



# **Comprehensive Palliative Care in Aged Care Measure – Evaluation Framework**

Department of Health

13 September 2021

*We acknowledge those people with a lived experience of palliative care, their families, friends and carers who provided input into this Evaluation Framework development or will provide input into the evaluation.*

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# Contents

1	Introduction.....	3
2	Policy and stakeholder context for the evaluation.....	6
2.1	Policy and stakeholder context of the Measure.....	6
2.2	Key features of the Measure relevant to the evaluation.....	8
3	Evaluation approach.....	9
3.1	Evaluation approach.....	9
3.2	Program theory.....	9
3.3	National outcomes.....	11
3.4	Governance arrangements.....	12
3.5	Key evaluation questions.....	13
4	Evaluation methodology.....	15
5	Data collection and analysis.....	18
5.1	Data collection methods.....	18
5.2	Data sources considered; however, not included in evaluation.....	29
5.3	Analysis methods.....	30
5.3.1	Qualitative analysis.....	30
5.3.2	Quantitative analysis.....	30
5.4	Data synthesis and triangulation.....	34
6	Stakeholder communication plan.....	35
6.1	Principles for engagement.....	35
6.2	Stakeholder communication plan.....	35
7	Dependencies, challenges and risks.....	38
7.1	Boundaries and dependencies of the evaluation.....	38
7.2	Key challenges and risks for the evaluation.....	38
7.3	Risk management approach.....	40
8	Ethics considerations.....	41
8.1	Ethics management.....	41
8.1.1	Privacy and data management.....	42
Appendix A	Stakeholders consulted in development of this Framework.....	43
Appendix B	Data collection tools.....	46
B.1	RACF survey.....	46
B.2	State and territory biannual reporting template.....	49
B.3	PCA consumer representative group interview guide.....	50
Appendix C	Evaluation indicators.....	53
Appendix D	Risk management plan.....	56
Appendix E	Glossary.....	60

# 1 Introduction

## THIS SECTION

This section outlines the:

- background and context for the evaluation
- purpose of the evaluation
- structure of this document – the Evaluation Framework.

## Background and context

The Comprehensive Palliative Care in Aged Care Measure (the Measure) provides \$57.2 million in Australian Government funding from 2018-2024, with funding to jurisdictions starting from 2019-20. The Measure aims to help older Australians living in residential aged care who are nearing the end of their life. It will:

- support the delivery of projects that expand existing models of care or new approaches to the way care is delivered or commissioned, to improve palliative and end-of-life care coordination for older Australians living in residential aged care facilities (RACFs).
- strengthen national efforts to improve access to quality palliative care as a component of an integrated health-aged care system.
- The Measure is provided through a cost-shared model, meaning states and territories match Australian Government funding. States and territories implement initiatives based on local needs and are required to evaluate initiatives in their jurisdiction to contribute to the national evaluation.

## Purpose of the national evaluation

Nous Group (Nous) has been engaged by the Australian Government Department of Health (the Department) to undertake a national evaluation (the evaluation) of the Measure between July 2020 and November 2023.

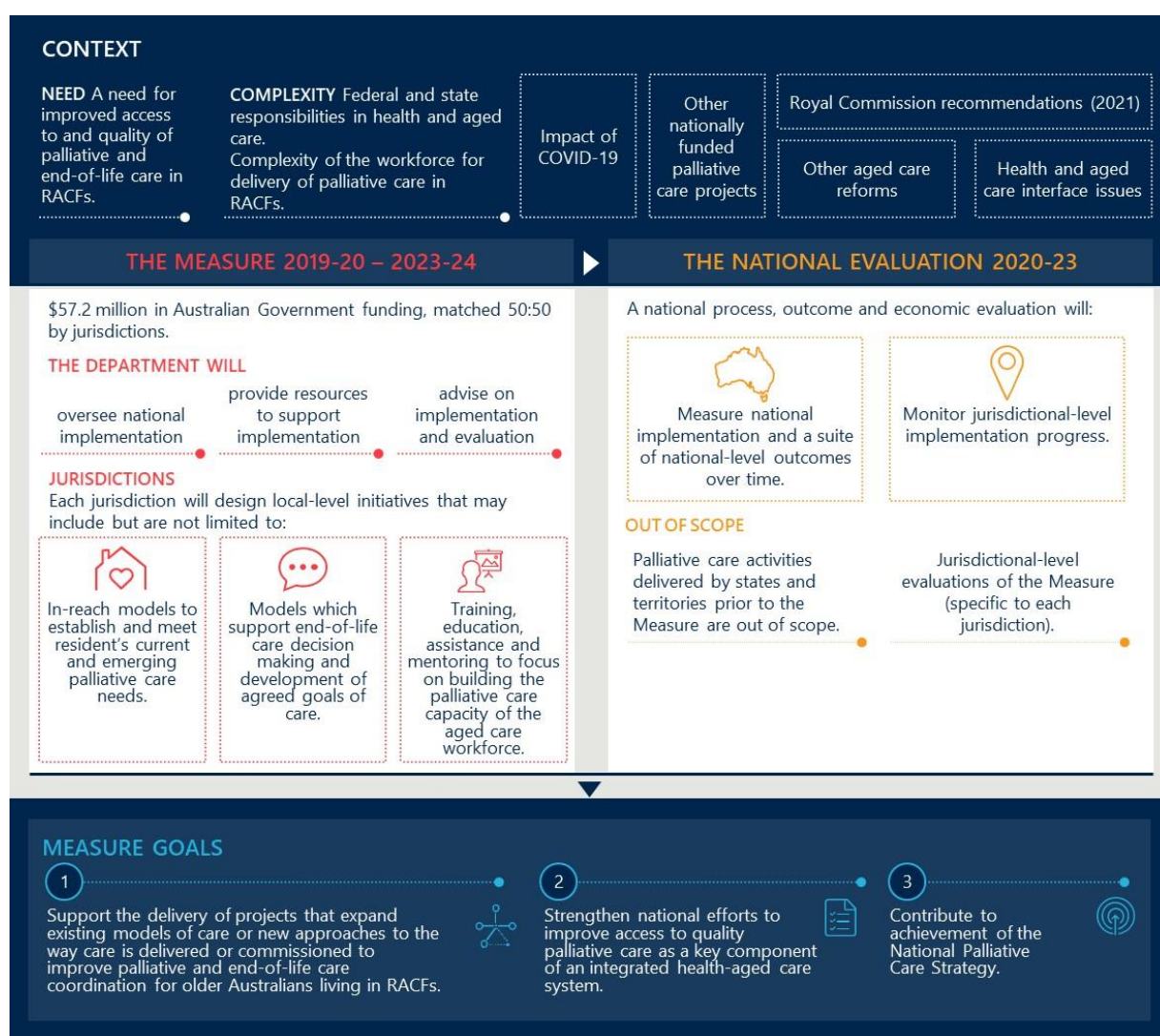
The evaluation will determine the extent to which the aims of the Measure have been achieved. The evaluation outcomes will contribute to the national evidence base and inform policy decisions about palliative care in aged care, including on best practice models of care.

