

Evaluation Plan for the Greater Choice for At Home Palliative Care Evaluation

Department of Health

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Acronyms

The table below outlines the key acronyms referenced throughout the report.

| Abbreviation | Definition |
|--------------|---|
| ACPA | Advance Care Planning Australia |
| AIHW | Australian Institute of Health and Welfare |
| ANOVA | analysis of variance |
| ANZSPM | Australian and New Zealand Society of Palliative Medicine |
| CALD | Culturally and Linguistically Diverse |
| ELDAC | End of Life Directions in Aged Care |
| GCfAHPC | Greater Choice for At Home Palliative Care |
| GP | General Practitioner |
| HREC | Human Research Ethics Committee |
| ICT | Information and Communications Technology |
| NPCP | National Palliative Care Programs |
| OPAN | Older Persons Advocacy Network |
| PCA | Palliative Care Australia |
| PCOC | Palliative Care Outcomes Collaboration |
| PHN | Primary Health Network |
| PREMs | patient reported experience measures |
| PROMs | patient reported outcome measures |
| RACGP | Royal Australian College of General Practitioners |
| RCT | Randomised controlled trial |

Glossary of terms

The table below defines the key terms used throughout the report.

| Term | Definition |
|----------------------------------|--|
| Compassionate Communities | A palliative care framework that aims to promote and integrate social approaches to dying, death and bereavement in the everyday life of individuals and communities. ¹ |
| End of life | The period when a patient is living with, and impaired by, a [terminal] condition, even if the trajectory is ambiguous or unknown. This period may be years in the case of patients with chronic or malignant disease, or very brief in the case of patients who suffer acute and unexpected illnesses or events, such as sepsis, stroke or trauma. ² |
| End of life care | Includes physical, spiritual and psychosocial assessment, and care and treatment delivered by health professionals and ancillary staff. It also includes support of families and carers, and care of the patient's body after their death. People are 'approaching the end of life' when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with advanced, progressive, incurable conditions, general frailty and co-existing conditions that mean that they are expected to die within 12 months, existing conditions, if they are at risk of dying from a sudden acute crisis in their condition, and life-threatening acute conditions caused by sudden catastrophic events. ² |
| Local stakeholders | In the context of this Evaluation Framework, local stakeholders refer primarily to service providers. However for some PHNs, it may also include community members relevant to the activities of the PHNs. |
| Model of care | A model of care defines the way that health services are delivered in a particular context. |
| Palliative care | An approach to treatment that improves the quality of life of patients and their families facing life-limiting illness, through the prevention and relief of suffering. It involves early identification, and impeccable assessment and treatment of pain and other problems (physical, psychosocial and spiritual). ² |
| Palliative care providers | All organisations providing palliative care, including health and social service providers and community members and networks. |

¹ Compassionate Communities Network, <http://www.compassionatecommunities.net.au/>

² National Consensus Statement: essential elements for safe and high-quality end-of-life care, <https://www.safetyandquality.gov.au/publications/national-consensus-statement-essential-elements-for-safe-high-quality-end-of-life-care/>

| | |
|--|--|
| Primary stream | The activity stream that reflects the priority/main mechanism by which the PHN is seeking to affect change and contribute to the Greater Choice objectives. |
| Secondary stream | The activity stream that is supplementary or complementary activity that will support the primary activity. |
| Service pathways/ referral pathways | Service pathways/referral pathways describe the order in which people access palliative care services and the mechanism by which they connect with new services within an existing model of care. |
| Service providers | Any professionals involved in the provision of palliative care services or referral to palliative care services. This may include specialist palliative care providers but also General Practitioners, health professionals at Local Hospital Networks, geriatricians, professionals at hospital palliative care branches, aged care providers or cancer care providers. |
| Agent of change | The immediate target primary user/ audience/ stakeholder of the PHN activities, via whom the longer-term patient and carer level outcomes (as the ultimate beneficiary) will be affected. For example, activities may be directed at palliative care providers as a way to improve access to palliative care at home for patients; other PHN activities may directly target patients and carers with information and awareness raising to achieve the GCfAHPC objectives. The agent of change can be thought of as the "who". |
| Mechanism of change | The ways through which the agents of change will act or change behaviour to contribute to the outcomes and objectives of the GCfAHPC measure. For example, activities may seek to improve provider knowledge about existing services, or change practice in the way they refer; other PHNs may implement a new model of care to provide better access to appropriate patient centred palliative care in their place of choice. The mechanism of change will be related to the agent of change. The agent of change can be thought of as the "how". |

Introduction



1 Introduction

As a precursor to the technical components of the report, this chapter provides contextual information related to the Greater Choice for At Home Palliative Care (GCfAHPC) measure, and outlines the scope and structure of the Evaluation Plan.

1.1 Background

Holistic palliative care services include physical, spiritual, and psychosocial assessment and care, delivered by health professionals and ancillary staff to people who are likely to die in the next 12 months. In Australia, end-of-life care is heavily institutionalised, with about half of Australians dying in a hospital, and a third in residential care.

Despite evidence suggesting that around 70% of people have a preference for dying at home, only 15% do die in their own home (Palliative Care Australia, 2017). Dying outside of home often leaves patients with a low quality of life as they experience feelings of disempowerment and loneliness during their final days. Home-based end-of-life care has been shown to improve the quality of life for the patient, and could be more cost effective than hospital-based care, particularly as the population ages.

Greater Choice for At Home Palliative Care measure

The GCfAHPC measure provides funding for palliative care coordination through Primary Health Networks (PHNs). The GCfAHPC measure is being trialled by 11 PHNs in six states covering metro, rural/regional and remote areas to improve coordination of care to ensure patients receive the right care in the right place at the right time. The locally-delivered nature of the GCfAHPC measure allows for the integration of palliative care with other forms of healthcare and community services more broadly. It also enables better engagement with underserved population groups including Indigenous Australians, and culturally and linguistically diverse (CALD) individuals.

Administering the GCfAHPC measure through PHNs aligns with the **2018 Final National Palliative Care Strategy**, which highlights the importance of both providing care at home and providing care locally in ways that integrate with the local community. The Draft Strategy notes that PHNs and local hospital or health networks as well as Aboriginal community-controlled health services, private and non-profit providers all have a contribution to make in working together to reduce duplication and unnecessary transfers to hospital where care could be provided in a more appropriate setting. A number of the PHNs receiving funding from the GCfAHPC measure are engaging with the **Compassionate Communities framework**. The framework has begun to be implemented in Victoria and Tasmania and aims to explore the role local government can perform in engaging local community organisations and individuals in providing support to people nearing the end of their lives.

1.2 Scope of the evaluation

The purpose of this document (the Evaluation Plan) is to set out the approach that will be undertaken to evaluate the GCfAHPC measure, including all relevant considerations relating to the planning and implementation of the evaluation.

Specifically, the objectives of this evaluation are to:

- Assess the implementation, appropriateness, effectiveness and costs of GCfAHPC measure;
- Identify the barriers and enablers to achieving intended outcomes;
- Identify any efficiencies and strategies for optimising sustainability and scalability; and
- Identify issues to inform palliative care policy development.

The main tasks pertaining to this evaluation are listed in Table 1.1.

Table 1.1: Key deliverables and timeframes for the GCfAHPC evaluation

| Deliverable | Details |
|---|--|
| Project plan: <i>Delivered July 2018</i> | <p>The project plan detailed the proposed process to develop and undertake the evaluation, including:</p> <ul style="list-style-type: none"> • details of all staff involved in carrying out the project; • a description of all activities to be undertaken; • a project schedule including timeframes and deliverables; • a stakeholder consultation plan outlining the key stakeholders that will be consulted throughout the project and any risks or sensitivities associated with this approach; and • a risk management plan. |
| Consultation, survey and workshops <i>Commenced in August 2018 and will continue until January 2019</i> | <p>Engage and consult with relevant stakeholders including the:</p> <ul style="list-style-type: none"> • 11 PHNs selected to implement the GCfAHPC measure; • Australian Government Agencies including the Department of Health and the Australian Institute of Health and Welfare (AIHW); • University of Wollongong – Palliative Care Outcome Collaborative (PCOC); • Palliative Care Australia and state member organisations; • Palliative care stakeholders from states and territory governments; and • Aged Care, CALD, Aboriginal and Torres Strait Islander, Regional & Remote representatives. <p>Convene two workshops with the 11 PHN pilot sites during the course of the project, which may include a face-to-face workshop.</p> <p>Participate in GCfAHPC Working Group teleconferences as the Evaluation expert.</p> <p>Survey and consult relevant stakeholders as part of the consultation activities outlined in Chapter 5.</p> |
| Evaluation plan <i>Final plan due: January 2018</i> | <p>Develop an Evaluation Plan (in discussions with the Department, it was agreed that the Evaluation Plan would include the 'Evaluation Framework') and conduct the evaluation for the GCfAHPC measure in consultation with stakeholders, which includes:</p> <ul style="list-style-type: none"> • revised/enhanced program logic; • detailed evaluation questions; • evaluation methodology; • detailed description of indicators, measures, data sources and analysis to be undertaken in collaboration with PHNs; • project schedule including timeframes and deliverables; • consultation plan outlining the key stakeholders to engage in the evaluation; and • risk management plan. |

| | |
|------------------------------------|---|
| Status report | The Status Report will be provided to the Department of Health and will include: |
| Due: February 2019 | <ul style="list-style-type: none"> • a brief description of the activities undertaken to date; • advice on any challenges or difficulties encountered during the reporting period and the action taken (or proposed to be taken) in overcoming these; • notification of any slippage in timeframes; and brief analysis of the early findings from the evaluation and lessons learnt. |
| Data collection | Develop, collect and analyse program related data by undertaking a co-design approach to the evaluation to include indicators (at both the program and PHN level). |
| Due to commence: March 2019 | |
| Evaluation report | This will be a detailed, comprehensive report to the Department of Health and will include: |
| Interim due: September 2019 | <ul style="list-style-type: none"> • an executive summary; • a summary of the evaluation process; and |
| Final due: May 2020 | <ul style="list-style-type: none"> • evaluation findings. |

1.3 Structure of this report

The remainder of the Evaluation Plan is structured as follows:

Chapter 2: Literature scan. This chapter provides an overview of the literature scan on at-home palliative care.

Chapter 3: Approach to the development of the Evaluation Framework. This chapter outlines the theoretical concepts used to develop the Evaluation Framework, including a description of the reporting domains and how program logic theory was used to inform key components of the Evaluation Framework.

Chapter 4: GCfAHPC Evaluation Framework. This chapter provides a clear outline of the evaluation questions, key performance indicators, secondary data sources, and primary data collection methods that will be used to execute the evaluation. It also provides a brief overview of the timing for the administration and reporting of each research modality across the five Evaluation Reports.

Chapter 5: Consultation plan. This chapter provides additional detail on the timing, recruitment and methodology of the consultation which will be carried out as part of the evaluation.

Chapter 6: Risk management plan. This chapter sets out the key risks of the evaluation, and mitigation strategies to manage risks should they occur.

Chapter 7: Evaluation implementation overview. This chapter comprises a brief overview of the project governance arrangements. It also outlines the key steps to be undertaken following the finalisation of the Evaluation Framework, including the construction of an appropriate comparator cohort, and the development of a comprehensive work plan.

Literature scan



2 Literature scan

Although 70% of Australians say they would prefer to die at home, approximately 15% do so, with around half of all deaths occurring in hospital, and just over a third in residential aged care (Palliative Care Australia, 2017). Research has shown that when palliative care is provided at home, palliative care patients are 87.5% more likely to remain in the community until death (Palliative Care Australia, 2017).

