program, PHNs were required to conduct Needs Assessments to understand palliative care gaps and priorities for their local communities. Based on these, PHNs have been tasked to 'design and implement innovative and locally appropriate initiatives.'[22] The types of activities that PHNs can implement can be categorised into the following workstreams:

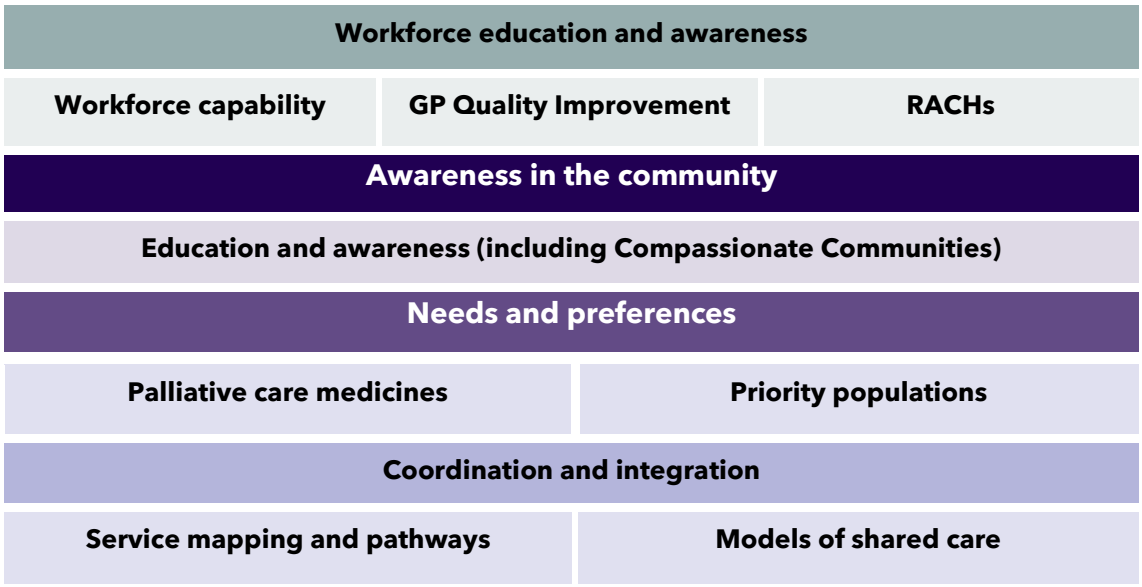
- Workforce education and awareness
- Awareness in the community
- Supporting needs and preferences, and
- Improving coordination and integration.

Through these key workstreams, PHNs are/will target activities that are driving a cultural and behavioural shift towards end-of-life care planning and developing choice in death and dying.

Each year PHNs document the activities they intend to implement in an AWP, with annual updates reported to DHDA. These activities are summarised in. Based on these workstream groupings a list of activities and status, by PHN, is summarised in Table 3.

[22] DHDA (2021). PHN Program Expansion of the GCfAHPC Measure Grant Opportunity Guidelines

Figure 7: PHN activity workstream groups



4.2 Key activities in PHN workstreams

4.2.1 Workforce Education and Awareness

PHNs have commenced a range of activities to improve workforce capability including education and training, working with GP practices on Quality Improvement (QI) activities, and working with RACHs to support workforce education and awareness of palliative care and ACPs.

Overview of Workforce Education and Awareness sub-categories

Table 3 below is a further breakdown of the activities within each subcategory by rurality, pilot vs non pilot and jurisdiction as a point in time capture.

Table 3: PHNs undertaking Workforce Education and Awareness activities by sub-category and PHN characteristics

	Total PHNs	Rural PHNs	Metro PHNs	Pilot PHNs	Non-pilot PHNs	Activities by jurisdiction
Workforce capability	26	14	12	9	17	NSW: 9, QLD: 6, VIC:6, ACT: 1, SA: 2, NT: 1, TAS 0, WA:1
RACH	16	7	9	7	9	NSW: 6QLD: 4, VIC:2, ACT: 1, SA: 1 NT: 1, TAS 1, WA:0

	Total PHNs	Rural PHNs	Metro PHNs	Pilot PHNs	Non-pilot PHNs	Activities by jurisdiction
GP QI	6	5	2	2	4	NSW: 1, QLD: 0, VIC:4, ACT:0, SA:0, NT:0, TAS 1, WA:0

PHN Activity Snapshot

To support standardised implementation of the PIPQI Program across GP practices in their region, Murray, Gippsland, and Western Victoria PHNs, as a Regional Victorian Palliative Care Collaborative, have created a 'Palliative Care Quality Improvement in General Practice' protocol and implementation toolkit.