The evaluation objectives are to:

- assess the implementation, appropriateness, effectiveness and cost-effectiveness of the activities and approaches undertaken in each jurisdiction
- measure and analyse the impact of each of the state and territory activities in relation to the Measure's program objectives
- identify the barriers and enablers to achieving the intended outcomes
- assess the effectiveness of the governance model of the Measure
- identify issues to be considered for future priorities for the Measure, taking into consideration demographics and health and aged care reforms
- analyse the achievements of the program in relation to the National Palliative Care Strategy
- develop recommendations to inform palliative care policy development.

Figure 1 summarises the context, key components and evaluation of the Measure. The evaluation will measure implementation and national-level outcomes (jurisdictional-level evaluations are out-of-scope, see section 3).

Figure 1 | Summary of context and design of the Measure



## Purpose of this document

The Evaluation Framework covers evaluation activities from April 2021 to November 2023. The primary audience for the evaluation is the Department and state and territory government representatives. This Evaluation Framework provides:

- an introduction to the Measure and evaluation (section 1)
- a description of the policy and stakeholder context (section 2)
- the evaluation approach, key questions and data collection and analysis methods (sections 3, 3.5, 4, 5)
- the stakeholder communication plan (section 6)
- dependencies, challenges and risks (section 7)
- ethics considerations (section 8).



### Development of the Evaluation Framework

Collaboration with states and territories is critical to develop a feasible Evaluation Framework and conduct the evaluation. Nous requires a deep understanding of jurisdictions' activities, specific circumstances, timing and approach to measurement and evaluation to conduct the national evaluation.

Nous worked with state and territory representatives between September 2020 and January 2021 to develop the draft Evaluation Framework. Nous will continue to do so during the evaluation, noting that many jurisdictional approaches are unlikely to be finalised by end of January 2021. The Evaluation Framework will be updated accordingly.

There are many activities underway in the palliative care, health and aged care sectors that will likely impact on Measure activities and evaluation findings. Nous engaged with peak bodies, national agencies and data experts to best understand the context and data availability (see Appendix A).

## 2 Policy and stakeholder context for the evaluation

### THIS SECTION

This section describes the context for the evaluation including:

- the policy, operational and stakeholder environment in which the evaluation sits
- key features of the Measure that impact on the conduct and interpretation of findings from the evaluation.

### 2.1 Policy and stakeholder context of the Measure

The policy and operational context and reforms of the health and aged care sectors are complex, as shown in Figure 2. The context is characterised by the following:

- **There are many stakeholders working in the palliative care in residential aged care environment.** States, territories and the Australian Government have different roles in the provision of palliative care in RACFs.
- **Palliative care is multifaceted and there is a need to improve its delivery in RACFs.** Much work has been done – as evidenced by the many strategies, standards and indicators – however, there is more to do.
- **The operating environment is complex and changing.** Many external factors and reforms in the aged care and palliative care sectors will impact upon the Measure’s implementation and outcomes.

Each of these points are expanded below.

Figure 2 | The policy, stakeholder and operating environment for the evaluation of the Measure



#### States, territories and the Australian Government have different roles in the provision of palliative care in RACFs

Provision of palliative care in RACFs brings health and aged care service delivery together, with many differently funded and managed parties holding a role in the delivery of care. This includes:

- The Australian Government acts as steward of the aged care system and primary funder and holds responsibility for general practice and primary health care funding and policy. The Australian Government also funds palliative care through agreements with hospitals.
- State and territory governments are responsible for the provision of palliative care services in their health systems, which include ambulance, emergency, public and private hospital and hospice inpatient, private health funds, and community services.
- General Practitioners (GPs), some Nurse Practitioners and allied health professionals (e.g. occupational therapy, psychology, speech pathology and social work) are independent small business owners, who are reimbursed on a fee for service arrangement by the Australian Government.
- RACFs are owned and managed in a range of ways, including for-profit and not-for-profit businesses or by state/territory governments. Individual residents are also significant funders of their own care.
- The degree of ownership and control of RACFs varies considerably by jurisdiction. For example, Victoria and Queensland operate more residential aged care beds than the other states with significant operations. Victorian Government-owned RACFs represent 26 per cent of all beds in the state.

This results in an overlap of responsibility when health services – including palliative care – are delivered in a residential aged care setting. In the context of the evaluation, this means that recognition of the role of all parties is critical. In particular, collaboration between the Australian Government and state and territory governments is a key factor in the design and conduct of evaluation activities.

The extent of control all levels of government have over delivery of services in RACFs is dependent on the RACF itself. For-profit and not-for-profit RACFs, as opposed to government administered facilities, have relatively more control over the types and mode of service delivered within the facility.

### **Palliative care is multifaceted and there is a need to improve its delivery in RACFs**

The provision of palliative care in RACFs is complex. Palliative care itself is multifaceted; it addresses physical, spiritual and psychosocial needs, and can be generalist or specialist in nature. This multifaceted nature also means that palliative care can be delivered in RACFs in a variety of ways. This may include, for example, through generalist and specialist staff within the RACF or through in-reach or outreach services. In addition, palliative care in the residential aged care setting is increasingly being used for temporary and intermittent support for non-permanent residents, not just permanent residents.

There is a need to improve the delivery of palliative care in residential aged care settings. Hearings from the Royal Commission into Aged Care Quality and Safety indicated that the availability and standard of palliative care provided in residential aged care is widely variable.<sup>1</sup> Other evidence indicates that early identification of palliative care needs and communication about palliative care and goals of care are a challenge for many – including residents, families, carers and staff.<sup>2,3</sup>

The Measure responds to these challenges and aims to strengthen national efforts to improve access to quality palliative care as a key component of an integrated health-aged care system.

### **Many external factors and reforms in the aged care and palliative care sector will impact on the Measure implementation and outcomes**

Ongoing activities, initiatives and reforms across the health and aged care sectors will impact upon the Measure and the evaluation. Key examples include:

- The outcomes of the Royal Commission into Aged Care Quality and Safety are likely to result in changes to the aged care sector that will change the strategic and operating context for the Measure.

<sup>1</sup> Royal Commission into Aged Care Quality and Safety, "Interim Report: Neglect", Volume 1, 2019.

<sup>2</sup> Lane, H, Philip, J, "Managing expectations: Providing palliative care in aged care RACFs," Australasian Journal on Ageing, 2015.

<sup>3</sup> Productivity Commission, "Introducing competition and informed user choice into human services: Reforms to human services. Chapter 3: End-of-life care in Australia", 2017.



- COVID-19 will have an ongoing impact on RACFs and may result in a reduced capacity to implement activities or collect data relating to the Measure.
- An increased emphasis on advance care planning has seen national efforts to increase the quality and accessibility of advance care planning which will continue in coming years.

Nous has taken these factors, and others, into consideration in designing the Evaluation Framework and will continue to in conducting the evaluation (see section 7). The nature of palliative care complicates data collection. Data is not nationally consistent or is unable to identify if the patient is from a RACF (see section 7).

## 2.2 Key features of the Measure relevant to the evaluation

The design of the Measure itself influences the design and conduct of the evaluation. Jurisdictions will implement the Measure differently, using varying levels of funding to implement activities based on local needs. Table 1 summarises key features of the Measure and how they impact on the evaluation.