Regardless of whether death occurs in a community or inpatient setting, a large proportion of the dying phase, including palliative care, may occur at home. However, at-home palliative care is not always appropriate for all individuals and families (Hudson, 2003). Furthermore, the best place for dying to occur may change over time as the needs of patients and their families change.

There is significant heterogeneity in the literature on at-home palliative care outcomes, and findings are highly context-specific. In every domain, at-home palliative care has been found to be both detrimental and beneficial to the physical, emotional and financial wellbeing of palliative care patients and their carers. It appears that dying at home is not *prima facie* a positive outcome, but rather requires the right formal and informal support network.

2.1 Quality-of-life and financial outcomes of at-home palliative care

Evidence is mixed as to whether patients receiving at-home palliative care experience better quality of life and symptom control than those receiving care in an institutional setting. However, there is strong evidence to suggest that home care better addresses patients' psychological needs, which may be secondary to physical needs in inpatient settings (Peters & Sellick, 2006). In a Western Australian Study by Peters & Sellick (2006), patients receiving home-based services had statistically significantly less symptom severity and distress, lower depression scores, and better physical health and quality of life than those receiving inpatient care. Home-care patients also reported statistically significantly more control over the effects of their illness, medical care and treatment received, and the course of the disease.

In general, at-home palliative care has been shown to be less costly than providing inpatient care (Peters & Sellick, 2006), particularly in situations where family caregivers take on more of the care once provided by nurses (Stajduhar et al, 2010). However, at-home care may be more costly for families, both in terms of foregone earnings due to caregiving, and securing formal assistance. For example, Canadian estimates suggest that family caregivers contribute about CAN\$6,000 of unpaid caregiving labour in the final four weeks of a patient's life (Stajduhar et al, 2008). Palliative care at home often requires significant out-of-pocket costs and as such, adequate financial resources are a key predictor of people dying at home (Peters & Sellick, 2006).

2.2 Health system determinants of dying at home

The availability of healthcare and community home-based palliative care services is crucial to both the likelihood and experience of patients dying at home. In particular, after-hours services or support, night-sitting services, access to volunteer and paid caregivers, community nurses and access to inpatient respite facilities were identified in research as important service determinants of dying at home (Aoun et al, 2007).

One research article identified community nurses as the most important service providers, however noted that they are also the most resource intensive service (Luckett et al, 2013). Specialist palliative care nurses are found to be particularly valuable as they can give the General Practitioners (GPs) and other team members a 'real time' assessment of patients, and can also give advice on possible therapeutic interventions or the need for inpatient admission (Yuen et al, 2003).

Access to inpatient and/or respite care is also important. While access to inpatient care may decrease the likelihood of dying at home (Hofmeister et al, 2018) it is an important factor in ensuring families, GPs and home teams have a successful experience with at-home palliative care, particularly if a patient's circumstances or symptoms change (Yuen et al, 2003).

The need for integrated and personalised services is highlighted in the literature. Horizontal programmes involving the patient and their doctors, families, and community services are important in ensuring that needs do not fall through the gaps and families feel supported. Local knowledge is particularly invaluable in this context (Wye et al, 2014).

It is important for carers to feel that the healthcare system is there to provide support and answer questions if an unpredictable event occurs (Stajduhar et al, 2008). If families are not supported by trusted healthcare professionals with experience in palliative care, they turn to hospitals and emergency services, particularly in a crisis (Wye et al, 2014).

2.3 Other factors determinants of dying at home

Other factors influencing dying at home include demographics, disease-specific factors, and the preferences of patients and the availability of carers.

Demographic factors influence the likelihood of dying at home. International studies have found home deaths to be least likely for patients under 45 years of age and patients aged 85 and above. Studies have also found that higher levels of education and income are positively correlated with dying at home, while there is a significant evidence that migrant and Indigenous communities can struggle to access end of life services, including home care, necessitating an approach that supports end of life care within different cultural contexts (Abel et al, 2013).

There is no consistent evidence regarding which diseases are associated with home care. A study conducted in Taiwan (Ko et al., 2017) found no strong association between type of illness and the likelihood of patients dying in their preferred place of death. In the same study, it was found that patients which required more hospitalisations (e.g. ≥ 7 times in 1 year compared to 0-6 times in 1 year) had a decreased likelihood of a home death.

Generally patients' preferences seem to have a powerful influence on achieving a home death, however this is often dependent of the availability of informal carers (Gomes & Higginson, 2006). Patients who are married or have a partner, or live with someone were more likely to die at home than those who do not. Compared to patients with a caregiver, patients with no caregiver were twice as likely to die in a hospice and 2.5 times as likely to die in a tertiary hospital (Aoun et al, 2007).

Family caregiving is a significant undertaking that can negatively affect carers' quality of life. Hudson (2003) found that almost a third of 106 Australian family caregivers reported confronting significant anxiety, and 12% experienced significant depression (Hudson, 2003). In a study by McNamara & Rosenwax (2010) conducted in Western Australia, carers indicated that they received insufficient support during the time of caring and during bereavement during the years 2005-2006. There is evidence that families may believe that inpatient care offers the best quality of life and death. Stajduhar & Davies (2005) reported a study that found that 80% of family caregivers believed inpatient palliative care offered the best quality of life and death, even for patients who had resisted admission to a palliative care setting. In particular, as the patient's disease progresses, caregivers often prefer hospital care and some caregivers have considerable misgivings about providing palliative care at home.

2.4 Patient reported outcome and experience measures

Patient reported outcome measures (PROMs) and patient reported experience measures (PREMs) are 'standardised, validated questionnaires that are completed by patients to measure their perceptions of their own functional status and wellbeing'. Australia is a world leader in the use of PROMs and PREMs in palliative care through the Palliative Care Outcomes Collaboration (PCOC) (Eagar et al, 2010). The PCOC is a national program that utilises standardised clinical assessment tools to measure and benchmark patient outcomes in palliative care. Results are available from 2009 to the present, and are measured against benchmarks set by the PCOC. The PCOC assessment framework incorporates five validated clinical assessment tools. Specialist palliative care data is reported for the hospital/hospice and community (including residential aged care) settings.

2.5 Methodological challenges in measuring palliative care outcomes

A number of papers have noted the significant methodological challenges involved with measuring palliative care outcomes. Challenges include lack of quality data, and ethical and practical difficulties in establishing control or comparator cohorts.

There are challenges in collecting data and administering PROMs/PREMs. Patients with advanced illness or cognitive impairment may be unable to complete PROMs/PREMs, potentially leading to situations where PROMs/PREMs are only used for patients with less severe problems, therefore excluding those with more severe issues and compromising the validity of the tools (Johnston et al, 2017). Furthermore, staff may have insufficient time or training to administer PROMs/PREMs, or experience a lack of time or general reluctance to collect outcome data in palliative care (Bausewein et al, 2011).

There are also ethical concerns which may make it difficult to evaluate palliative care outcomes. A key concern is around whether completing PROMs/PREMs might intrude on the patient's preferred use of time at the end of life (Johnston et al, 2017). Ethical concerns may also make it difficult to establish strong controls and robust studies such as randomised control trials (RCTs). For example, an RCT on home-based palliative care undertaken in Norway noted the need to be careful not to persuade vulnerable patients to accept a service that they did not want (Hofmeister et al, 2018; Jordhøy et al, 2000).

Finally, it is often difficult to establish cause and effects. In many instances, data is only collected from patients on entry into home or inpatient palliative care, making it difficult to assess the effect of care itself on patient outcomes. In other cases, outcomes are measured only after admission into care, making it difficult to establish causation. Furthermore, data may be incomplete, and not include the experience of all relevant parties, including patients, families and healthcare providers (Bausewein et al, 2011).

Approach to the development of the Evaluation Framework



3 Approach to the development of the Evaluation Framework

This chapter outlines the theoretical concepts used to develop the Evaluation Framework, including a description of the reporting domains and how program logic theory was used to inform key components of the Evaluation Framework.

3.1 Introduction

The purpose of the Evaluation Framework is to guide assessment of the GCfAHPC measure's implementation, processes, outcomes and impact. The specific components completed to develop the Evaluation Framework include:

- a **Program Logic Model** which links the inputs, activities, and outputs of the GCfAHPC measure to the intended short, medium and long-term outcomes;
- a suite of **evaluation questions**, which canvass the key areas for investigation;
- a series of **performance measures** identifying the intended and unintended outcomes of the GCfAHPC measure, as well as any contextual factors (political, social, economic and cultural) that have the potential to impact on outcomes;
- a data strategy that provides an **outline of the data sources** that should be used to inform the performance measures, in addition to the timing and methods for data collection; and
- a proposed methodology for collecting **comparator (counterfactual) data** and an overview of the **data analysis methodology**.

This chapter provides an overview of the approach used to design the Evaluation Framework, and includes a description of each component comprising the Evaluation Framework.

3.2 Refinement of the program logic

A Program Logic Model outlines the intended activities, outputs and outcomes of a program or policy change. It is a tool used by evaluators to understand the intended outcomes of a program or policy change, and how those outcomes are expected to be achieved. The inputs, outputs and outcomes in the Program Logic Model are used to develop the program indicators which are used to monitor whether the program is on track to achieving its intended outcomes, or if there is need to take corrective action.

In developing the program logic for the GCfAHPC measure, the first step involved refining the program logic developed by the Department of Health to ensure it sufficiently and accurately reflected the activities that PHNs are undertaking as part of the GCfAHPC measure and the outcomes that each of the PHNs intend to achieve in the short, medium and long term. Specifically, the process involved:

- 1) **Initial consultations** with the Palliative Care team at the Department of Health to better understand the objectives, outcomes and activities that PHNs are undertaking as part of the GCfAHPC measure,
- 2) **Analysis of the preliminary project logic and PHN activity work plans in order to develop four activity streams**. PHNs were then asked to nominate the primary and secondary focus of their GCfAHPC related activities and were allocated into a relevant stream,
- 3) A **webinar workshop with PHN representatives and the Department of Health** was then used to refine the activity streams that formed the basis of the program logic, but also take the opportunity for them to gain a better understanding of the importance of how the processes and activities are crucial to translation into outputs and, more importantly, outcomes for patients and their families.
- 4) **One on one consultations with PHNs** was then used to further refine the activity stream and evaluation questions.

The program logic model supports the development of the Evaluation Framework in three ways:

- 1) First, it will articulate the outcomes that the program was or is **expected to deliver**, along with the inputs, activities and outputs that will support realisation of these outcomes.
- 2) Second, by defining these elements, the program logic model will assist in **identifying the evidence** that will be needed to indicate that the program has contributed to an outcome. It follows that evaluation questions, data collection and data analysis must be cognisant of and aligned with this finalised program logic model.
- 3) Third, involving the key stakeholders in the final design of the program logic model facilitates a **common understanding** of the objectives and desired outcomes and how they are expected to be achieved. It better enables **knowledge transfer** and continuation of evaluation activity after the engagement.

The taxonomy used to construct the Program Logic Model and guide the development of the Evaluation Framework is outlined in Table 3.1.