The toolkit was co-designed with input from a Clinical Advisory Panel. Each PHN will recruit 4-8 general practices to participate in the 12-month QI intervention program. Interested practices will be able to register to participate in the PIPQI measure through an agreed inclusion criterion and be given a QI facilitator to support the process of quantitative data collection through GP medical record data and relevant surveys.

Workforce capability

Most PHNs (26 of 31) have planned to or are implementing activities to improve workforce capability in palliative care. Workforces that PHNs target education and awareness initiatives towards include GPs and nurses, health care professionals, allied health service providers, paramedics, and aged care.

There is diversity in the way workforce capability initiatives are being delivered. There is also variation in the scale and implementation PHNs have made in developing and delivering education, training and knowledge sharing. Key delivery methods and examples of workforce capability building initiatives undertaken by PHNs in their regions are outlined below.

Workforce education activities:

- Delivering education events, such as workshops, lunch and learns, webinars, eLearn modules and evening events to engage GPs. Topics explored include ACP awareness, dementia- education, digital technologies, pain management, syringe driver use, symptom management and confidence in holding conversations about death and dying with people and carers.
- Using partnerships with other PHNs, private organisations, universities, Hospital and Health Services (HHSs), LHDs and specialist palliative care services to administer education sessions. PHNs have partnered with state and territory palliative care peak bodies and nationally funded projects, such as PEPA, ELDAC, CareSearch, ACP Australia, OACP, La Trobe University, Dementia Australia, among others.

- Developing GP education sessions that can be claimed under Continuing Professional Development (CPD) hours and accreditation, as approved by the Royal Australian College of General Practitioners (RACGP). This incentivises GPs to engage in education and training, without renumeration.

Workforce quality improvement activities:

- Establishing 'grand rounds' for GPs to advise and discuss palliative care case studies with palliative care specialists.
- Subsidising and supporting GPs and practice nurses to gain PEPA placements as well as scholarships in achieving palliative care graduation certificates or upskilling courses.

Developing resources for the workforce:

- The creation of care guidelines for paramedics and first responders in palliative care service provision.
- Producing toolkits, learning modules, and programs for health professionals to partake in, that include ACP education, data sharing improvements and key data collection activities such as After Death Audits.
- Developing resources for education purposes such as booklets/ handbooks, and online webpages.

GP Quality Improvement (QI)

Currently 6 of 31 PHNs are undertaking GP Quality Improvement (QI) activities, with one PHN planning and scoping the feasibility to implement this in their region. This includes engaging in recruiting interested practices to participate in quality improvement activities relating to palliative care, as well as case coordination and management activities, data collection and reporting, education and awareness and identifying early palliative care symptoms.

While the QI toolkit and activities are viewed favourably by PHNs, few have chosen to pursue this activity (currently) as part of the Program. This could be due to existing saturation of GP quality improvement activities as part of other programs, and limited capacity as it requires strong buy-in and significant investment of time from GPs.

Residential aged care homes

16 of 31 PHNs are currently planning or have implemented activities targeted towards RACHs' workforce and systems. As aged care and palliative care services and workforces are well linked, the aged care sector often encounters people who require palliative care services.

PHN activities focused on workforce education and awareness in RACHs have included:

- Palliative care training and education targeted towards, nurses, care workers and trained aged care volunteers. Topics include pain medication management, Advance Care Planning, recognising resident deterioration, syringe driver use, and supporting bereavement and loss.

- Supporting the implementation of PACOP, ELDAC, and palliative care data collection in RACHs.
- Supporting the uptake of palliative care IMPREST systems in RACHs. Currently medicines, including those for palliative care, are supplied for specific residents, not as 'ward stock' to RACHs. The IMPREST system serves as a stock management process for timely access to palliative care medicines.
- Supporting the use of PainChek, a digital health tool which utilises AI technology to assess facial movements to detect symptoms of pain in residents and provides pain scores that can be associated with best-practice care. One PHN is providing subscriptions to the tool for use in RACHs, and for pain and deterioration assessment training.

4.2.2 Measuring impact of Workforce Education and Awareness

As part of the Baseline tranche, a suite of primary data collection methods and tools were co-designed and distributed for PHNs to use in monitoring their activities. As part of Midpoint and Endpoint, we anticipate more widespread use and embedding of these tools as part of 'business as usual' practices for Program activities.