**Table 1 | Key features of the Measure and relevance for the evaluation**

Key feature	Implications for the evaluation
Each jurisdiction is at a different point of maturity in their delivery of palliative care in RACFs.	Each jurisdiction will have a different starting point for the evaluation. This will influence the activities that each jurisdiction chooses to implement under the Measure and the potential impact of those activities.
Each jurisdiction can choose what activities they implement under the Measure.	There will be variability, resulting in challenges determining national outcomes. Additional variability may be introduced at the Local Health Network (LHN), Local Health District (LHD) or Hospital and Health Service (HHS) level.
Activities implemented under the Measure could relate to either generalist or specialist palliative care.	This will increase the scope of activities and stakeholders involved. The evaluation must be cognisant of the types of palliative care that may be delivered and how their impact can be measured.
Each jurisdiction will implement in different timeframes and may scale up or stage implementation over time.	Timeframes will have to be considered at the jurisdictional-level when considering the evaluation. Staged implementation will mean that measuring impact and attribution over time will be challenging.
Activities may build upon initiatives outside of the Measure.	Activities outside of the Measure such as advance care planning initiatives or training programs (e.g. End-of-life Directions for Aged Care (ELDAC)) may be used as a foundation for activities implemented under the Measure. The evaluation will have to separate the impact of activities outside and under the Measure, which may be challenging.
Each jurisdiction has varying amounts of funding under the Measure, which is not ongoing.	Each jurisdiction has a varying amount of funding under the Measure, which is time limited to the five years of the Measure. This will impact on the types of activities implemented and therefore the way they are evaluated.
A number of jurisdictions are not planning formal evaluation activities which may result in limited information.	The evaluation will likely need to pair the information received from states and territories with some additional jurisdictional data collection. This will not replace the jurisdictional-level evaluations; however, will serve to inform national outcomes and indicators designed to measure the overall progress and achievement of the Measure against its stated aims.

Nous has considered these factors in the design of the evaluation – see the approach to addressing them in section 5. The factors above may result in a challenge in setting a baseline for the evaluation. Where features of the Measure may introduce challenges in measuring outcomes or in attribution, the Evaluation Framework notes challenges and mitigation strategies.

## 3 Evaluation approach



This section details the approach and framework that structures the evaluation. It includes the:

- evaluation type and scope
- program theory, including the theory of change and program logic
- governance arrangements.

### 3.1 Evaluation approach

Given the evaluation aims, the evaluation includes process, outcome and economic components:

- **Process component:** This refers to the process of implementation and delivery of the Measure, including the effectiveness of joint funding and delivery arrangements between the Australian Government and states and territories.
- **Outcome component:** This refers to understanding the extent to which intended outcomes and overarching goals were achieved over the life of the Measure.
- **Economic component:** This refers to understanding the cost-effectiveness of the Measure.

Three factors will support successful delivery and underpin the evaluation design and delivery. These are:

- **Ongoing collaboration and engagement with states and territories.** Support for and participation in the evaluation by all states and territories is critical to inform and contextualise findings (see section 6).
- **Innovative use of data sources.** Given the challenging data landscape (see section 7), the evaluation uses a suite of innovative data sources to build the most comprehensive picture possible (see section 5).
- **Incorporation of the views of families and carers.** The evaluation will seek to understand families and carers' experiences of palliative care in RACFs (see section 5). Residents, families and carers are a diverse group and where possible, the evaluation will take into account any differences in the experiences of different population groups. For example, this includes how the palliative care journey differs for people living with dementia (a growing cohort), people from CALD backgrounds, Aboriginal and Torres Strait Islander people and people living in rural and remote areas.

### 3.2 Program theory

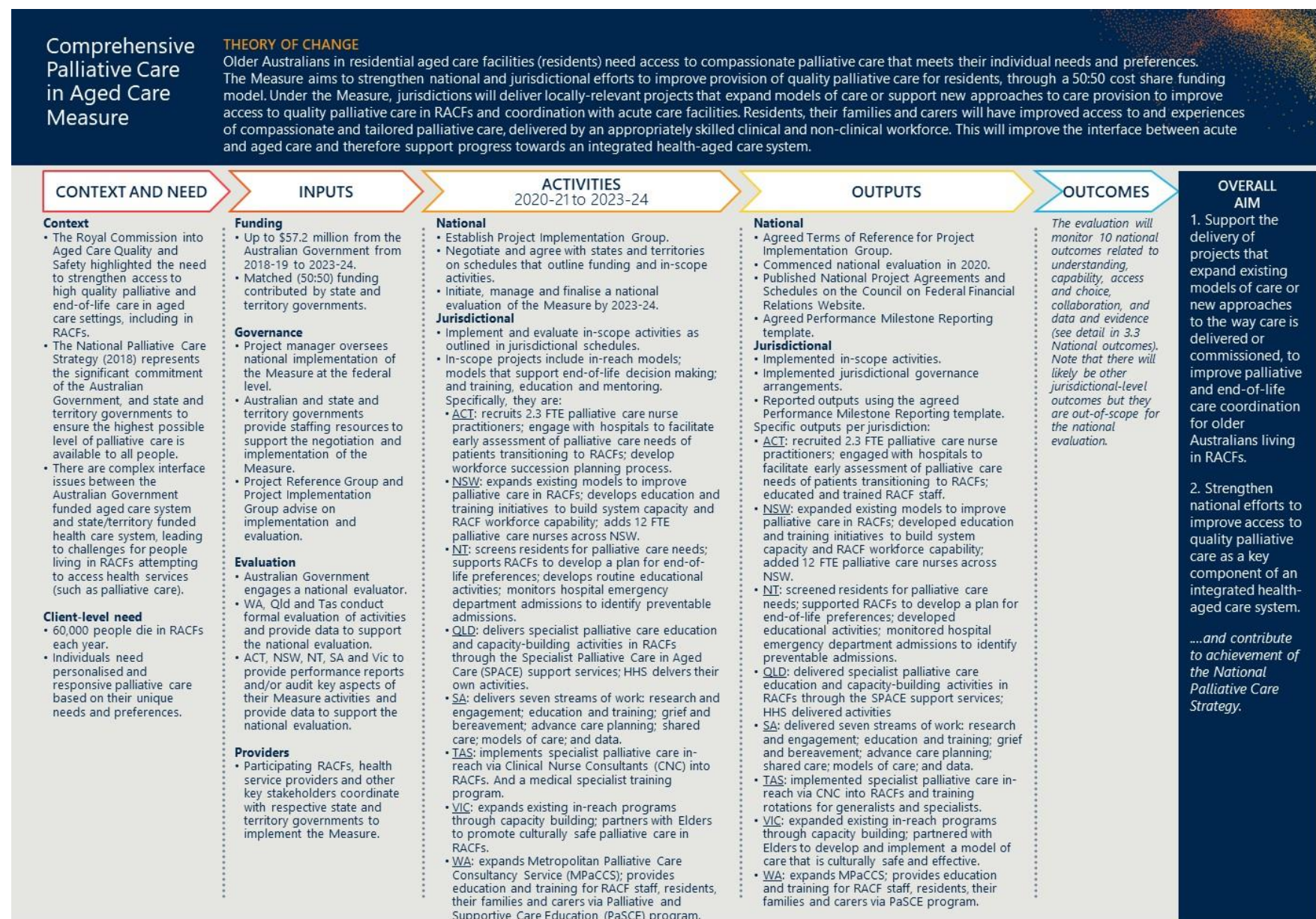
A **program theory** articulates how the Measure is intended to achieve its goals and underpins the evaluation. The program theory is comprised of two elements:

- The **theory of change** summarises the program logic and explains how activities are understood to produce results that contribute towards achieving the broader goals of the Measure.
- The **program logic** provides a visual representation of how the Measure intends to work. It articulates the relationship between desired outcomes of the Measure and the required inputs, activities and outputs.