Table 3.1: Program logic – key concepts

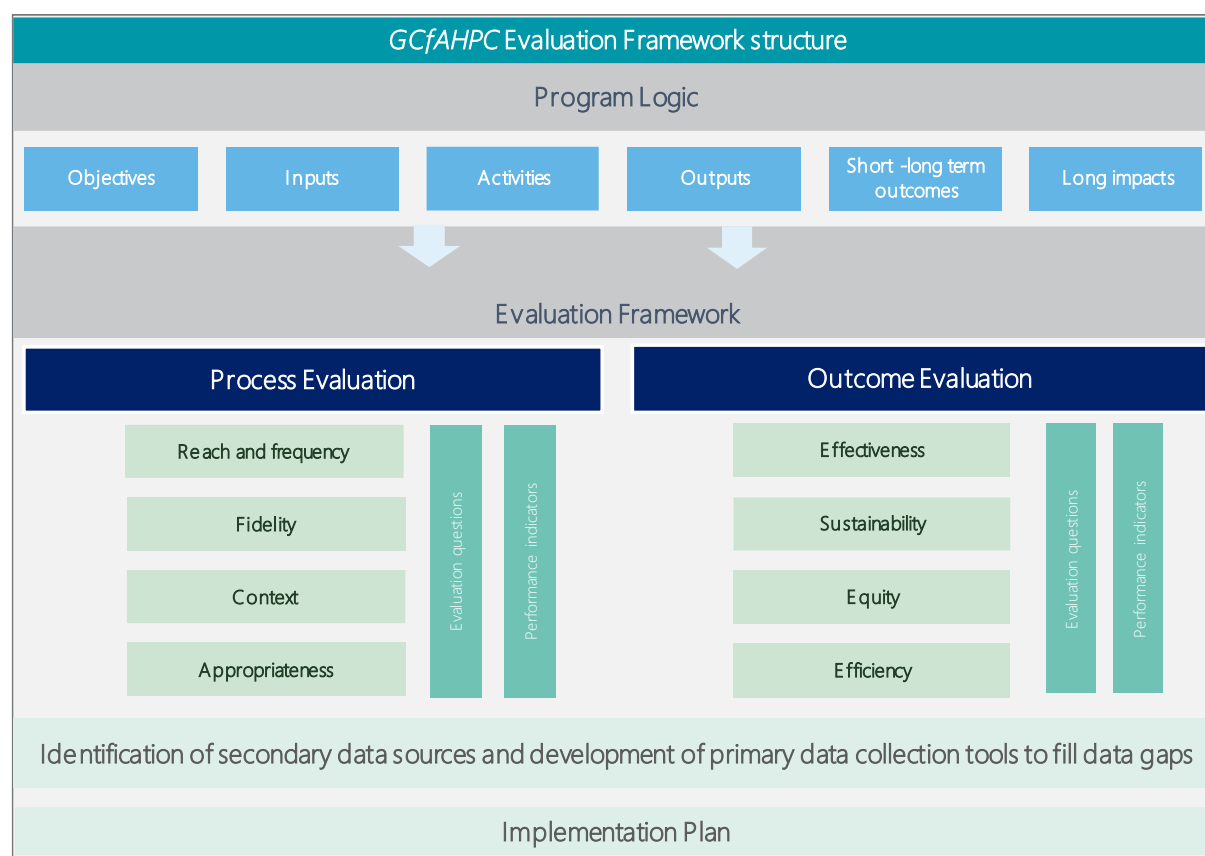
| Terms | Definitions |
|------------------------------------|---|
| <i>Goals</i> | High level, long-term outcomes or benefits to which policy makers and the community aspire. This provides the reason for the existence of the GCfAHPC measure. |
| <i>Objectives</i> | Statements describing the results to be achieved. They should be articulated in a specific, measurable, achievable, relevant and time-bound (SMART) manner. Multiple objectives are usually required to achieve a goal. |
| <i>Inputs</i> | The resources invested to produce outputs. |
| <i>Process</i> | The activities completed to produce outputs. |
| <i>Outputs</i> | The short term, tangible products delivered by the activities. |
| <i>Short to Long Term Outcomes</i> | The specific outcomes desired by stakeholders of the GCfAHPC measure Outcomes may be achieved over time – in the short, medium or longer term. |
| <i>External Influences</i> | Factors external to the GCfAHPC measure and beyond the control of service providers, which may affect/contribute to the achievement of outcomes. |
| <i>Impacts</i> | Impacts are what the long-term outcomes inevitably work towards. They should resonate with the goals of the service. |

3.3 Evaluation questions and performance measures

A suite of evaluation questions have been designed which cover the key areas for investigation and a series of performance measures identifying the intended and unintended outcomes of the GCfAHPC measure as well as any contextual factors (political, social, economic and cultural) that have the potential to impact on outcomes.

The Evaluation Framework has been designed to allow evaluators to undertake both a Process and Outcome Evaluation, as well as a comprehensive Economic Evaluation. These forms of evaluation are complementary yet serve distinct purposes. A description of each respective evaluation type is summarised in Figure 3.1 below.

Figure 3.1: Overview of the Evaluation Framework structure



3.3.1 Process Evaluation

In order to examine the outcomes of an intervention, it is first necessary to understand how well the project has been implemented within the existing health care environment. Process evaluation assesses the way in which a program has been implemented, and how it is affected by the context within which it operates. It aims to inform how the program could be improved during its implementation. Process evaluation should commence as early as possible in the life of a program (Bamberger et al, 2012).

3.3.2 Outcome Evaluation

Outcome evaluation assesses the quality, merit, worth or shortcomings of the program. Outcome evaluations assess the extent to which the short, medium, and where possible, longer-term outcomes of the program have been achieved (Bamberger et al, 2012). The outcome evaluation will also include analysis of the costs of the GCfAHPC measure.

3.3.3 Evaluation reporting domains

A suite of evaluation domains have been developed to ensure both the Process and Outcome Evaluation questions explore lines of inquiry that meet the information needs of key stakeholders.

Definitions of the Process Evaluation domains are as follows:

- **Appropriateness.** The service is appropriate if it meets a client's needs. Appropriateness indicators seek to measure how well services meet participants' needs.
- **Reach and Frequency.** The extent to which target groups have been adequately reached, and the extent to which they have adopted or accessed the service.
- **Fidelity.** Extent to which the program has been delivered as intended or planned.
- **Context.** Key environmental elements that may influence success of the program.

Definitions of the Outcome Evaluation domains are as follows:

- **Effectiveness.** Refers to the effectiveness with which a given set of inputs is used to achieve the outcomes. That is, how well the program is on-track towards maximising benefits to the target population.
- **Sustainability.** Involves assessing the capacity of the service to sustain workforce and infrastructure, to innovate, and respond to emerging needs.
- **Equity:** Equity is the absence of avoidable or remediable differences among groups of people, whether those groups are defined socially, economically, demographically or geographically.
- **Costs:** Refers to the costs associated with implementing the GCfAHPC measure, including financial and other costs. .

3.4 Methodological considerations and rationale

The scope of this Evaluation Plan is the GCfAHPC measure overall, as compared to an individual program-level evaluation of the initiatives or activities being implemented at each PHN. To enable an overarching evaluation to be undertaken, activity streams have been identified enabling PHN initiatives to be aligned for common process and outcomes questions and indicators to be collected and compared across the 11 sites. In addition, stream-specific evaluation questions that have been developed for the Effectiveness domain (see Table 4.4).

Due to the variability in the types of activities being undertaken, and the timeline over which the evaluation is being carried out, the evaluation will focus on determining whether the measure is on track towards achieving its stated outcomes over the period to May 2020. Across the sites, significant measurable patient and carer level outcomes are unlikely to be realised, as articulated in the Program Logic Model, which was collaboratively developed with the Department of Health (see Figure 4.2). As such, rather than measuring efficiency during this evaluation, the costs component will be evaluated, with an opportunity in the future to determine how costs compared with outcomes achieved.

GCfAHPC Measure Evaluation Framework



4 GCfAHPC Evaluation Framework

This chapter provides an outline of the activity streams and program logic model developed to guide the evaluation. It also lists the evaluation questions, evaluation indicators, data sources, and data collection methods that will be used to execute the evaluation.

4.1 Activity streams

Each of the PHNs have planned different programs of work to contribute to the achievement of the overall goals and objectives of the GCfAHPC Measure. To allow for the evaluation to account for the different approaches, we have identified **four activity streams** based on information available in PHN Activity Work Plans and feedback from PHNs.

Each PHN's activities has been aligned with a primary and a secondary stream for the purpose of the evaluation. The primary stream reflects priority/main mechanism by which the PHN is seeking to affect change and contribute to the Greater Choices objectives, while the secondary stream is supplementary or complementary activity that will support the primary activity. The immediate primary user/ audience/ stakeholder (who can be thought of as the 'agent for change') has been identified, for each stream, noting that the ultimate long-term beneficiary of all activities are patients and carers.

In addition to engaging in the activity streams, it is understood that PHNs will be carrying out some degree of formative research and planning, which then leads into focussed activities depending on the priority needs identified. These activities then contribute to the long-term outcomes and impacts of the GCfAHPC measure overall.

The four activity streams and additional enabling activity are outlined below:

1. **General improvement in service pathways and coordination.** This stream captures improvements to the way existing tools and services are accessed and utilised.
 - Examples include improving referral pathways within the existing service landscape (without fundamentally changing the way providers share information or integrate their service provision), and leveraging existing tools such as MyHealth Record, or systems supported through National Palliative Care Programs (NPCP), such as End of Life Directions in Aged Care (ELDAC), Advance Care Planning Australia (ACPA), Caresearch, Palliative Care Outcomes Collaborative (PCOC) and Palliative Care Australia (PCA).
2. **Development of a new model of care or tool.** This stream captures fundamental changes in the way care is provided, for example the ways providers share information or integrate their service provision or changes to the roles or scopes of members of the palliative care provider teams.
 - This stream can include modifying what care is provided by whom, and where; examples include using telehealth (where it has not been used previously), expanding the role of nursing and/or allied health in the provision of care and support, or establishing a new triage service to direct and refer care.
3. **Capacity building among palliative care providers.** This stream captures activities targeted at palliative care providers, including health and social service providers.
 - This stream captures both the development of new educational resources where information gaps or requirements exist, and the distribution/leverage of existing resources, which may complement the referral pathways or new model of care streams.
4. **Raising awareness and capacity of patients, carers and communities.** This stream captures activities targeted at patients, carers and communities, including through the use of the Compassionate Communities Framework.



- This stream is appropriate for PHNs that plan to engage directly with patients/ carers and expect to realise these outcomes within the timeframe of the evaluation. This stream is also appropriate for PHNs planning on building capacity amongst broader community members and networks as agents of change, e.g. use of the Compassionate Communities framework.

All PHNs will engage in the enabling activity stream of **data collection, sharing, and analysis**. Data sharing and collaboration will be driven by PHNs, including through the GCfAHPC working group.

PHNs were asked to select a primary and secondary activity stream which most closely aligned with their planned activities through an electronic survey in August 2018. Some PHNs later updated their primary and secondary activity streams via e-mail. Figure 4.1 shows the activity streams selected by PHNs, noting that this may still be changed by PHNs during the initial phases of the evaluation. The final activity streams for PHNs will be confirmed through the first survey of PHNs in March 2019.