The key data tools which could assist to provide evidence for impact of workforce education and awareness at Midpoint and Endpoint include:

- Post-event survey data
- Death Literacy Index (DLI forms)
- After Death Audit forms
- Other PHN documentation (summary / evaluation reports, activity reports, and potential web-based data such as clicks, views and unique users etc.)

This will be supplemented by an analysis of publicly available datasets such the AIHW Palliative Care Services in Australia datasets, and the Palliative Care Outcomes Collaboration (PCOC). AIHW currently reports data on GP and palliative care specialist prescription behaviour and patient outcomes benchmarks, which could indicate potential Program impact on workforce education and awareness.

4.2.3 Awareness in the Community

PHNs are currently planning or have implemented activities with the aim of raising awareness and education of palliative care in the community. This includes implementation of the Compassionate Communities model, and work to improve death literacy.

Overview of Awareness in the Community category

Table 4 below is a further breakdown of the activities within each subcategory by rurality, pilot vs non pilot and jurisdiction as a point in time capture.

Table 4: PHNs undertaking Awareness in the Community activities by PHN characteristics

	Total PHNs	Rural PHNs	Metro PHNs	Pilot PHNs	Non-pilot PHNs	Activities by jurisdiction
Community awareness and education	20	13	7	7	13	NSW: 9, QLD: 5, VIC: 2, ACT: 0, SA: 2, NT: 0, TAS 1, WA:1

PHN Activity Snapshot

Central Queensland, Wide Bay, Sunshine Coast PHN in partnership with the QLD Office of Advance Care Planning (OACP) have developed an Advance Care Planning (ACP) in the community project, aimed to raise awareness and understanding of ACPs. This included establishing community champions and has supported 500 people with demonstrated improved confidence and awareness in participants.

Community awareness and education

More than half of PHNs (20 of 31) are planning to or have implemented activities that target people, families, carers and loved ones in their communities. The aim of many of these activities is to increase knowledge of palliative care options and improve death literacy and confidence in talking about death.

Many PHN activities are in the scoping and planning phases of their engagement with their community. For some PHN activities this involves one-off awareness events while others involve a schedule of community events and activities as part of work to implement the Compassionate Communities model.

Activities PHNs have commenced to improve awareness in their communities include:

- The development of resources such as guides, booklets/handbooks, and webpages for the community on palliative care, Advance Care Planning, and available services and supports. Audiences for these resources include carers, families, loved ones and individuals themselves.
- Engaging communities and relevant community organisations in key palliative care dates such as Dying to Know Day and Palliative Care Week to promote Advance Care Planning and increase death literacy.
- Commissioning organisations to deliver face-to-face or online courses for carers such as the international standardised Last Aid program.
- Promotion, ongoing support and maintenance of 'Lately', a digital tool that provides end-of-life options and advice to community.
- Facilitating community workshops, educational morning teas and forums, as well as supporting the implementation of the Death Literacy Index and other community-appropriate self- assessment tools during these events.

4.2.4 Measuring impact of Awareness in Community

We anticipate that measuring Awareness in the Community will be a limitation in this evaluation, and for PHNs. This is partly due to the prevalence of qualitative storytelling that comes from engaging with community about topics related to death and dying, as well as limited publicly available data indicators for community awareness.

However, as part of Midpoint and Endpoint, the key data tools that could assist to provide a level of evidence for awareness in the community include:

- Post-event survey data
- Death Literacy Index (DLI forms)
- Office of Advanced Care Planning (OACP) ACP completion data for Queensland PHNs.

The Death Literacy Index, while a useful tool to monitor the potential impact of awareness due to PHN activities, it should be noted that it is currently being refined to increase its appropriateness it is used with workforces and First Nations people.

4.2.5 Needs and preferences

PHNs are currently planning or have implemented activities to better meet the palliative care needs and preferences of people at home and in the community through improving access to palliative care medicines and focusing on priority populations in their regions.

Overview of Needs and Preferences sub-categories

Table 5 below is a further breakdown of the activities within each subcategory by rurality, pilot vs non pilot and jurisdiction as a point in time capture.