The program logic model for the evaluation is provided in Figure 3. Outcomes in the program logic align to relevant outcomes from the National Palliative Care Strategy 2018.<sup>4</sup>

<sup>4</sup> Goal 5 (Investment) and Goal 7 (Accountability) of the National Palliative Care Strategy are not necessary to be included as national outcomes for this evaluation.

Figure 3 | Theory of change and program logic for the Measure





### 3.3 National outcomes

National outcomes provide a consistent basis to measure the progress and impact of the Measure. Table 2 presents the national outcomes, grouped under goals of the National Palliative Care Strategy.<sup>5,6</sup>

There may be some additional jurisdictional-specific outcomes. It is out-of-scope for the national evaluation to measure additional jurisdictional-specific outcomes; however, Nous will include aggregate information on all outcomes in reports. Appendix B provides more detail on indicators to measure these outcomes.

**Table 2 | National outcomes for the Measure**

#	Outcome
Understanding	
1	More discussions focused on end-of-life care decision making between residents, families, carers, GPs and specialist palliative care services including use of Advance Care Plans.
2	Improved access to information that informs end-of-life care decisions for residents and families.
Capability	
3	A higher proportion of clinical and non-clinical staff in RACFs have skills and confidence appropriate to their roles to recognise and respond to the holistic palliative care needs of residents, in a culturally safe way.
Access and choice	
4	Improved access to quality palliative care in RACFs, including: <ul style="list-style-type: none"> <li>increased use of assessments to establish residents' palliative care needs</li> <li>decreased health service use related to futile or non-beneficial treatments and inpatient bed days</li> <li>decreased healthcare expenditure arising from decreased service use.</li> </ul>
	Improved quality of palliative care provided in RACFs, including: <ul style="list-style-type: none"> <li>reduced symptom burden</li> </ul>
	Improved quality of life for residents during the period they access palliative care <ul style="list-style-type: none"> <li>better experience of death and dying for residents, families/carers and staff, including meeting physical, psychosocial, cultural and spiritual needs.</li> </ul>
6	Greater patient choice in palliative care, including: <ul style="list-style-type: none"> <li>more people dying where they want</li> <li>increased person-centred care informed by an individual's choice.</li> </ul>
Collaboration	
7	Improved care coordination with GPs/primary care, acute care services and specialist palliative care services.
8	Improved integration between the health and aged care systems.
9	More palliative care services and health planners are informed by performance information on appropriateness, effectiveness, efficiency and outcomes.
Data and evidence	
10	Improved clinical governance to identify and implement quality improvement initiatives and evaluation of outcomes within RACFs.

<sup>5</sup> Australian Government Department of Health, National Palliative Care Strategy 2018.

<sup>6</sup> Goal 5 (Investment) and Goal 7 (Accountability) of the National Palliative Care Strategy are not necessary to be included as national outcomes for this evaluation.

## 3.4 Governance arrangements

The key group involved in governance of the evaluation is the **Department project team**. The Department provides oversight of evaluation progress and delivery, whilst Nous undertakes an independent evaluation of the Measure. This group is the evaluation team's key point of contact during the evaluation.

Several groups will provide critical input to Nous over the course of the evaluation. The **National Palliative Care and End-of-life Project Reference Group** includes representatives from all jurisdictions. This will be a forum to share information among jurisdictions and discuss progress on implementing the National Palliative Care Strategy.

States and territories are critical partners in the evaluation. They will need to provide data and information regularly, and advice in interpreting findings. Nous will meet with state and territory representatives regularly, including collectively through the **Project Implementation Group or joint evaluation-focused meetings**. This group consists of palliative care and/or aged care representatives and shares a similar membership to the **National Palliative Care and End-of-life Project Reference Group**.

Nous will report regularly to the Department as shown in Table 3.

**Table 3 | Evaluation reporting**

Deliverable	Description	Due date
<b>Stage 2 (2021-2023)</b>		
Draft Midpoint (interim) Progress Report	The Draft Midpoint Report will describe findings from the evaluation to date, structured by the key evaluation questions (KEQs). It will describe consultation and data analysis findings and link in insights from the literature review and system mapping.	30 June 2022
Final Midpoint (interim) Progress Report	The Final Midpoint Progress Report will be as described above, finalised and incorporating feedback from the Department.	31 July 2022
Progress Reports (seven in total, three per year)	Each Progress Report will follow a similar format. It will be a process-based update, describing evaluation progress to date, activities completed, emerging findings (structured by the KEQ) and planned activities remaining. Progress Report 2 will provide the baseline.	30 March 2021/31 July 2021/30 November 2021/ 30 March 2022/31 July 2022/30 November 2022/ 30 March 2023
<b>Stage 3 (2023)</b>		
Interim Evaluation Report	The Interim Evaluation Report will draw together and synthesise all findings and recommendations. It will summarise the evaluation process and draw together insights from across all streams of work.	30 August 2023
Evaluation Stakeholder Briefs	The briefs will contain a summary of consultations, grouped by stakeholder.	30 September 2023
Final Evaluation Report	The Final Evaluation Report will be as described for the Interim Evaluation Report above, finalised with the incorporation of feedback.	30 October 2023

## 3.5 Key evaluation questions

### THIS SECTION

This section provides the overarching context for the evaluation. It provides information on:

- the KEQs that will support the evaluation
- the research questions that will steer the evaluation.

The Department identified eight KEQs to guide the evaluation, which reflect the process, outcome and economic components. The KEQs and research questions are shown in Table 4. These will guide data collection, analysis and structure reports.

**Table 4 | KEQs and research questions**

KEQ	Research question	Evaluation component		
		Process	Outcome	Economic
1. Has the Measure been implemented as planned and what are the implementation lessons from the Measure?	What is important to understand about the policy and operating contexts in which the Measure is delivered?	✓		
	What is the aim of the Measure?		✓	
	Has the Measure been implemented as planned?	✓		
	How could the implementation process have been improved?	✓		
2. How appropriate is the Measure to meet the needs of residents, families and carers in the RACF setting?	What are the palliative care needs of residents, families/carers and staff in RACF settings?		✓	
	How well did the Measure meet those needs?		✓	
3. How effective have the joint funding and delivery arrangements been for implementing and achieving the aims of the Measure? How could governance arrangements be more effective?	What evidence exists on best practice approaches to funding and delivery arrangements?	✓		
	To what extent do the joint funding and delivery arrangements enable the Measure to achieve its aims?	✓		
	How could the funding and delivery arrangements be improved?	✓		
4. To what extent has the Measure achieved its intended outcomes?	What are the intended outcomes?		✓	
	How can outcomes be measured?		✓	
	What is the baseline for the evaluation?		✓	
	How have outcomes changed over the life of the Measure?		✓	
5. How cost-effective is the Measure?	What are the costs of the "do nothing scenario" across the RACF, hospitals, transport, medication and elsewhere?			✓
	What are the costs of the Measure across the RACF, hospital, transport, medication and elsewhere?			✓
	What is the difference in costs between the "do nothing scenario" and the Measure?			✓