Figure 4.1: Activity streams currently selected by PHNs

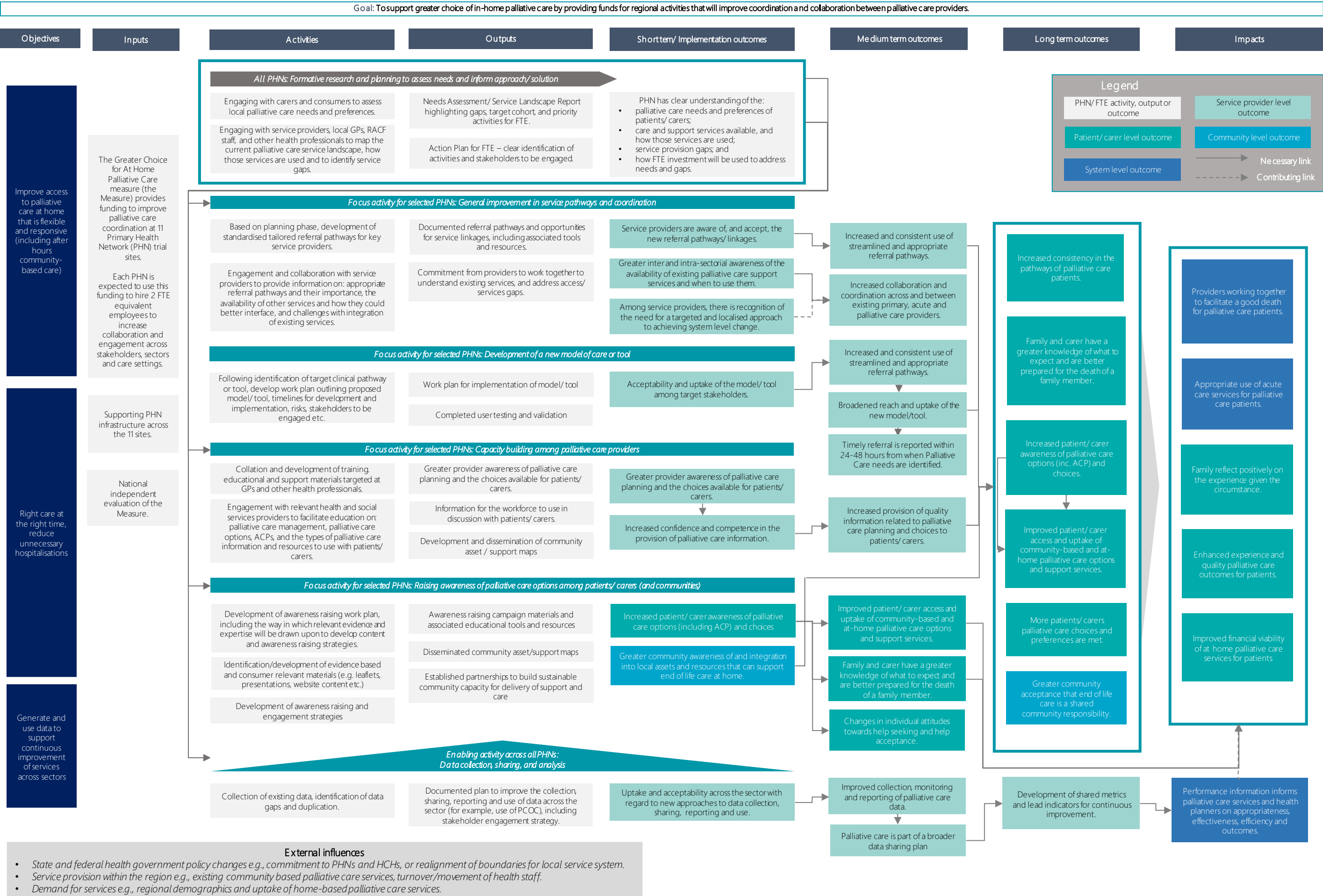
| | Stream 1: General improvement in service pathways and coordination | Stream 2: Development of a new model of care or tool. | Stream 3: Capacity building among palliative care providers | Stream 4: Raising awareness and capacity of patients, carers and communities. |
|-------------------------|---|--|--|---|
| Adelaide | Primary activity | | Primary activity | |
| Brisbane South | | Primary activity | Secondary activity | |
| Country WA | | Primary activity | | Secondary activity |
| CQWBSC | Primary activity | | Primary activity | |
| Eastern Melbourne | Primary activity | | Primary activity | |
| Gold Coast | | Primary activity | Secondary activity | |
| Murrumbidgee | Primary activity | Secondary activity | | |
| North Western Melbourne | Primary activity | | Secondary activity | |
| Tasmania | Primary activity | | Secondary activity | |
| South Western Sydney | | Primary activity | | Secondary activity |
| Western NSW | | Primary activity | Secondary activity | |

 Primary activity
  Secondary activity

4.2 Program Logic

A Program Logic Model is used to establish the inputs, processes, outputs and short, medium and long term outcomes and impacts of the GCfAHPC measure. This Program Logic Model was developed in collaboration with the Department of Health and PHNs that form part of this study through a co-design workshop with key project members from the Department of Health, and a webinar with all PHNs. The Program Logic Model for the GCfAHPC measure is illustrated in Figure 4.2.

Figure 4.2: Program Logic Model for the GCfAHPC measure



4.3 Evaluation questions

The process and outcome evaluation questions were developed and refined through a collaborative process with Department of Health and PHNs. Based on the co-design workshop, the process evaluation questions designed to assess the implementation of the GCfAHPC measure are outlined in Table 4.1. The outcome evaluation questions designed to assess the extent to which the GCfAHPC measure is achieving its objectives are outlined in Table 4.2.

Table 4.1: Process Evaluation Questions

| Process Evaluation Domains | Process Evaluation Questions |
|----------------------------|---|
| Appropriateness | <p>How appropriate is the GCfAHPC measure to meet the needs of clients, families and carers?</p> <p>Did PHNs assess local needs and determine program requirements for implementation of the GCfAHPC measure? If so, what process was used?</p> |
| Reach and Frequency | To what extent are the relevant stakeholder groups (such as health professionals, service providers, patients, carers, or the broader community) aware of the objectives and scope of the GCfAHPC measure? |
| Fidelity | <p>Has the GCfAHPC measure been implemented according to PHNs' plans?</p> <p>To what extent has implementation and delivery of the GCfAHPC measure differed <i>between</i> PHNs? What are the implications of variation?</p> |
| Governance | How effective have local governance arrangements been for implementing and achieving the aims of the GCfAHPC measure? And how could governance arrangements be more effective? |
| Context | <p>What are the contextual enablers/ barriers to the effective implementation of the service?</p> <p>What are the contextual enablers/ barriers to the efficient implementation of the service?</p> |

Table 4.2: Outcome Evaluation Questions

| Outcome Evaluation Domains | Outcome Evaluation Questions |
|---|---|
| Effectiveness (applicable to all streams) | Is there greater awareness among key stakeholders on the availability of palliative care support services and when to use them? |
| | To what extent has the GCfAHPC measure increased awareness amongst key stakeholders of regional access and service gaps (including family commute times)? |
| | Has there been uptake and acceptability across the sector with regard to new approaches to data collection, sharing, reporting and use? |
| | Has collection, monitoring and reporting of palliative care data improved, and how has it influenced the measure? |
| Effectiveness (varied, as per activity stream) | To what extent have PHNs been successful in establishing strong networks with health professionals and the community more broadly? |
| | To what extent has the GCfAHPC measure achieved its intended outcomes? |
| Equity | Are there any barriers to equity of access and outcomes for certain population groups (e.g. Aboriginal and Torres Strait Islander people, rural/ remote, disease type)? |
| Costs | To what degree have implementation costs for the Department aligned with allocation and expectations? What additional or unplanned costs have been incurred? |
| | To what degree have the implementation costs for PHNs aligned with allocation and expectations? What additional or unplanned costs have been incurred? |
| Scalability | What aspects of the GCfAHPC measure would need to be modified for scaling? |
| Sustainability | To what extent has the GCfAHPC measure captured and linked relevant data to inform service and sector improvements? |
| | Are continuous quality improvement/ feedback loops used? |

4.4 Evaluation indicator framework

To address each of the process and outcome evaluation questions, a series of indicators have been identified. In some cases multiple indicators have been selected to provide a range of perspectives and data sources; enabling triangulation and validation of the evaluation findings. In addition, a brief description of the data source(s) required to measure each indicator is provided. These data sources, alongside methods and frequency of collection, are described in further detail in the following section. Primary data collection tools have been proposed in instances where data gaps existed, or where additional contextual insights were required.

Table 4.3: Process Evaluation – Performance Indicator Framework

| Process Evaluation Questions | Process Evaluation Indicators | Data Sources |
|--|---|--|
| Appropriateness | | |
| How appropriate is the GCfAHPC measure to meet the needs of clients, families and carers? | Outcomes of the needs assessments carried out by PHNs. | PHN survey, PHN interviews, PHN documentation |
| | Activities carried out by the PHNs under the GCfAHPC measure. | PHN survey, PHN interviews, PHN documentation |
| | Reported needs of clients, families and carers and reported perception of how appropriate the activities carried out under the GCfAHPC measure are to meet these needs. | Consumer survey |
| | Extent to which local stakeholders feel that the aims and activities under the GCfAHPC measure are appropriate to meet the needs of clients, families and carers. | Local stakeholder surveys, local stakeholder interviews. |
| Did PHNs assess local needs and determine program requirements for implementation of the GCfAHPC measure? If so, what process was used? | Reported outcomes of the needs assessment carried out by the PHNs. | PHN survey, PHN interviews, PHN documentation |
| | Reported needs assessment methodology by PHNs. | PHN survey, PHN interviews, PHN documentation |
| Reach and Frequency | | |
| To what extent are the relevant stakeholder groups (such as health professionals, service providers, patients, carers, or the broader community) aware of the objectives and scope of the GCfAHPC measure? | Reported extent to which key referral sources are satisfied with their relationships with other health professionals. | Local stakeholder surveys, Local stakeholder interviews |
| | Number of formal referral pathways or mechanisms created through the GCfAHPC measure. | PHN survey, PHN interviews |

| Process Evaluation Questions | Process Evaluation Indicators | Data Sources |
|--|---|---|
| Fidelity | | |
| Has the GCfAHPC measure been implemented according to PHNs' plans? | Extent to which the actions outlined in the activity work plans and other documentation aligns with the activities carried out by PHNs. | PHN survey, PHN interviews, PHN documentation |
| To what extent has implementation and delivery of the GCfAHPC measure differed <i>between</i> PHNs? And what are the implications of this variation? | PHN activity work plans and delivery activities. | PHN survey, PHN interviews, PHN documentation |
| | PHN activity work plans, delivery activities and preliminary outcomes. | PHN survey, PHN interviews, PHN documentation |
| Governance | | |
| How effective have local governance arrangements been for implementing and achieving the aims of the GCfAHPC measure? And how could governance arrangements be more effective? | Reported views on the extent to which local governance arrangements have enabled effective implementation of the GCfAHPC measure. | PHN survey, PHN interviews, local stakeholder survey, local stakeholder interviews |
| | Reported views on the extent to which local governance arrangements could be improved to result in more effective implementation of the GCfAHPC measure. | PHN survey, PHN interviews |
| Context | | |
| What are the contextual enablers/ barriers to the <i>effective</i> implementation of the service? | Reported contextual enablers or barriers to the effective implementation of the GCfAHPC measure across PHNs. Key areas of interest include: <ul style="list-style-type: none"> • local referral pathways and practices; • attitude towards capacity building/ ongoing professional development; • access to other local health and support services; • local levels of demand; and • degree of support/ buy-in from local health professionals and other key stakeholders. | PHN survey, PHN interviews, local stakeholder surveys, local stakeholder interviews |
| What are the contextual enablers/ barriers to the <i>efficient</i> implementation of the service? | Reported contextual enablers or barriers to the efficient implementation of the GCfAHPC measure across PHNs. Key areas of interest include: <ul style="list-style-type: none"> • barriers to uptake of new referral pathways/ models of care; • drivers of different service utilisation patterns; • degree of local in-kind support; and • access to local service setting enablers (e.g. ICT system, clinic space, data sharing). | PHN survey, PHN interviews, local stakeholder surveys, local stakeholder interviews |