Table 5: PHNs undertaking needs and preference activities by sub-category and PHN characteristics

	Total PHNs	Rural PHNs	Metro PHNs	Pilot PHNs	Non-pilot PHNs	Activities by jurisdiction
Palliative care medicines	7	2	5	3	4	NSW: 2, QLD: 1, VIC:4, ACT: 0, SA: 0, NT: 0, TAS 0, WA:0
Priority populations	8	2	6	5	3	NSW: 3, QLD: 2, VIC:0, ACT: 0, SA: 2, NT: 0, TAS 0, WA:1

PHN Activity Snapshot

Eastern Melbourne, North Western Melbourne and South Eastern Melbourne PHNs in collaboration with the Pharmaceutical Society of Australia have created a metropolitan-wide

approach to developing interactive maps of community pharmacies that stock core palliative care medicines. This is also in progress in South Western Sydney PHN.

Palliative care medicines

5 of 31 PHNs are planning to or are undertaking initiatives that aim to improve access to palliative care medicines in their region. As part of this activity, PHNs are:

- Partnering with Pharmaceutical Society of Australia (PSA) to obtain a list of community pharmacies that stock core palliative care medicines in their regions. This may include having to reconcile several sources into one core list.
- Working with PSA to enlist more community pharmacies to stock the core palliative care medicines, and support knowledge sharing with pharmacists.
- Mapping community pharmacies across the region for use by GPs, with some PHNs aiming to turn this into interactive online maps.
- Working with Palliative Care Australia (PCA) to list 'palliative friendly pharmacies' that stock all five core categories of end-of-life medications (based on the Queensland Core End of Life medicines list) on the Commonwealth supported National Palliative Care Services Directory accessible to prescribers and pharmacists.
- Providing subsidisations, access to or training on emerging palliative care technologies to assist aged care facilities in managing their palliative care medicine stock ahead of urgent need. Examples include the IMPREST system in RACHs, and services such as Pall Consult (formally palliPHARM), a statewide palliative care service available in Queensland.

Priority Populations

6 of 31 PHNs are currently planning or have implemented activities that target identified priority populations in their regions. This refers to activities that aim to improve palliative care services for, but not limited to, the following communities:

- Aboriginal and Torres Strait Islanders
- CALD and migrant populations
- People living with disability
- LGBTQIA+ populations
- Homeless populations

Many PHNs are in the scoping and planning phases of their activities that target priority populations, and there is significant variety, as expected, in the initiatives being rolled out. Activities being designed or implemented include:

- Establishing relationships with service providers to understand palliative care needs of First Nations people, with intention to co-create culturally appropriate education and training and death literacy initiatives.

- The progression of disability action plans and knowledge frameworks to support service providers in understanding palliative care needs of people with a disability.
- Collaborating with organisations such as 2M Language Services to facilitate workshops for interpreters who work in health networks to have conversations about palliative care, death and dying in their languages.
- Tailoring the GoShare tool to be culturally appropriate such that Community Elders at each LHN can speak to their communities about ACPs, palliative care and dying on Country.
- Education and training of health professionals at Aboriginal Community Controlled Health Organisations that provide chronic disease management to Aboriginal and Torres Strait Islander people on how to recognise deterioration, understand trajectories of chronic disease, what palliative care is, services available, and how to support people with Advance Care Planning. This includes building knowledge on cultural nuances and customs in relation to how different First Nations communities talk about death and dying.

4.2.6 Measuring impact of Needs and Preferences

As part of Midpoint and Endpoint, we anticipate that Palliative Care Medicines and Priority Populations will have differing data inputs to evidence potential Program impact.

The key data tools which could assist to provide evidence for impact for needs and preferences include:

- Post-event survey data – particularly in relation to increasing awareness of culturally appropriate palliative care service provision, or education for priority population groups.
- PHN activity summary and evaluation reports – particularly from activities that relate to Palliative Care Medicines.
- Other PHN documentation (including uptake of resources, and potential web-based data such as clicks, views and unique users etc).

This will be supplemented by an analysis of publicly available datasets such the AIHW Palliative Care Services in Australia datasets, and the Palliative Care Outcomes Collaboration (PCOC). AIHW currently reports data on palliative care hospitalisations by population cohorts, access to palliative care in RACHs by population cohort and patient outcome benchmarks for families and carers.

4.2.7 Coordination and Integration

PHNs are currently planning or have implemented activities such as service mapping to improve palliative care access, coordination, and navigation in their regions.

Overview of Coordination and Integration sub-categories

Table 6 below is a further breakdown of the activities within each subcategory by rurality, pilot vs non pilot and jurisdiction as a point in time capture.