KEQ	Research question	Evaluation component		
		Process	Outcome	Economic
	What activities undertaken through the Measure are the most cost efficient?			✓
	What processes for implementing the Measure were the most cost efficient?	✓		✓
6. Is there a specific model of care that has been implemented that has proven to be more successful than others?	Which models of care implemented under the Measure have been most successful?		✓	
	What models of care exist elsewhere that have proven successful?		✓	
7. How well does the Measure align and contribute to the National Palliative Care Strategy? Are there opportunities for improvement?	How do the Measure's listed outcomes align with the goals and priorities of the National Palliative Care Strategy?	✓		
	How has the Measure contributed to the goals and priorities of the Strategy?		✓	
	How could the Measure be better aligned to the Strategy?		✓	
8. Does the Measure and the models adopted in each jurisdiction help to address health system interface issues?	What are the key interface issues?	✓		
	How have the models adopted within the Measure acted to address interface issues?		✓	
	How have other palliative care in RACF initiatives outside of the Measure sought to address health interface issues?		✓	

## 4 Evaluation methodology

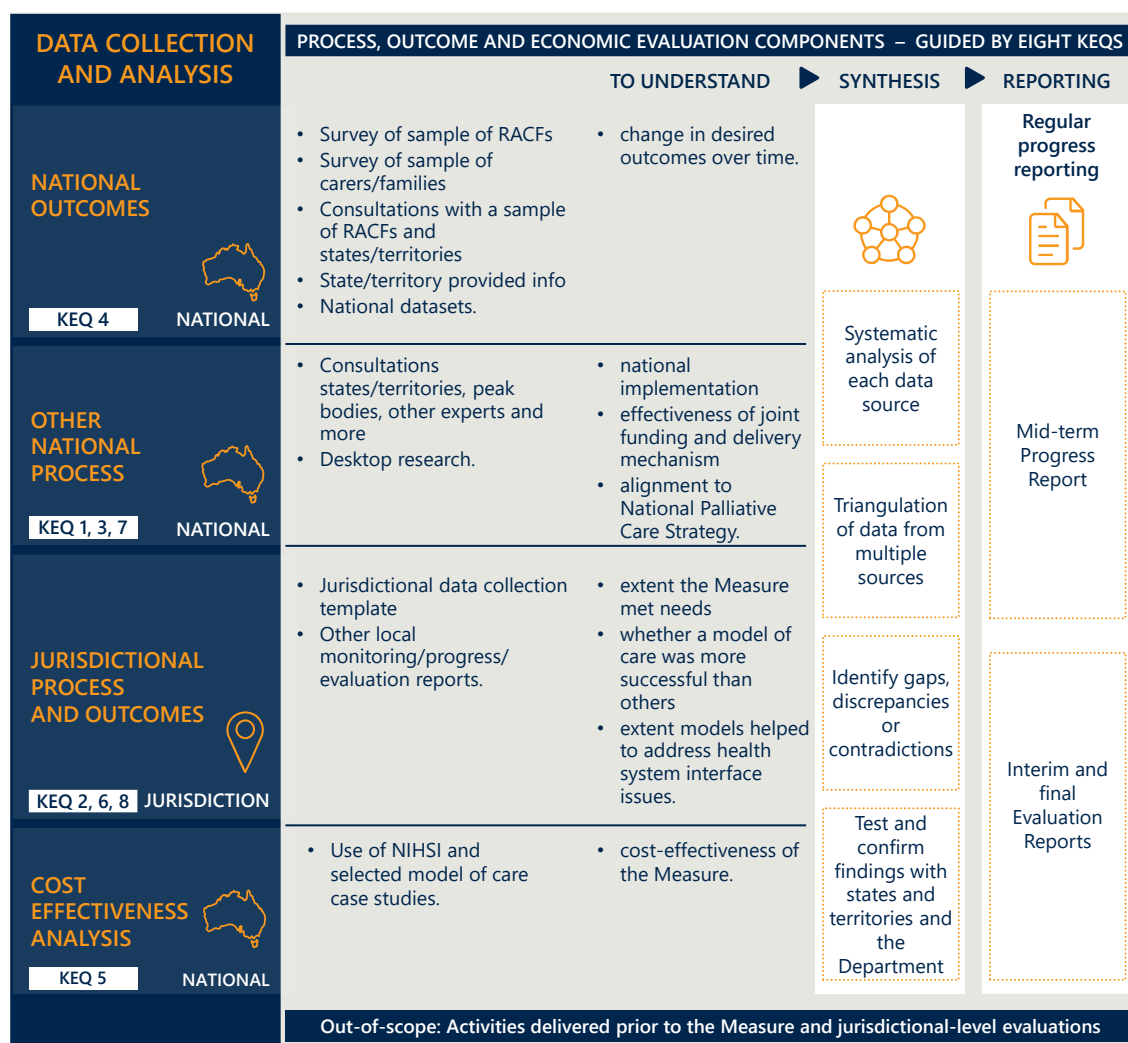
### THIS SECTION

This section describes key elements of the evaluation methodology including the timeline and methodology overview.

The evaluation includes four key elements, shown in Figure 4 and summarised below:

- **Measurement of national outcomes.** This evaluation will assess national outcomes over time (KEQ 4).
- **Analysis of other national-level information.** Nous will examine national implementation of the Measure, the effectiveness of the joint funding and delivery mechanism and alignment to the National Palliative Care Strategy (KEQ 1, 3, 7).
- **Synthesis of jurisdictional information and data.** Jurisdictional-level information will inform the process evaluation and the extent to which the Measure meets an identified need. This includes whether a model of care was more successful than others and the extent to which health system interface issues were addressed. Evaluating jurisdiction-level activities is out-of-scope (KEQ 2, 6, 8).
- **Analysis of cost-effectiveness.** Nous will examine the cost-effectiveness of the Measure (KEQ 5).