Table 4.4: Outcome Evaluation – Performance Indicator Framework

| Activity stream | Outcome Evaluation Questions | Outcome Evaluation Indicators | Data Sources |
|---|---|--|--|
| Effectiveness (applicable to all activity streams) | | | |
| Awareness | Is there greater awareness among key stakeholders on the availability of palliative care support services and when to use them? | Reported views on whether their awareness of palliative care support services has improved through the GCfAHPC measure (retrospectively). | Local stakeholder surveys, local stakeholder interviews, consumer survey |
| | To what extent has the GCfAHPC measure increased awareness amongst key stakeholders of regional access and service gaps (including family commute times)? | Reported access and service gaps based on the needs assessment carried out by PHNs | PHN survey, PHN interviews |
| | | Regional access and service gaps reported by local service providers. | Local stakeholder surveys, local stakeholder interviews |
| | | Local/regional access and service gaps reported by palliative care patients and carers. | Consumer survey |
| Data collection | Has there been uptake and acceptability across the sector with regard to new approaches to data collection, sharing, reporting and use? | Reported views on the new approaches to data collection, sharing, reporting and use by sector stakeholders. | Local stakeholder surveys, local stakeholder interviews |
| | | Degree of data collection or use through the new approach. | Service provider data, PHN data, PHN documentation |
| | Has collection, monitoring and reporting of palliative care data improved? | Degree of data collection or use through the new approach. | Service provider data, PHN data, PHN documentation |
| | | Increase in data collection, monitoring and reporting compared to before the GCfAHPC measure was implemented. | Service provider data, PHN data, PHN documentation |
| Networks | To what extent have PHNs been successful in establishing strong networks with health professionals and the community more broadly? | Reported extent to which key stakeholders including referral sources, health professionals or the broader community are satisfied with their relationships with PHNs and other health professionals. | Local stakeholder surveys, local stakeholder interviews |

| Effectiveness of stream one (service pathways and coordination) | | | |
|---|--|---|---|
| Referral pathways | Are service providers aware and accepting of the new referral pathways/ linkages developed through the GCfAHPC measure? | Proportion of service providers who indicate being aware of the new referral pathways or linkages. | Local stakeholder surveys, local stakeholder interviews |
| | | Reported views of service providers on the new referral pathways or linkages. | Local stakeholder surveys, local stakeholder interviews |
| | Is there an increased and consistent use of streamlined and appropriate referral pathways? | Reported views on the use of referral pathways by service providers, and whether this has improved under the GCfAHPC measure. | Local stakeholder surveys, local stakeholder interviews |
| | | Proportion of palliative care patients are being appropriately and effectively referred (compared to before the GCfAHPC measure was implemented). | Local level data, PCOC data. |
| | | Reported views of palliative care patients and carers on their experience with referral pathways. | Consumer survey |
| | | Number of formal referral pathways or mechanisms and relationships created through the GCfAHPC measure. | PHN survey, PHN interviews |
| Coordination | Is there recognition among service providers of the need for a targeted and localised approach to achieving system level change? | Reported views of service providers on local approaches for achieving system level change. | Local stakeholder interviews |
| | Has collaboration and coordination across and between existing primary and acute palliative care service providers increased? | Reported views on whether collaboration and coordination has increased compared to before the GCfAHPC measure was implemented. | Local stakeholder surveys, local stakeholder interviews |
| | | Formal and documented collaboration or coordination agreements or pathways are set up by service providers. | Program documentation, local stakeholder surveys, local stakeholder interviews, PHN survey, PHN interviews. |

| Effectiveness of stream two (new model of care or tool) | | | |
|--|--|---|---|
| Acceptance and uptake | Has the newly developed/implemented model or tool been received as <i>acceptable</i> among target stakeholders? | Reported views of target stakeholders on the new model or tool. | Local stakeholder surveys, local stakeholder interviews |
| | Has the new model or tool had <i>uptake</i> and has it been implemented by target stakeholders? | Proportion of target stakeholders who have implemented the new model or tool. | PHN survey, PHN interviews, local stakeholder surveys, local stakeholder interviews |
| Effectiveness of stream three (capacity building among palliative care providers) | | | |
| Information dissemination | Has the provision of quality and tailored information related to palliative care planning and choices to patients/ carers increased? | Palliative care patients and carers feel that they received accurate and complete information about their palliative care planning options and choices. | Consumer survey |
| | | Reported views of palliative care service providers on whether they believe provision of quality information has increased under the GCfAHPC measure. | Local stakeholder surveys, local stakeholder interviews |
| | | Activities carried out by PHNs to build capacity of service providers, and evidence collected by PHNs that these have made an impact. | PHN survey, PHN interviews |
| | Has the confidence and competence of providers in the provision of palliative care information increased? | Reported views on whether providers feel more confident providing palliative care information since the GCfAHPC measure was implemented. | Local stakeholder surveys, local stakeholder interviews |

| Effectiveness of stream four (raising awareness and capacity of patients, carers and the community) | | | |
|---|---|--|---|
| Patient and carers | To what extent has the GCfAHPC measure increased patient and carer reported awareness of palliative care options and choices (including Advance Care Planning)? | Reported views on whether the GCfAHPC measure increased patient and carer awareness of palliative care options and choices. | PHN survey, PHN interviews, local stakeholder surveys, local stakeholder interviews |
| | | Proportion of patients and carers who indicate (increased) awareness of palliative care options and choices. | Consumer survey |
| | To what extent do families and carers feel that they have a greater knowledge of what to expect and are better prepared for the death of a family member. | Proportion of families and carers of palliative care patients who feel that they have an understanding of what to expect. | Consumer survey |
| | To what extent has the GCfAHPC measure enabled more patients/carers palliative care choices and preferences to be met? | Reported views on whether the GCfAHPC measure enabled more patients/carers palliative care choices and preferences to be met. | PHN survey, PHN interviews, local stakeholder surveys, local stakeholder interviews |
| | | Proportion of patients and carers who indicate that their palliative care choices and preferences were met. | Consumer survey |
| | To what extent has the GCfAHPC measure resulted in changes in individual attitudes towards help seeking and help acceptance? | Self-reported proportion of palliative care patients and carers who feel able, confident and comfortable to seek and accept help. | Consumer survey |
| | | Reported views on changes noticed by service providers in the proportion of palliative care patients and carers who feel able and confident and comfortable to seek and accept help. | Local stakeholder surveys, local stakeholder interviews |
| | | Increased numbers of palliative care patients or carers initiating contact with service providers. | Service provider data, PHN data |
| Community | To what extent has the GCfAHPC measure led to greater <i>community awareness</i> of local assets and resources that can support palliative care at home? | Reported community views and awareness regarding (at home) palliative care. | Survey of community members through PHN networks |
| | Have the activities under the GCfAHPC measure led to greater <i>community acceptance</i> that palliative care is a shared community responsibility? | Reported community views and acceptance of palliative care as a shared community responsibility. | Survey of community members through PHN networks |

| | | | |
|----------------------|---|---|--|
| | Has the access and uptake of <i>community-based</i> and at-home palliative care options and support services by palliative care patients and carers increased? | Data on community-based and at-home palliative care options and support services shows an increase in use. | Service provider data, PHN data. |
| | | Reported increase in community-based and at-home palliative care options and support services. | Local stakeholder surveys, local stakeholder interviews |
| Equity | | | |
| All activity streams | Are there any barriers to equity of access and outcomes for certain population groups (e.g. Aboriginal and Torres Strait Islander people, rural/ remote, disease type)? | Reported extent to which local stakeholders believe there are barriers to equity of access to the activities carried out under the GCfAHPC measure. | Local stakeholder surveys, local stakeholder interviews |
| | | Disparity in access or outcomes evident in access and outcomes data related to the GCfAHPC measure. | Data collected by service providers and PHNs. |
| | | Perceived barriers to accessing services experienced by palliative care patients and carers. | Consumer survey |
| Costs | | | |
| All activity streams | To what degree have implementation costs for the Department aligned with allocation and expectations? What additional or unplanned costs have been incurred? | Costs of the GCfAHPC measure for the Department of Health | Department of Health cost data provision. |
| | To what degree have the implementation costs for PHNs aligned with allocation and expectations? What additional or unplanned costs have been incurred? | Potential additional costs above the Department of Health funding | PHN survey, PHN interviews, PHN documentation. |
| Scalability | | | |
| All activity streams | What aspects of the GCfAHPC measure would need to be modified for scaling? | Reported aspects of the GCfAHPC measure which may be impact successful scaling to more PHNs and locations. | PHN survey, PHN interviews, PHN documentation, local stakeholder surveys, local stakeholder interviews |

| Sustainability | | | |
|----------------------|---|--|--|
| All activity streams | To what extent has the GCfAHPC measure captured and linked relevant data to inform policy, service and sector improvements? | Reporting undertaken by service providers to PHNs. | PHN survey, PHN interviews, PHN documentation |
| | | Data collected by PHNs. | PHN survey, PHN interviews, PHN documentation |
| | Are continuous quality improvement/ feedback loops used? | Reported lessons learnt for establishing and implementing the GCfAHPC measure (positive and negative), and whether this has been used to improve the implementation of the GCfAHPC measure. | PHN survey, PHN interviews, PHN documentation |
| | | Extent to which PHNs and service providers collect feedback from palliative care patients and carers, and whether feedback has been used to improve the implementation of the GCfAHPC measure. | PHN survey, PHN interviews, PHN documentation, local stakeholder surveys, local stakeholder interviews |

4.5 Approach to data collection and reporting

The purpose of this section is to:

- 1) describe the main data sources and key informants in further detail;
- 2) outline the timing for data collection and analysis across each research modality; and
- 3) outline the approach to reporting across the reports over the evaluation reporting period.

Over the course of the evaluation, data will be collected from all PHNs and their stakeholders; in addition, a subset of four PHNs will be selected as case study sites in consultation with the Department of Health using a criteria-led process. Additional data collection activities will include interviews with local stakeholders, and a patient and carer survey, as outlined in Table 4.5.

4.5.1 Secondary data and documentation

The evaluation indicator framework identifies a range of pre-existing data sources (PHN documentation and data) as well as a series of primary data collection tools. The nature of the GCfAHPC measure is flexible, with a range of different implementation methodologies and contexts. As a result, the types of data collected by PHNs, and the data required to measure the indicators, is varied.

Throughout the evaluation, Deloitte and PHNs will work to assess what data is available at the local level. PHNs may have access to local data that could provide insights that are not available at the measure level. While the focus of this evaluation is on the broader GCfAHPC measure, local data may provide important information that can be explored through case study analysis.

Where available, the following secondary documentation and data sources will feed in to the evaluation:



- 1) PHN documentation related to the GCfAHPC measure, including any planning documents, reporting to the Department of Health (such as Performance Reports), formal communication or referral arrangements, and the activity work plans;
- 2) Program data collected by PHNs (e.g. number of referrals through the new referral pathways, number of training sessions/ materials delivered);
- 3) Care pathway or outcomes data collected by the PHNs, referral source or service providers, and other local or national bodies, including data collected by the Palliative Care Outcomes Collaboration (PCOC).
- 4) Data generated by PHNs as part of their own evaluation activities.



Collecting data directly from PHNs is not without limitations, as it is possible that the PHNs will only provide data that is favourable towards their initiative. For this reason the evaluation team will apply scrutiny when analysing and interpreting any data provided by PHNs.

4.5.2 Primary data

The evaluation indicator framework identifies a range of primary data collection tools which would contribute to answering the identified evaluation questions. Primary data sources and collection tools proposed are shown in Table 4.5.