Table 6: PHNs undertaking coordination and integration activities by sub-category and PHN characteristics

	Total PHNs	Rural PHNs	Metro PHNs	Pilot PHNs	Non-pilot PHNs	Activities by jurisdiction
Service mapping and pathways	14	9	5	3	11	NSW: 8, QLD: 2, VIC:2, ACT: 1, SA: 0, NT: 1, TAS 0, WA:0
Models of shared care	11	7	4	5	6	NSW: 5, QLD: 2, VIC:2, ACT: 1, SA: 1, NT: 0, TAS 0, WA:0

PHN Activity Snapshot

Murrumbidgee PHN have funded a general practice to host monthly multidisciplinary team meetings where all health professionals who care for a patient can discuss aspects of the patient's physical and supportive care needs, divide roles and responsibilities and collaboratively plan appropriate care pathways and referrals.

Service mapping and pathways

14 of 31 PHNs have planned or are already currently implementing activities to support service navigation and updating pathways of referral in their regions. Service navigation of palliative care services has been noted as a key issue by PHNs, due to the complexity and the fragmentation of the landscape. Key activities of PHNs to support service mapping, navigation and pathways include:

- Updating and implementing HealthPathways, a platform used by health practitioners to identify services to refer their patients and the pathways of care that are available. Some PHNs have also linked these with dementia pathways.
- The development of palliative care service directories and navigation resources, for differing audiences in conjunction with LHDs and local health services and networks. Specific directories for priority population journeys have also been created. Some have been published on key sites as interactive maps and webpages.
- Mapping services for inclusion into Care Connect, which is a central information website on services, resources and information targeted towards families and carers.

Models of shared care

11 of 31 PHNs have implemented or are planning to implement models of shared care to support integration and coordination between different stakeholders. This activity is one of the

least common activities to be undertaken by PHNs. This could be because coordination activities require a long-term approach due to the significant engagement and buy-in needed from all stakeholders, including service providers that may be time-poor.

PHN activities include:

- Developing workshops and interventions that support shared knowledge from specialist palliative care clinicians to GPs or nurses in generalist primary care settings.
- Providing funding to enable GP practices to host monthly palliative care multi-disciplinary team meetings and forums.
- The implementation of new models of care, such as after-hours models of care in collaboration with LHDs, RACHs, GP Shared Care models, and GP nurse enhancement models.
- Establishing information sharing pilots with key local health networks to improve joint care and communication provided by multi-disciplinary palliative care teams.
- The build of an interoperability function to better enable eReferrals of palliative care patients from GP medical record systems to palliative care services.
- The creation and launch of tools that enable individuals to self-assess bereavement and share responses with GPs, which supports accurate referrals to bereavement supports.

4.2.8 Measuring impact of Coordination and Integration

We acknowledge that measuring the level of coordination that a PHN is conducting may not often present itself quantitatively. However, an additional 'Partnerships and activity catalogue' to accompany evaluation reports will showcase the breadth of partnerships and coordination that are being undertaken by PHNs to develop and deliver Program activities.

As well as this, tools which could assist to provide evidence for impact of coordination at Midpoint and Endpoint include:

- After Death Audit forms and other examples of joint case management
- HealthPathways and other clinical management information systems data
- Other PHN documentation (uptake of service directories, service maps and resources and potential web-based data such as clicks, views and unique users etc.)

Over time, this workstream (and education and awareness activities) will likely benefit significantly greater than others from the addition of analysis from publicly available datasets such as the AIHW Palliative Care Services in Australia datasets, and the Palliative Care Outcomes Collaboration (PCOC). AIHW may show Program impact through changes in referral sources and settings for palliative care, patient discharges from public hospitals to RACHs, as well as palliative care medicine attendances and case conferenced provided by palliative care specialists.

4.3 Summary of how impact will be measured

The following table provides a summary of data sources that provide evidence of impact based on workstreams, as well as the stage of the evaluation where this will be collected and analysed

Table 7: Data sources that provide evidence of impact

Data source	Will contribute to measuring impact in:			
	Workforce Education and Awareness	**Awareness in the Community**	**Needs and Preferences**	**Coordination and Integration**
AIHW Palliative Care Services in Australia datasets	✓	✓	✓	✓
Palliative Care Outcomes Collaboration (PCOC)	✓	✓	✓	✓
Death Literacy Index (DLI)	✓	✓		
Scyne proposed After Death Audit form	✓			
Post-event attendance surveys	✓	✓	✓	

The following table outlines supplementary data that will be collected from PHNs to augment our understanding of impact.