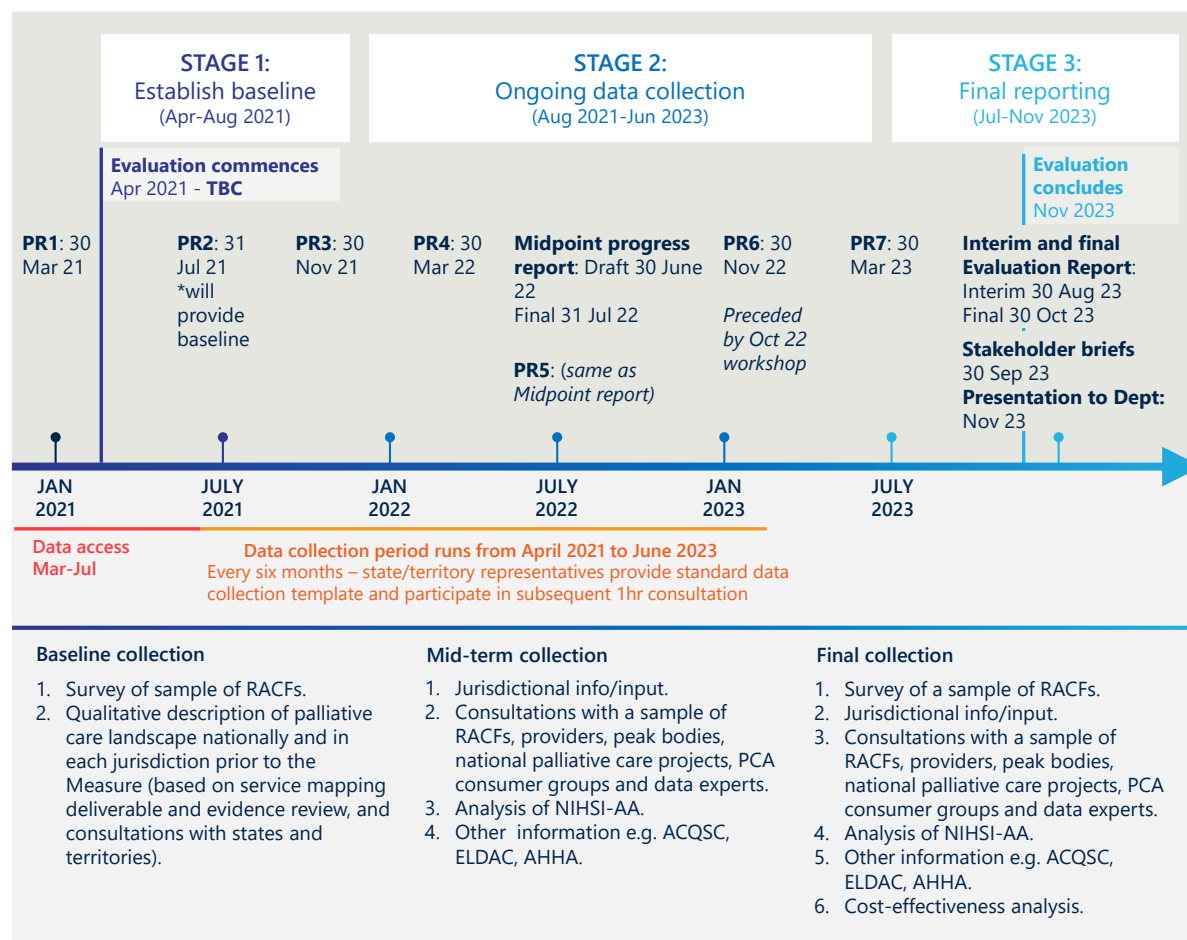
Figure 4 | Overview of methodology



Nous will deliver the evaluation between April 2021 to November 2023, see Figure 5. In summary, the evaluation stages are:

- Stage 1 (April 2021 to August 2021):** The purpose is to finalise access to data sources and establish a national baseline for the evaluation. Some data sources that will inform the national baseline will not be available for inclusion during Stage 1 (e.g. relevant data from National Integrated Health Services Information Analysis Asset (NIHSI-AA) is expected to be available in the second half of 2021). This data will be incorporated during Stage 2.
- Stage 2 (August 2021 to June 2023):** The purpose is to undertake regular data collection and reporting to monitor implementation progress and outputs at the national-level.
- Stage 3 (July 2023 to November 2023):** The purpose is to measure outcomes from the Measure against the baseline established in Stage 1, undertake the cost-effectiveness analysis and develop the Final Evaluation Report, including overall findings and recommendations.

Figure 5 | Evaluation timeline



Evaluation timeframes are dependent on jurisdictional timeframes to:

- sign up to the Measure
- determine the specific activities they will undertake (and in what locations)
- determine the evaluation approach and timeframes for the jurisdictional evaluations – noting that most jurisdictions are not planning formal evaluations, rather monitoring and reporting activities.

## 5 Data collection and analysis

### THIS SECTION





This section details the data collection methods and analysis plans.

### 5.1 Data collection methods

The evaluation will use qualitative and quantitative methods, as shown in Table 5. The mixed methods approach enables triangulation and informs the process, outcome and economic components.

State and territory consultations and the survey of a sample of RACFs will contribute to the evaluation baseline (to be provided in the July 2021 Progress Report 2). NIHSI-AA will contribute to the baseline but will be reported retrospectively in the midpoint report, as data will not be available for the July 2021 Progress Report 2.


Table 5 | Summary of data collection methods

	DATA SOURCE	RATIONALE
<b>SURVEYS</b> 	Survey of a sample of RACFs.	The survey helps to capture information to inform measurement of national outcomes and other information not available in existing data sources.
<b>CONSULTATIONS</b> 	Consultations with: <ul style="list-style-type: none"> <li>state and territory health departments</li> <li>a sample of RACFs</li> <li>palliative care service providers including GPs, specialist palliative care services and other clinicians</li> <li>peak bodies and other national palliative care projects</li> <li>Palliative Care Australia (PCA) consumer representative groups in jurisdictions.</li> </ul>	Consultations provide rich qualitative information on Measure implementation in each jurisdiction, success of models of care, family/carer experiences and needs and clinician/provider views.
<b>EXISTING NATIONAL GOVERNMENT DATA SETS</b> 	NIHSI-AA. Aged Care Quality and Safety Commission (ACQSC) complaints data.	National data sets contain information on palliative care activities and feedback specifically in RACFs.
<b>OTHER DATA SETS</b> 	ELDAC provided data/information. Australian Healthcare and Hospitals Association (AHHA) progress reports.	Additional data sets do not have a national scope; however, will provide additional information to inform the evaluation.




## Data collection method: Surveys

Nous will conduct a survey of a sample of RACFs to supplement palliative care data provided in existing data sets, as detailed below.

	Survey of a sample of RACFs	Reported in: Progress Report 2 (baseline) Final Report
<b>Purpose and rationale</b>	<p>Nous has developed a purpose-built survey to capture information about almost all national outcomes that are intended to be achieved by the Measure (see section 3.3). Currently, limited data exists regarding the provision of palliative care in RACFs including access, quality, planning and training at the facility level. This survey seeks to fill that gap by directly engaging with RACFs. A copy of the survey is provided in Appendix B.1.</p>	
<b>Collection methodology</b>	<p>Nous will administer the survey electronically through the Alchemer platform (previously SurveyGizmo). Nous will use different mechanisms to distribute and collect data through the survey across jurisdictions. Multiple mechanisms are necessary to maximise the quantity and quality of responses while also reflecting the different approaches jurisdictions are taking to implement the Measure. Nous intends to distribute the survey leveraging the Australian Department of Health database of approved providers and RACFs. We will also use networks and mechanisms in states and territories to follow-up and maximise responses where possible. We will aim to distribute the survey to all RACFs in Australia to the extent that is possible.</p> <p>Surveys distributed by Nous will have a unique link to the survey that can be used to identify the facility and track responses. Nous will use unique identifiers to conduct targeted follow-ups with RACFs that have not yet responded and encourage responses across all jurisdictions. Nous will also use unique identifiers to identify RACFs that are underrepresented in responses and encourage responses. For example, if there are limited responses from a particular jurisdiction or type of RACF, Nous or jurisdictional representatives will reach out to specific RACFs to encourage responses.</p> <p>Nous will conduct a small pilot of the survey with RACFs to ensure that RACFs are able to provide meaningful responses for the evaluation.</p>	
<b>Considerations</b>	<p>Nous developed the survey to provide data for specific indicators that measure the national outcomes of the measure (section 5.3.2). The questions also align to the goals of the National Palliative Care Strategy.</p> <p>RACF survey responses will contribute to the evaluation baseline (provided in Progress Report 2, July 2021) and Final Report.</p> <p>Key considerations in developing the survey included:</p> <ul style="list-style-type: none"> <li>• Reducing response burden by minimising the number of questions, using clear and concise questions and not requiring participants to provide extended text responses.</li> <li>• Ensuring questions are fit-for-purpose and can be answered by RACF staff. Nous tested the survey with RACF staff including facility managers and palliative care nurse practitioners. Nous will also pilot the survey before national distribution.</li> <li>• Stakeholders including RACFs understand the purpose of the survey and buy-in to its use for the evaluation. Stakeholders including RACFs, peak bodies and health departments (both Australian and states and territories) have been consulted and provided feedback for the survey.</li> </ul> <p>Ethics approval is not required because it will be conducted at the facility level, completed by people in their professional capacity and not include any personal information. Communications associated with the survey will make clear that the response should reflect the RACF not the respondent's personal view.</p>	