Table 4.5: Approach to primary data collection

| Modality | Stakeholder | Purpose and description | Timing |
|---|--|---|------------------------------|
|  2 x electronic surveys of key PHN staff involved in implementing the GCfAHPC measure. Approx. 15-question survey, as a mixture of Likert and short response. | All PHN staff involved in implementing the GCfAHPC measure. | Surveys of PHNs will track progress of the activities carried out under the GCfAHPC measure and to capture important information from all GCfAHPC officers periodically to inform indicators. This will include lessons from implementation, barriers and enablers, sustainability planning, and unintended impacts. These findings will triangulate secondary data sources and be built on with targeted project team interviews | March 2019 September 2019 |
|  1 x interviews with PHN staff at each of the 11 PHNs. 30-45 minute face-to-face or telephone interview using a semi-structured interview script guide to facilitate discussion | PHN staff involved in implementing the GCfAHPC measure. | Semi-structured interviews with PHN staff will allow for additional depth of information collected from PHNs towards the end of the evaluation, including reflections over the course of the project on both process and outcome lines of inquiry. Findings will be triangulated with patient and carer surveys, and program stakeholder. This will feed into the outcome evaluation. | January 2020 |
|  2 x surveys of local stakeholders. | Local stakeholders may include primary health care providers (e.g. General Practitioners) and other key referral sources; specialist health care providers (e.g. cancer specialists); Specialist palliative/end-of-life care providers, Community Nurses, and community members if relevant to PHN activities. | Two surveys of palliative care professionals and referral sources will provide baseline data as well as 'current-state' data on the buy-in, acceptability and other views on the activities under the GCfAHPC measure. We would discuss with PHNs who are taking a Compassionate Communities approach the avenues they have to reach appropriate community members being targeted through activities. The purpose of the first survey would be to collect baseline data to be compared with the second survey. Both surveys would feed into the outcome evaluation. | March 2019 September 2019 |
|  1 x semi structured interviews with central program stakeholders (30-45 minute face-to-face or telephone interviews). | Key government and industry stakeholders, including Department of Health, ANZSPM, PCA, Palliative Care Nurses Australia, RACGP, Consumer Health Forum, and other identified relevant community and sector groups. | To gain detailed insights and reflections from government, industry and consumer stakeholders on the implementation, outcomes achieved, barriers and enablers, and view of lessons learned. Information about projects that received continued funding will be compared with information captured in the retrospective evaluation interviews. | May 2019 |

| Modality | Stakeholder | Purpose and description | Timing |
|---|--|--|----------------------|
|  1x consultation with a sample of local stakeholders (30-45 minute face-to-face or telephone interviews). | Selection of 3 local stakeholders from the representative subset of 4 case study PHNs . This may include primary health care providers and other key referral sources; specialist health care providers; Specialist palliative/end-of-life care providers, and community members. | The purpose of the consultation with a sample of local stakeholder is to gain a deeper understanding of themes which emerge from the surveys including the extent to which the GCfAHPC measure is achieving its intended objectives, barriers and enablers to uptake, and the degree to which the model is scalable and sustainable. | January 2020 |
|  A survey of palliative care patients and carers. | Current palliative care patients and carers, and people who were previously carers of palliative care patients from the representative subset of 4 case study PHNs . | This would be a short survey run over 6 months aiming to collect both comparator data and data on experiences under the GCfAHPC measure if possible. Fielding will be planned in consultation with PCA State and Territory bodies. | July – December 2019 |

4.6 Establishing a comparator cohort

The evaluation team propose the following primary and secondary data collection strategies to enable a degree of contribution to the measure when interpreting evaluation findings.

4.6.1 PHNs

Local level secondary data sources may provide comparator information for the evaluation. For example, where local level data is available on palliative care-related hospitalisation before and after the GCfAHPC measure is implemented, this would be used. Similarly, PHNs and local service providers may have records of care and referral pathways and service use before and after the GCfAHPC measure was implemented. Depending on the methods used by PHNs to undertake the needs analysis for the GCfAHPC measure, this information may also form part of the comparator data. We would work with PHNs to determine what secondary data sources would be available for this evaluation.

In addition to the secondary data, we propose to ask a range of targeted questions in the PHN survey and consultation. Questions in the PHN survey and consultation instruments will be developed in consultation with the Department of Health.

4.6.2 Local stakeholders

We note that a comparator is required in order to answer some evaluation questions pertaining to local stakeholders. At this stage of the implementation of the GCfAHPC measure, it appears that many PHNs have begun discussions with local stakeholders and implementing activities, and it is therefore unlikely that it will be possible to collect comparator data through surveys of the local stakeholders. Surveying local stakeholders through PHNs which are not involved in the GCfAHPC measure also has significant limitations, including the different patient and carer needs and palliative care service landscapes which is likely to exist in different PHNs.

We propose to use the survey of local stakeholders in March 2019 to ask questions related to the process evaluation indicators, as well as retrospectively asking service providers about their experience with palliative

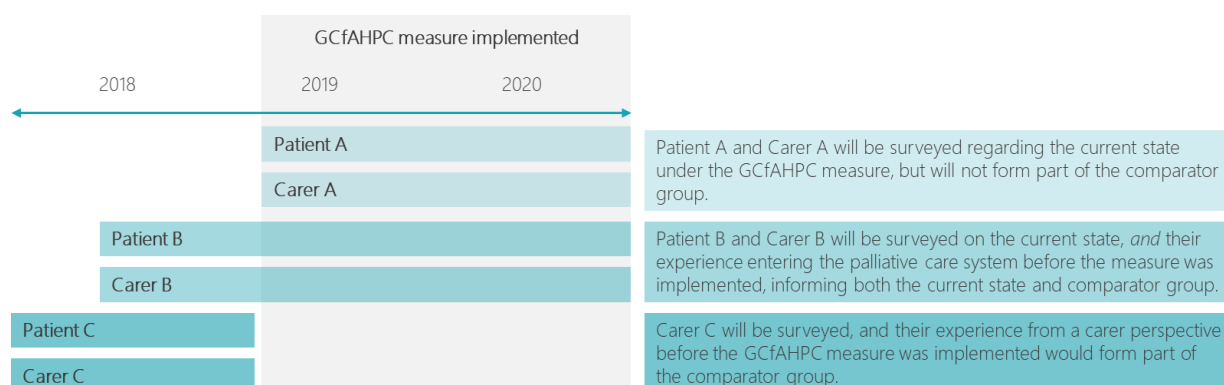
care service delivery before the GCfAHPC measure was initiated. This will be used as comparator information and will be analysed with findings from the survey of the local stakeholders in January 2020 which will collect data on the outcome evaluation indicators. The survey questions will be developed in consultation with the Department of Health.

This approach is limited by the ability of local stakeholders to correctly recall their experience of palliative care services before the implementation of the measure. It also dependent on local stakeholders being aware of the activities being conducted by their local PHN in relation to the GCfAHPC measure, and a sense of when those activities were introduced.

4.6.3 Palliative care patients and carers

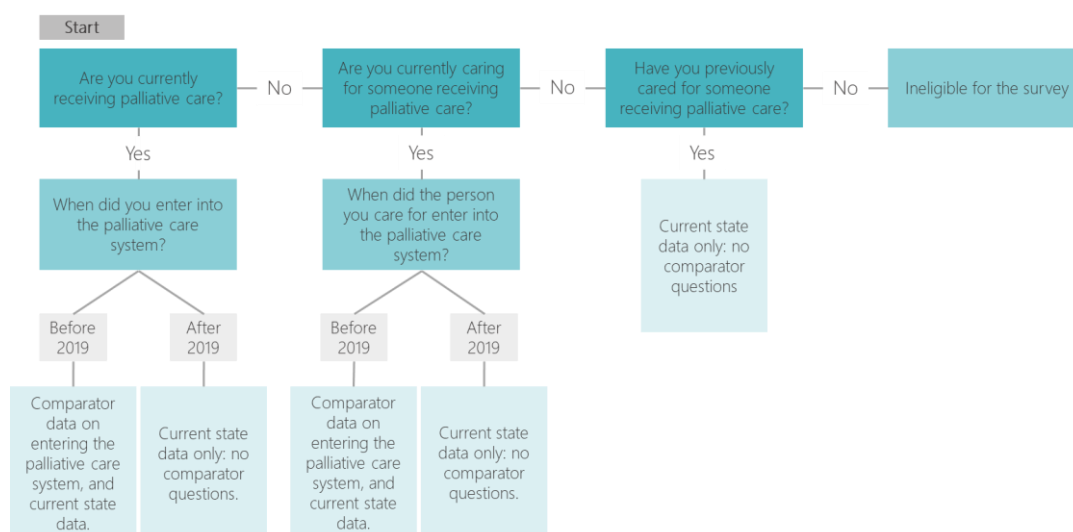
We propose that comparator data for evaluation questions relating to palliative care patients and carers could be collected through surveying carers of people who received palliative care before the GCfAHPC measure was implemented, as well as patients and carers who are currently receiving palliative care but entered the system prior to the activities under the GCfAHPC measure starting. The latter would be to reflect on their initial phases of palliative care. Initial entry into the palliative care system is of significance as this is when many referrals are likely to take place. Patient and carer data collection will only be carried out at the subset of 4 case study PHNs.

Figure 4.3: Schematic showing patient and carer groups and corresponding data collection



Patients and carers would be stratified within the survey, resulting in appropriate survey questions collecting current state and comparator data. Figure 4.4 shows an indicative survey pathway for stratifying palliative care patients and carers so that both current state and comparator data can be collected.

Figure 4.4: Indicative patient and carer survey stratification to current state and counterfactual questions



Note: the cut-off date of 2019 is indicative and dependant on the PHN activity start dates.

Where PHN activities are implemented later, data collected from patients and carers currently in the palliative care system may be able to form counterfactual data until activities are implemented. We propose to collect postcode data from survey respondents, and use this to classify responses into PHN locations. This would then be triangulated with information from PHNs regarding the extent to which activities under the GCfAHPC measure have been implemented.

The survey of palliative care patients and carers is highly dependent on buy-in from key stakeholders and referral sources and their willingness to distribute a survey to their clients, noting that it is likely to be a very sensitive and challenging time for people. In particular for group C in Figure 4.3, successful data collection would also be dependent on local service providers and referral sources maintaining a database of clients and still having details for carers of clients they are no longer providing services to.

To address this challenge, we will collaborate with relevant State and Territory PCA member organisations when fielding patient and carer surveys. Consultation with these organisations is ongoing, however those engaged with to date have expressed their support for the evaluation, and have committed to connect the evaluators with key stakeholders and assist with fielding patient and carer surveys through their networks.

We will continue to work with the Department of Health on the most appropriate methods for data collection from palliative care patients and carers as well as the appropriateness of the survey questions and indicators. We will also continue to discuss the possibilities with the PHNs, relevant service providers and the PCA, and detail any ethical considerations in our ethics application.

4.7 Data analysis methodology

Throughout the evaluation, we would work with the Department of Health and the PHNs to identify appropriate quantitative data sources and decide on the most appropriate methods for quantitative analysis. Data analysis methodologies will be informed by the nature and quantity of the data received and collected (including size, statistical significance, distribution, variables, independent vs paired). If sufficiently granular current and historical data is available, the evaluation team may for example use benchmarking across various key metrics to identify trends and patterns across time and geographies.

The types of data we may collect will vary according to activity stream and may include:

- the number of health care providers/patients using the service pathway following the improvements implemented by the PHN;
- the number of health care providers/patients using the new model of care;
- the number of training sessions attended or materials accessed by health care and social service providers; and
- the number of attendees at community engagement/awareness sessions.

Qualitative data collected through surveys and semi-structured interviews will be analysed thematically, ensuring the privacy of evaluation participants is maintained. The survey and consultation questions will be tailored to each stakeholder group. The patient and carer survey will focus on their reported experience of the at home palliative care as well as their understanding of palliative care options available to them. The PHN and local stakeholder surveys will focus on the implementation and outcomes of the measure. More information on the evaluation questions is provided in Section 4.3.