Table 8: Supplementary data sources collected for this evaluation, where available

Data source	Description
The Program of Experience in the Palliative Approach (PEPA)	PEPA collects pre and post survey data from education and training sessions to the healthcare workforce.
Lumos Program (NSW)	Lumos provides insights on the patient journey through the NSW health system.
HealthPathways	HealthPathways is a web-based portal for health professions to access clinical management pathways, referral advice from specialist services, educational resources for patients, and treatment options.
Post-event attendance form	Post-event attendance form or surveys collect feedback from participants on events conducted by PHNs.
GP practice intelligence system extracts	Clinical intelligence systems designed to support GPs in providing the best patient care.
GP record system extracts	GP record data may include practice data on ACPs, conditions and care provided (palliative care and other).
PalCare Software – Clinical medical record data (VIC)	Web-based palliative care patient information management system, available in real- time.
integrated Real-Time Activity Data (iRAD) Software	The software allows doctors to share patient information between hospitals, general practices and other connected healthcare professionals.
Office of Advance Care Planning (QLD)	Advance Care Planning data including values and preferences for persons with, and without decision-making capacity.
Coping with Death Scale	An assessment tool to measure bereavement and competence in coping with death or dying of a loved one.
Other materials	May include collateral that captures further inputs, activities, outputs and outcomes within the PHN region.

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Appendix A: Glossary

Term	Definition
ACD	Advance Care Directive
ACP	Advance Care Plans
ACPA	Advance Care Planning Australia
ADA	After Death Audit
AIHW	Australian Institute of Health and Welfare
APP	Advanced Personal Plan
AWPs	Activity Work Plans
CoP	Community of Practice
DLI	Death Literacy Index
DHDA	Department of Health, Disability and Ageing
EOLC	End-of-Life Care
FTE	Full Time Equivalent
GCfAHPC	Greater Choice for At Home Palliative Care program
GP	General Practitioner
HELP	Healthy End of Life Program
iRAD	integrated Real-Time Activity Data
KPI	Key Performance Indicator
LoE	Line of Enquiry
MBS	Medicare Benefits Schedule
OACP	Office of Advance Care Planning
PBS	Pharmaceutical Benefits Scheme
PCA	Palliative Care Australia
PCPSS	Palliative Care Problem Severity Score
PACOP	Palliative Aged Care Outcomes Program
PCOC	Palliative Care Outcomes Collaboration
PEPA	The Program of Experience in the Palliative Approach

Term	Definition
PHN	Primary Health Network
QI	Quality Improvement
RACF	Residential Aged Care Facility
SAS	Symptom Assessment Scale
SPaRTa	Specialist Palliative Care Rural Telehealth service

Appendix B: Limitations

This Baseline evaluation should be considered alongside a number of limitations that pertain to:

- Program impact magnitude
- Direct input from families, carers and individuals
- Data limitations

These are overviewed below.

Program impact magnitude

Effective implementation of PHN activities is not likely to drive significant and systemic changes within the palliative care system. Contributing factors to this include:

- Overall Program funding of $37.5 million is likely insufficient to finance significant changes to the delivery of palliative care.
- Planning and implementing activities to support structural changes in palliative care are unlikely to be feasible within the current three-year lifespan of the Program.
- The size, scale and complexity of the palliative care system (including within each PHN region) requires a nuanced approach by PHNs to address the unique needs of their stakeholders. This reduces the likelihood of consistent priorities and activities between jurisdictions and geographies.

Direct input from families, carers and individuals

To date, PHNs had limited opportunity to directly engage with families, carers and individuals as part of Program implementation and design. While many have consumer voices and carer perspectives embedded into their governance processes and consultation, PHNs are not involved in the care delivery pathway and so direct exposure to needs and preferences was limited. This has limited the inclusion of any insights relating to the voices and perspectives of consumers within the Baseline report. A survey targeted towards these families, carers and individuals is to be released during Midpoint and Endpoint to better understand what influence the Program may be having on their needs and preferences.

Data limitations

Palliative care is a growing area of healthcare within Australia that does not currently have a nationally consistent minimum dataset currently to support quantification of total activity or patient throughput. For data that is available, quality is an issue due to inconsistent collection and reporting methods. These present a challenge for leveraging existing data to understand the current state of palliative care in Australia, as well as for monitoring changes over time throughout the Program's implementation.