	Nous will collate contextual information about the RACFs including the jurisdiction, region (metropolitan, regional, rural), size, provider organisation using the facility's name collected through the survey and through unique identifiers used to distribute the survey.
<b>Frequency of collection</b>	Nous will conduct the survey twice during the evaluation: in April 2021 and April 2023.
<b>Scope</b>	<p>All RACFs will be invited to participate in the survey and Nous will ensure that responses cover a representative sample. The representative sample will include responses across:</p> <ul style="list-style-type: none"> <li>• all jurisdictions participating in the Measure</li> <li>• metro, regional and remote areas</li> <li>• not-for-profit, for-profit, community and government providers</li> <li>• RACFs of varying sizes (in terms of number of residents)</li> </ul> <p>Where possible, we will seek to be able to identify and gather responses from:</p> <ul style="list-style-type: none"> <li>• providers focused on residential aged care for people living with dementia</li> <li>• providers that support people from CALD backgrounds and/or Aboriginal and Torres Strait Islander people and communities.</li> </ul>



## Data collection method: Consultations

Consultations will provide qualitative insights to complement quantitative data. This is important given the limitations of the quantitative data sets and the need to collaborate with states and territories. Through consultations, Nous will identify additional relevant information, understand operating contexts and hear from RACFs about their delivery of activities under the Measure. Nous will consult with:


- palliative care and aged care representatives from state and territory health departments
- a sample of RACFs that is representative across participating RACFs (to be determined in consultation with jurisdictions)
- palliative care service providers including GPs, nurses, specialist palliative care services and other clinicians<sup>7</sup>
- key stakeholders including peak bodies and other national initiatives (e.g. Palliative Care Outcomes Collaboration (PCOC), ELDAC, Advance Care Planning Australia, Palliative Care Australia (PCA))
- PCA consumer representative groups.

More detail is below. See also the stakeholder communication plan at section 6.

	<b>Consultations with palliative care and aged care representatives from state and territory health departments</b>	Reported in: Progress Report 2 (baseline) Other Progress Reports Midpoint Report Final Report
<b>Purpose and rationale</b>	Input from jurisdictions is critical to understand implementation and explore models of care. This includes whether activities were implemented as planned, effectiveness of joint funding and delivery arrangements, and success of models of care.	


<sup>7</sup> Other clinicians refer to professionals from allied health disciplines, including but not limited to occupational therapy, psychology, speech pathology and social work. These clinicians may be part of a multi-disciplinary team at the RACF.

<b>Collection methodology</b>	<p>Nous will seek input from jurisdictions every six months as follows:</p> <ul style="list-style-type: none"> <li>• <b>Written data collection template:</b> Nous will provide a standard data collection template for states and territories to complete on a six-monthly basis (see Appendix B). It collects information about implementation of the Measure activities in each jurisdiction, challenges and progress and any relevant jurisdiction-level evaluation or monitoring reports useful to inform the national evaluation. Note: <ul style="list-style-type: none"> <li>• Nous anticipates that jurisdictions will provide a major update every 12 months via the template, with a more minor update in the intervening six-month period.</li> </ul> </li> <li>• <b>Consultation:</b> Nous will undertake a subsequent teleconference with each jurisdiction to explore the information provided and collect other qualitative information to answer process and impact KEQs. It is also an opportunity to identify specific monitoring or evaluation reports available from each jurisdiction to inform the national evaluation.</li> <li>• <b>End of evaluation showcase:</b> During the second half of the evaluation, Nous will conduct a “showcase” with all states and territories to give each jurisdiction an opportunity to share their achievements and highlight successful models of care that they have implemented.</li> </ul>
<b>Considerations</b>	<p>The benefit of a standard template is efficient collection of standard process and progress information from each jurisdiction, which is required for the national evaluation (given the variability in evaluation approaches).</p> <p>Jurisdictional input will contribute to the evaluation baseline (provided in Progress Report 2, July 2021).</p> <p>Jurisdictional-level evaluations are out-of-scope, so Nous will not conduct analysis of jurisdictional outcomes; however, where possible, will synthesise existing information to inform the national evaluation.</p> <p>States and territories will also provide a report on their progress to the Australian Department of Health on an annual basis, which Nous will review as part of the evaluation.</p>
<b>Frequency of collection</b>	A six-monthly basis between March/April 2021 <sup>8</sup> and May/June 2023. Nous will also consult ad-hoc with state and territory representatives as needed.
<b>Scope</b>	All jurisdictions participating in the Measure.


	<b>Consultations with a representative sample of RACFs</b>	Reported in: Midpoint Report Final Report
<b>Purpose and rationale</b>	<p>Consultations with RACFs will provide information on the delivery, access and quality of palliative care in RACFs to help identify Measure outcomes. A representative sample of RACFs across participating RACFs will be determined in consultation with jurisdictions.</p> <p>Consultations with RACFs will also inform the evaluation on the impact of external factors (such as COVID-19 or the unique circumstances of RACFs). They will provide qualitative information on the success of activities under the Measure in meeting the needs of residents, families and carers, and in addressing health interface issues.</p>	
<b>Collection methodology</b>	<p>Nous will hold semi-structured 60-minute focus group teleconferences with a sample of RACFs in each jurisdiction twice during the evaluation. Larger jurisdictions may involve multiple focus groups to ensure all perspectives are captured.</p> <p>Nous will identify RACFs to invite to participate in consultations through two channels:</p> <ul style="list-style-type: none"> <li>• state/territory health departments will be asked to nominate RACFs in their jurisdiction</li> <li>• RACFs will be able to indicate their willingness to participate in focus groups through the RACF survey.</li> </ul>	


<sup>8</sup> We note that Queensland has commenced implementation activities from January 2021, and will seek input that reflects that for baseline data collection.

	Nous will ensure that RACFs invited to consultations include a representative sample (see Considerations below). Nous will also identify potential RACFs through state and territory health departments and existing contacts of Nous.
<b>Considerations</b>	<p>Nous will aim to ensure that the sample of RACFs in consultations is representative of the RACFs participating in the Measure and includes a mix across:</p> <ul style="list-style-type: none"> <li>• all jurisdictions participating in the Measure</li> <li>• metro, regional and remote areas</li> <li>• not-for-profit,<sup>9</sup> for-profit, and government providers</li> <li>• RACFs of varying sizes (in terms of number of residents)</li> </ul> <p>Where possible, we will seek to consult with:</p> <ul style="list-style-type: none"> <li>• providers focused on residential aged care for people living with dementia</li> <li>• providers that support people from CALD backgrounds and/or Aboriginal and Torres Strait Islander people and communities.</li> </ul> <p>The number of RACFs engaged will be determined by survey response rates and state/territory nominations; however, Nous intends to conduct one focus group in each state and territory, and two to three focus groups in larger jurisdictions such as NSW, Queensland and Victoria.</p> <p>Consultations with RACFs will need to be cognisant of external pressures such as COVID-19 that might delay timeframes.</p>
<b>Frequency of collection</b>	Twice during the evaluation: in May 2022 and June 2023.
<b>Scope</b>	All jurisdictions participating in the Measure.