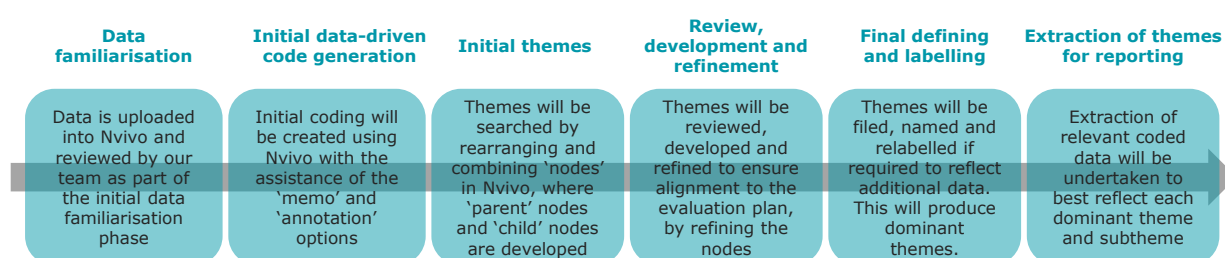
The evaluation team will analyse the survey and consult data using a variety of techniques, including

- thematic analysis of long form responses;
- comparative analysis of short form responses; and
- descriptive statistics for numerical responses.

If a significant amount of qualitative data is collected, we would use NVivo 11 to systematically analyse all primary research findings. NVivo 11 (QSR International) is analysis software specifically designed for qualitative analysis of

interview transcripts, videos, photographs, drawings, surveys, and other information. It will be useful for analysing in-depth interviews with key stakeholders. While maintaining confidentiality, direct excerpts or stories may also be included in reports delivered to the Department of Health to ensure the voice of the community and end-users remain intrinsic to the evaluation. The use of this thematic data coding technique ensures that findings can be directly traced back to the raw data, providing a transparent analytical method. A high-level approach to this qualitative data analysis approach is set out in Figure 4.5.

Figure 4.5: Six-step thematic analysis with NVivo 11



4.8 Summary of the approach to reporting

Evaluation findings will be presented in the following reports:

- 1) **Status Report (February 2019):** A report with a summary of the status of the evaluation, including the surveys of local stakeholders and PHNs and the status of the ethics approval process. The Status Report would include a brief description of activities undertaken, any challenges or difficulties and actions taken in response, notification of performance against the timeframe, and any early findings and lessons learnt.
- 2) **Draft and final Interim Evaluation Report (July and September 2019):** We propose that the Interim Evaluation Report will comprise primarily of findings from the process evaluation. Prior to delivery of the Interim Evaluation, we would convene a workshop via Teleconference (Workshop 2) in which we would discuss findings reported in the Interim Evaluation with stakeholders and seek feedback.
- 3) **Draft and final Evaluation Report (April and May 2020):** The Evaluation Report will be a detailed and comprehensive report bringing together all aspects of the evaluation including the findings from the process evaluation, as well as the findings from the outcomes evaluation and the cost analysis. As with the Interim Evaluation Report, we will share and validate the findings in the report with key stakeholders.

Evaluation Implementation Overview



5 Consultation Plan

This chapter provides a high-level overview of the consultation plan. This evaluation involves surveys and consultation with PHNs, local stakeholders, central stakeholders and palliative care patients.

5.1 PHNs

The evaluation team will aim to survey all 11 of the PHNs in March 2019 and September 2019, and consult with all of the PHNs in January 2020.

5.1.1 Electronic survey

Survey data will be collected from the 11 PHN sites that form part of the trial, namely Murrumbidgee PHN; Gold Coast PHN; South Western Sydney PHN; North Western Melbourne PHN; Eastern Melbourne PHN; Central QLD, Wide Bay and Sunshine Coast PHN; Brisbane South PHN; Adelaide PHN; Country WA PHN; Western NSW PHN; and Primary Health Tasmania. The first survey will be administered in March 2019 and focus on the implementation process for the measure and the second survey will be administered in September 2019 and focus on both the implementation process and outcomes from the measure.

5.1.2 Semi-structured interviews

Additional semi-structured interviews will be conducted with the 11 PHNs that form part of the trial in January 2020. Interviews will form 'case studies', aiming to capture more detailed insights regarding factors such as the extent to which the GCfAHPC measure is achieving its intended objectives, barriers and enablers to uptake, the degree to which the model is scalable, and the degree to which the model is sustainable.

5.2 Local stakeholders

The evaluation team will aim to survey a number of local stakeholders at each of the 11 PHN sites in March 2019 and September 2019. The consultations in January 2020 will focus on three local stakeholders at each of the four selected PHN sites.

5.2.1 Electronic survey

Data will be collected from local stakeholders through two electronic surveys (proposed for March 2019 and September 2019). Surveys will capture important information from local stakeholders to inform indicators such as those relating to appropriateness of the program for users, level of uptake by the target user group, effectiveness of the projects, and unintended impacts.

Local stakeholders may include both palliative care service providers, and key referral sources:

- Local (specialist) palliative care service providers
- General Practitioners
- Local Hospital Networks
- Geriatricians
- Hospital palliative care branches
- Aged care providers
- Cancer care providers
- Key community members targeted under the GCfAHPC measure activities (if relevant to PHN).

Contact details for all local stakeholders would be provided by PHNs. We note that there is a risk of bias, as PHNs are more likely to have and provide contact details for local stakeholders who are being engaged through the GCfAHPC measure activities. This could be mitigated by requesting from PHNs a 'minimum list' of contact details for particular service providers, as well as any additional service providers PHNs propose to include. For

instance we propose that service providers are asked to provide contact details for at least all specialist palliative care providers and hospital palliative care branches in their area.

The evaluation team will aim to survey up to twenty local stakeholders at each of the 11 PHN sites in March 2019 and September 2019.

5.2.2 Semi-structured interviews

Additional semi-structured interviews will be conducted with a sample of local stakeholders in January 2020. Interviews will form 'case studies', aiming to capture more detailed insights regarding factors such as the extent to which the GCfAHPC measure is achieving its intended objectives, barriers and enablers to uptake, the degree to which the model is scalable, and the degree to which the model is sustainable. These findings will be triangulated with the patient and carer surveys and the PHN interviews from these sites to gain a deeper understanding of the successes and challenges of delivery of the activities in different contexts.

The semi-structured interviews will be held with a selection of 3 local stakeholders from 4 PHN locations. The sampling of the case studies will be determined in discussion with the Department of Health closer to the time of the interviews. This is so that PHN-level progress of the PHN activities under the GCfAHPC measure, and findings from the surveys can be taken into consideration in selecting the sites. This may ensure that findings in the interim evaluation report, or areas of particular interest to the Department of Health, are able to be explored further through the semi-structured interviews with local stakeholders. Most likely, the four PHN sites will be strategically selected as to ensure the sample is both representative of the different activity streams and the diversity in the Australian population more generally.

5.3 Central stakeholders

We will undertake consultation with a range of central stakeholders in May 2019, to gain detailed insights and reflections from government, industry and consumer stakeholders on the implementation, outcomes achieved, barriers and enablers, of the GCfAHPC measure. We will survey a representative sample of 10 relevant stakeholders from the identified government, industry and consumer groups, who will be consulted through 30-45 minute face-to-face or telephone semi-structured interviews. We will work with the Department of Health to finalise the stakeholders, and propose this is re-assessed closer to May 2019 to ensure relevance. The following stakeholders may be included:

- The Department of Health internal teams
- Australian and New Zealand Society of Palliative Medicine (ANZSPM)
- Palliative Care Nurses Australia
- Palliative Care Australia (PCA)
- The Royal Australian College of General Practitioners (RACGP)
- Cancer Council Australia
- Carers Australia
- CanTeen (noting that we will not collect any data directly from people under the age of 18)
- The Older Persons Advocacy Network (OPAN)
- Consumer Health Forum

We will be reliant on the Department of Health to provide us with contact details for central stakeholders, and we propose that buy-in from central stakeholders may be improved if the Department of Health initiates contact via email initially, introducing Deloitte and the Evaluation of the GCfAHPC measure.

5.4 Palliative care patients and carers

We will aim to field a survey of palliative care patients and carers from June till December 2019. The survey will target a sample of palliative care patients and carers receiving services in areas targeted by the GCfAHPC measure in a subset of 4 PHNs. We will discuss the most appropriate PHN locations to field the survey with the Department of Health. The sample of PHNs may be locations where there is an emphasis on patient and carer

level outcomes, and where the PHNs have good relationships with service providers willing to assist in fielding the survey.

The evaluation team will aim to survey up to twenty palliative care patients and carers from each of the four selected PHN sites in late 2019. The four PHN sites will be strategically selected as to ensure the sample is both representative of the different activity streams and geographically diverse.

The survey of palliative care patients and carers is highly dependent on buy-in from key stakeholders and referral sources, and their willingness to distribute a survey to their clients, noting that it is likely to be a very sensitive and challenging time for people. Successful data collection would also be dependent on local service providers and referral sources maintaining a database of clients as well as availability of details for carers of clients service providers may no longer be providing services to.

We note that PHNs may also have alternative methods for sampling palliative care patients and carers in addition to through assistance from service providers. We will workshop the possibilities for sampling palliative care patients and carers with the PHNs, relevant service providers, and central bodies including the PCA. We will also detail any ethical considerations in our ethics application.

6 Risk management plan

This chapter provides a high-level overview of the risk management plan. The purpose of risk mitigation is to identify and rate the main potential risks to the completion of the project, and then provide strategies to minimise each potential risk.

6.1 Risk mitigation strategies

Identification of risk and mitigation strategies is a process of reducing or eliminating adverse events encountered (or which have the potential to occur) during the evaluation process. The approach to manage evaluation risk involves:

- identifying encountered or potential risks to the evaluation process;
- assessing the likelihood and resulting impact of risks in the context of consequences to the GCfAHPC evaluation; and
- identifying and implementing strategies to mitigate or lessen evaluation risks from occurring during the evaluation process.

The identified risks, associated likelihood and impact, and suggested strategies for mitigation are presented in Table 6.1.

Table 6.1: Indicative risk mitigation strategy

| Risk | Likelihood and impact | Mitigation strategies |
|---|--|---|
| Key stakeholders, may be difficult to contact to arrange a suitable time interview | Likelihood: Possible Impact: Moderate | We will identify key contacts and stakeholders early in the evaluation planning phase, and as part of consultation strategy we will ensure each relevant contact is aware at which points they would be engaged and for what purpose. Deloitte Access Economics will seek input from the Department Project Team on suitable contacts to interview and appropriate methods for contacting them. |
| Recruitment of patients and carers to engage in primary research activities may be challenging due to practicalities and priorities | Likelihood: Likely Impact: Moderate | We will work with the sample PHNs to develop an engagement and recruitment strategy that bears minimal impact of service providers and patients and carers. Survey tools will be designed to be short form to minimise time burden, and electronic methods of dissemination is an option to reduce invasiveness of engagements. Through the process of developing our ethics protocol and going through the approval process, considerations of informed consent, privacy and data handling will be carefully considered and addressed. |

Continued over page

| Risk | Likelihood and impact | Mitigation strategies |
|--|--|---|
| Establishing a baseline against which to evaluate the GCfAHPC measure may be difficult due to challenges in identifying a comparator cohort due to practical and ethical reasons | Likelihood: Likely Impact: Moderate | We propose that comparator data for evaluation questions relating to palliative care patients and carers could be collected through surveying carers of people who received palliative care before the GCfAHPC measure was implemented, as well as patients and carers who are currently receiving palliative care but who entered the system prior to the activities under the GCfAHPC measure starting. |
| Sensitivities may exist regarding current discussions of end-of-life care. | Likelihood: Possible Impact: Minor | We will be sensitive to the views of stakeholders regarding palliative and end-of-life care. Engagement tools will be developed with review from the Department of Health and relevant experts (for example PCA) to ensure questioning is respectful. |
| Contextual issues may play a significant role in project success/failure yet be difficult to identify | Likelihood: Possible Impact: Moderate | The evaluation questions have been designed with the Department Project Team and PHN representatives to capture context-specific content. These initial contextual issues will help inform the more in-depth stakeholder consultations undertaken with PHNs and other local service setting representatives. Limitations will be clearly defined. |
| Communications regarding outcomes of the evaluation with the palliative care community may be contentious | Likelihood: Possible Impact: Moderate | We will work with the Department of Health and other key stakeholders to anticipate any sensitivities or contentious findings from the evaluation. |
| Feedback and input not received from Department Project Team in due timeframe | Likelihood: Unlikely Impact: Moderate | Clear expectations and agreed timeframes have been set through the project plan. In the event that consolidated feedback in relation to review periods and deliverables is not received in time, we would liaise with the Department of Health with a possible view to adjusting delivery date/s accordingly. |

Continued over page

| Risk | Likelihood and impact | Mitigation strategies |
|--|--|--|
| The composition of either the Deloitte Access Economics team or the Department Project Team is altered during the project life due to unforeseen circumstances | Likelihood: Possible Impact: Moderate | We will ensure internal team processes allowed for continuity and at the first instance of need for potential change, we would immediately notify the Department Project Team and provide CVs of suggested replacement for approval. All team members proposed for this project are available for the duration of the project, however in the event that a member of the proposed team is unable to deliver the engagement, we have over 40 members of the national Health Economics and Social Policy team who are highly skilled and able to deliver services. We expect the Department Project Team to communicate with Deloitte Access Economics in the event that their team is altered. |

7 Implementation overview

This chapter provides a high-level overview of the governance arrangements and key evaluation timeframes, including timing of stakeholder consultation, data collection and reporting over the evaluation period.