In addition, the following Program specific data limitations have impacted the Baseline evaluation:

- Inconsistent data collection methodologies and use of tools: PHN approaches to data collection during the Baseline tranche contained some inconsistencies. In a few cases, the use of specific tools intended for subsequent tranches (e.g., the DLI) were used by early adopting PHNs to support the ongoing monitoring and continuous improvement of their activities. Implementation of these tools varied and lacked standardisation, which limited the usefulness of insights. These tools have excluded from the Baseline analysis.

Appendix C: LoE mapping to data collection tools

Table 9: LoEs mapping to data collection tools used in the Evaluation

Data collection tool	LoE(s)
PHN consultations	2, 3, 4, 5, 6, 7, 9.
Scyne provided surveys to PHNs	2, 3, 4, 5, 6, 7, 9.
Scyne provided surveys to service providers	1, 2, 4, 6, 8, 9, 11, 12, 13, 15, 16.
Death Literacy Index	11, 12, 13, 15.
Scyne proposed After Death Audit Form	1, 8, 10, 11, 13, 15, 16.
AIHW National Integrated Health Services Information Analysis Asset (Palliative Care)	1, 8, 10, 11, 12, 14, 16.
Palliative Care Outcomes Collaboration (PCOC)	1, 2, 3, 6, 7, 8, 10, 11, 12, 13, 15, 16.

Key:

#	Line of Enquiry (LoE)
1	To what extent has the Program reduced preventable hospitalisations?
2	Is the design of the Program appropriate and effective in achieving the Program objectives?
3	How appropriate is the current funding and resourcing model to enable PHNs to meet the Program objectives? Is this consistent across PHNs?
4	How effective have governance arrangements been for implementing and achieving the objectives of the GCFAHPC Program?
5	To what extent do activities/initiatives implemented by PHNs align with Program objectives?
6	How appropriate are PHN activities and initiatives in meeting the preferences and needs of individuals/carers/ workforce?
7	Has the Program been implemented as planned (within PHNs, as well as nationally)?
8	To what extent are services coordinated, integrated, and are able to provide continuity of palliative care?
9	To what extent has the Program generated and used data to support continuous improvement of services across sectors?

#	Line of Enquiry (LoE)
10	To what extent has the Program improved access to palliative care at home and in the community?
11	How appropriate is the Program at meeting the needs and preferences of families, individuals and carers?
12	To what extent has awareness of palliative care in the community (including family and carers) increased?
13	To what extent has the Program increased individual awareness of palliative care options and choices (including ACP)
14	How cost-effective is the Program?
15	To what extent has the Program increased workforce knowledge and awareness of palliative care options and services available?
16	To what extent has Program increased workforce confidence and skills in providing palliative care services?

Appendix D: Baseline indicators and hypotheses

As part of the Baseline tranche of the Evaluation a set of key indicators have been identified that are intended to serve as a benchmark for future comparison to assess impact of the Program at Endpoint.

Indicators at a local level are discussed in section 4.2 Key activities in PHN workstreams. These indicators differ according to the category of activity (i.e. Workforce Education and Awareness; Awareness in the Community; Needs and Preferences; and Coordination and Integration). Changes in data between Baseline and Endpoint may be indicative of the GCfAHPC impacting on one or more of these categories. Data sources include:

- Post-event survey data,
- DLI forms
- After Death Audit forms and other examples of joint case management
- Office of Advanced Care Planning (OACP) ACP completion data for Queensland PHNs.
- PHN activity summary and evaluation reports
- HealthPathways and other clinical management information systems data
- Other supplementary PHN data sources (e.g. summary / evaluation reports, activity reports, and potential web-based data such as clicks, views and unique users etc.)

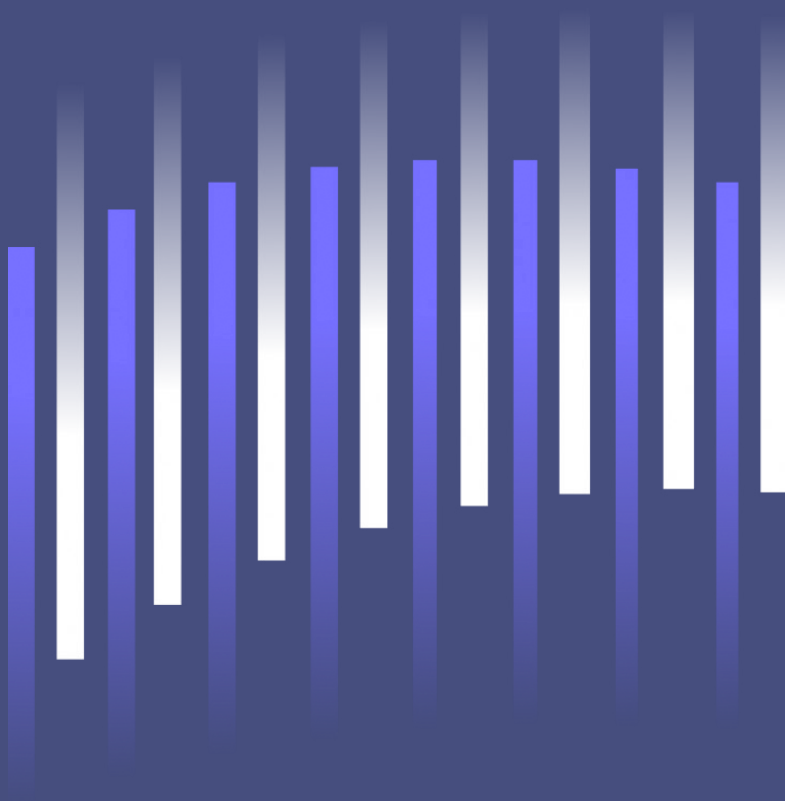
Table 10 below shows selected system-wide indicators, which leverage national palliative care datasets from AIHW. At Endpoint, analysis will be done to determine whether there has been any observable change in these metrics that could be associated with the Program. This will be supplemented with analysis of other system-wide indicators from datasets such as PCOC and OACP.

Table 10: Summary of system wide impact indicators and hypotheses

#	Metric	Indicator	Hypothesis
1A	GPs and palliative medicine specialists prescription behaviour by medication group	Number of prescriptions from GPs and palliative medicine specialists per 100,000 population by medication group, 2021-22.	If the Program is effective there will be more palliative medicine prescription by GPs and less through specialist care. However, because GPs already issue prescriptions for pain relief, it is not clear whether any change will be evident.
1B	Patient outcomes benchmarks	**KPI One:** 60% of patients in moderate /severe pain at phase start must be reduced to absent/mild pain at phase end as rated by the clinician	If the Program is effective, then the severity of pain and other symptoms will reduce at the end of a phase of care. Therefore, patient and community outcomes should improve.

#	Metric	Indicator	Hypothesis
		on the PCPSS tool. **KPI Two:** 60% of patients with moderate/severe distress from breathing problems at phase start reduced to absent/ mild distress from breathing problems at phase end as rated by the patient on the SAS tool.	
2A	Palliative care hospitalisation rate by PHN	Palliative care-related hospitalisations in public hospitals by PHN per 10,000 population, 2020-21	If the Program is effective in driving behaviours that better meet the needs and preferences of individuals, the rate of hospitalisations for palliative care per 10,000 population would be expected to reduce.
2B	Palliative care hospitalisations by population cohort	Hospitalisations for all hospitals, per 10,000 population, 2020-21	If the Program is effective in driving behaviours that better meet the needs and preferences of individuals, the rate of hospitalisations for palliative care per 10,000 population would be expected to reduce. However, this trend may be difficult to observe for certain vulnerable populations.
2C	Access to palliative care in RACHs by population cohort	Residents and admissions to residential aged care homes by population cohort, 2021-22	Increases within admission rates may indicate Program impact as more patients choose to die at home (where 'home' exists within a RACH).
2D	Patient outcome benchmarks for families and carers	60% of patients with moderate/ severe family/carer problems at phase start have problems reduced to absent/mild at phase end as rated by the clinician on the PCPSS tool.	An increase within these figures may indicate positive Program impact.
3A	Referral sources and settings for palliative care	Palliative care episodes by referral sources and settings, 2020-21	Program impact may be reflected in increased referrals within and to the community as people's preferences are better met.

#	Metric	Indicator	Hypothesis
3B	Patients discharged to RACHs from public hospitals by state and territory	Proportion (%) of patients discharged to RACHs from public acute care facilities by state and territory	Discharge rates would increase if integration between service providers and RACHs improve because of the Program.
3C	Palliative medicine attendances and case conferences provided by palliative medicine physicians/ specialists	MBS-subsidised palliative medicine attendances and case conferences provided by palliative medicine physicians/ specialists, 2021-22	Trends within attendances towards other settings and improvements in the case conference to medicine attendance ratio may indicate positive Program impact over time.



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