7.1 Governance arrangements

The governance of the evaluation is important to its overall efficacy and robustness. As such, governance arrangements are established with the goal of maintaining objectivity and independence whilst considering practicalities and logistics. Key groups involved in the evaluation and their responsibilities are outlined in Table 7.1.

Table 7.1: Overview of key roles and responsibilities

| Personnel | Responsibilities |
|--|---|
| Deloitte Access Economics Project Team | <ul style="list-style-type: none"> • Develop the Evaluation Plan (this document) • Undertake ethics approval processes for collection of patient experience and outcomes data • Execute the evaluation as per the Evaluation Plan, including the collection and analysis of primary and secondary data from PHNs, and primary data from local stakeholders, patients and their carers. • Report on progress and main findings as per the reporting schedule |
| Department of Health | <ul style="list-style-type: none"> • Provide relevant information and pre-existing data to Deloitte Access Economics • Assist with primary data collection (e.g. provision of email distribution lists and contact details for the and administration of surveys and site-case studies) • Provide one set of consolidated feedback on draft evaluation outputs • Assist with development and implementation of an information dissemination strategy |
| PHNs | <ul style="list-style-type: none"> • Provide GCfAHPC-related documentation, including any planning documents, reporting to the Department of Health, formal communication or referral arrangements, and the activity work plans • Provide GCfAHPC-related program data (e.g. number of referrals through the new referral pathways, number of training sessions/materials delivered) • Provide care pathway or outcomes data (if applicable) |

The Deloitte Access Economics and the Department of Health will remain in regular contact over the course of the evaluation. Deloitte Access Economics will conduct weekly or fortnightly project status update meetings with the Department of Health. Each status update meeting would include a progress report that contains the following information at a minimum: activities completed, key milestones, key deliverables, planned activities,

project issues or risks, as well as mitigation strategies. Deloitte will also participate in the PHN GCfAHPC Working Group teleconferences and to the PHN SharePoint Greater Choice Working Group page.

7.2 Evaluation timeframes

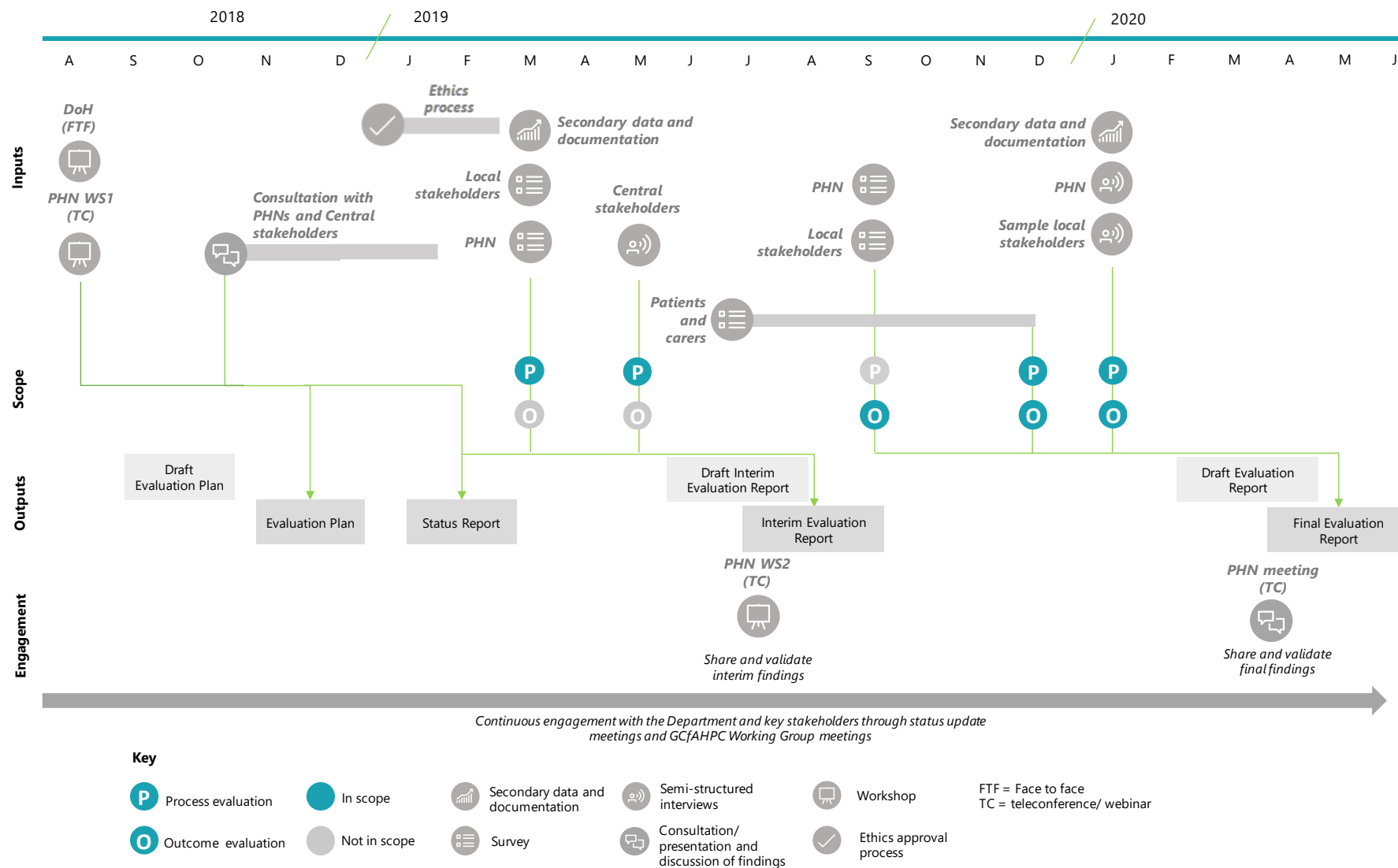
A summary of the key milestones for the GCfAHPC evaluation are provided in Table 7.2 and summarised in Figure 7.1.

Table 7.2: Key deliverables and timeframes for the GCfAHPC evaluation

| Date | Deliverables |
|---------------|--|
| December 2018 | <p>Design survey instruments for PHNs, local stakeholders, patients and carers. The survey questions will be based on the indicators and questions outlined in the Evaluation Framework, and will be targeted at both the process and outcome evaluation. Specifically, the initial design stage will involve the following tasks.</p> <ol style="list-style-type: none"> 1) Design <u>two electronic surveys for PHN staff</u> involved in implementing the GCfAHPC measure. The survey will contain Likert and short responses, and take around 15 minutes to complete. The first electronic survey will be administered in March 2019, and the second survey will be administered in September 2019; 2) Design <u>an initial and follow-up survey for local stakeholders</u> such as General Practitioners or palliative care providers. The initial survey will be administered in March 2019 and the follow up survey will be administered in September 2019; and 3) Design a <u>survey for palliative care patients and carers</u>, as this information is required as part of the ethics approval process. <p><u>Ethics process</u>: As our proposed approach to the evaluation involves engagement with sensitive stakeholders such as palliative care patients, we will require ethical approval from Bellberry Ltd, an established HREC. To meet the requirement, we will develop a research protocol for any required ethics clearances following the finalisation of the Evaluation Framework. This protocol would be guided by the National Statement on the Ethical Conduct in Human Research (2015).</p> |
| February 2019 | <p><u>Prepare and deliver a Status Report</u> that describes the activities undertaken to date, identifies challenges and the steps taken in overcoming these, and provides a brief overview of early findings.</p> |
| March 2019 | <p>Administer the <u>electronic PHN survey</u> and <u>collect relevant secondary data</u> from the PHNs, such as GCfAHPC-related program and activity data, or patient outcomes data. The purpose of the initial survey is to collect important data on the final activity streams and process evaluation indicators outlined in the Evaluation Framework.</p> <p>Administer the <u>survey of local stakeholders</u>, and collect process evaluation data relating to the local stakeholders as per the Evaluation Framework.</p> <p>As the surveys are short in length they will be <u>analysed and compared to the initial survey</u> as it filters in.</p> |

| | |
|-----------------------|---|
| <i>April 2019</i> | <u>Design semi structured interviews for key government and industry stakeholders</u> , including Department of Health, ANZSPM, PCA, Palliative Care Nurses Australia, RACGP, Consumer Health Forum, and other identified relevant community and sector groups. |
| <i>May 2019</i> | <u>Conduct semi structured interviews with central stakeholders</u> to gain detailed insights and reflections from government, industry and consumer stakeholders on the implementation, outcomes achieved, barriers and enablers, and view of lessons learned. Information about projects that received continued funding will be compared with information captured in the retrospective evaluation interviews. |
| <i>June 2019</i> | <u>Administer survey for current palliative care patients and carers</u> , and people who were previously carers of palliative care patients. The survey would be short in length, and administered over a six month period aiming to collect both comparator data and data on experiences under the GCfAHPC measure if possible. |
| <i>July 2019</i> | Summarise preliminary findings from the GCfAHPC evaluation in the <u>Interim Evaluation Report</u> and present the key findings to the Department of Health for their comment and review. |
| <i>August 2019</i> | Provide the Department of Health with the <u>final interim evaluation report</u> . |
| <i>September 2019</i> | Administer a <u>follow up survey with local stakeholders</u> and a third electronic PHN survey. The purpose of conducting multiple surveys is that the initial survey will provide baseline data on the buy-in, acceptability and other views on the activities under the GCfAHPC measure, and subsequent surveys will help to demonstrate whether these measures have changed over time. |
| <i>January 2020</i> | <u>Conduct semi-structured interviews with PHN staff</u> to collect their reflections of the GCfAHPC measure over the course of the project on both process and outcome lines of inquiry. Findings will be triangulated with patient and carer surveys, and stakeholder interviews and <u>secondary data collected by the PHNs</u> . This will feed into the outcome evaluation. <u>Consult with three local stakeholders</u> from the representative subset of four PHNs to gain a deeper understanding of themes which emerge from the surveys including the extent to which the GCfAHPC measure is achieving its intended objectives, barriers and enablers to uptake, and the degree to which the model is scalable and sustainable. |
| <i>April 2020</i> | Summarise the findings from the GCfAHPC evaluation in the <u>Final Evaluation Report</u> and present the key findings to the Department of Health for their comment and review. |
| <i>May 2020</i> | Provide the <u>Final Evaluation of the GCfAHPC measure</u> to the Department of Health. |

Figure 7.1: Data collection and reporting plan



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