	<b>Consultations with palliative care service providers including GPs, specialist palliative care services and other clinicians</b>	<b>Reported in: Midpoint Report Final Report</b>
<b>Purpose and rationale</b>	<p>Consultations with palliative care service providers – such as GPs, specialist palliative care services and other clinicians – will provide the palliative care providers perspective to inform the evaluation of the Measure.</p> <p>The provider's perspective on palliative care will include qualitative information on delivery, care coordination across the health and aged care sectors and training. These consultations will supplement limited data on palliative care service delivery within RACFs.</p>	
<b>Collection methodology</b>	<p>Nous will hold semi-structured 30- to 60-minute focus group teleconferences twice during the evaluation.</p> <p>Nous will aim to hold two focus groups per jurisdiction – one for generalist palliative care providers and specialist palliative care providers; however, in larger jurisdictions (Victoria, NSW, Queensland), we may hold up to four (e.g. two each for generalist and specialist providers). Nous may combine smaller jurisdictions into one focus group if there are small numbers.</p>	
<b>Considerations</b>	Nous will request states and territories to nominate clinician contacts via the six-monthly standard data collection templates they will provide.	
<b>Frequency of collection</b>	Twice during the evaluation: in May 2022 and June 2023.	
<b>Scope</b>	A sample of service providers from all jurisdictions participating in the Measure.	

<sup>9</sup> Not-for-profit RACFs include religious, community-based, charitable, and religious/charitable as per GEN-agedcaredata.gov.au.

	Consultations with other key stakeholders including peak bodies and other national palliative care projects	Reported in: Midpoint Report Final Report
<b>Purpose and rationale</b>	<p>Consultations with key stakeholders, such as aged care and palliative care peak bodies and other national initiatives will provide qualitative information to inform the evaluation of the Measure. They will inform the operational context and provide information to assist in understanding the process and impact aspects of the evaluation. This will include identifying successful models of care and how health interface issues have been addressed.</p> <p>Consultations with bodies that may hold relevant data, such as Australian Institute of Health and Welfare (AIHW), ELDAC and PCOC, will be held throughout the evaluation to their current data holdings and how they may inform the evaluation.</p>	
<b>Collection methodology</b>	Nous will hold semi-structured 30- to 60-minute teleconferences twice during the evaluation.	
<b>Considerations</b>	Stakeholders in this group will likely include national and jurisdictional PCA bodies, Leading Age Services Australia (LASA), Council on the Ageing Australia (COTA), PCOC, ELDAC and others. See section 6 for further information.	
<b>Frequency of collection</b>	Twice during the evaluation: in May 2022 and June 2023.	
<b>Scope</b>	A sample of stakeholders across all jurisdictions participating in the Measure.	

	Consultations with PCA consumer representative groups	Reported in: Midpoint Report Final Report
<b>Purpose and rationale</b>	<p>Consultations with PCA consumer representative groups, with chapters in each state and territory, will provide critical input from the perspective of carers and families.</p> <p>The PCA consumer groups provide the family and carer perspective on palliative care delivery in RACFs, the needs of residents, carers and families, and reflections on successful models of care. Where possible, their input may help to identify the change in quality of service delivery during the evaluation.</p>	
<b>Collection methodology</b>	<p>Nous will hold semi-structured 60- to 90-minute focus groups with PCA's consumer representative group. We will also hold focus groups with up to three state/territory PCA chapters should they have an existing consumer representative group that would like to provide input to the evaluation.</p> <p>Nous will provide interview questions to the consumer representative group ahead of the teleconferences (see Appendix B.3).</p>	
<b>Considerations</b>	There is a small risk of inconvenience or discomfort if consumer representatives reflect on personal experiences; however, Nous will conduct the consultations ethically and sensitively (see section 6.1). The risk is largely mitigated by the fact that participants have opted in to the PCA consumer group specifically to participate in these types of consultations. Nous will work with the PCA chapter ahead of the consultation to understand any other important considerations.	
<b>Frequency of collection</b>	Twice during the evaluation: in May 2022 and June 2023.	
<b>Scope</b>	All jurisdictions participating in the Measure.	




## Data collection method: Existing national government datasets


Nous will use national datasets as a major source of information for the outcome and cost-effectiveness components of the evaluation. National data sets vary in their quality and availability in jurisdictions (see section 7). National data sets, such as NIHSI-AA, may contain linked data between state and territory data sets and nationally held data sets. Nous will use two key national data sets, which are:

- NIHSI-AA
- ACQSC complaints data.

Each of these are detailed below.

	NIHSI-AA	Reported in: Midpoint Report Final Report
<b>Purpose and rationale</b>	<p>AIHW has worked with the Australian Department of Health and state and territory health authorities to create NIHSI-AA, a multi-jurisdictional linked data asset that includes hospital admitted, non-admitted and emergency department care, residential aged care, mortality, and the MBS and PBS.</p> <p>Analysis of NIHSI-AA is likely to be highly useful as it provides robust information on the health services (including palliative care) accessed by residents in RACFs. This is not available in other unlinked datasets.</p> <p>Many of the evaluation indicators provided in section 5.3.2 require linked data such as NIHSI-AA to identify RACF residents within other health datasets (MBS, PBS, hospital datasets).</p>	
<b>Collection methodology</b>	<p>Nous is working with AIHW to initiate a project that will produce analysis from NIHSI-AA that can then be included in the evaluation. It is expected that Nous will be involved in this project as part of the Project Advisory Committee. Details regarding the provision of data from this project are still being determined with AIHW.</p>	
<b>Considerations</b>	<p><b>The inclusion of NIHSI-AA in the evaluation is still to be confirmed.</b> Access to NIHSI-AA is limited to state and territory health authorities, the Department and AIHW. Nous is seeking to contract AIHW to conduct analysis of NIHSI-AA due to restrictions on access.</p> <p>Should this be unsuccessful, Nous will work with states and territories to develop an alternative plan for jurisdictional data analysis. This would include identifying opportunities to link data within jurisdictions to generate similar insights. It is not expected that it will be possible to create a national linked dataset like NIHSI-AA for this evaluation. It is also expected that there will be varying capabilities of jurisdictions to link data. In some jurisdictions, linkage may need to occur for specific regions or hospitals where it is possible rather than the jurisdiction as a whole.</p> <p>Approval from the NIHSI Advisory Committee is necessary for the project to go ahead. AIHW has existing ethics approvals in place to conduct analysis with NIHSI-AA; however, the project will need approval from the head of the AIHW Ethics Committee.</p> <p>There are limitations regarding the coverage and timeliness of NIHSI-AA data which are expected to improve during the evaluation. NIHSI-AA is a new dataset that started being built in 2018 and currently contains four jurisdictions: NSW, South Australia, Tasmania and Victoria. It is expected that further states and territories will be included in NIHSI-AA in 2021. NIHSI currently holds data between 2010-11 and 2016-17; however, it is anticipated to be updated to include 2019-20 in 2021. Further data should be included throughout the evaluation. This may mean that indicators that report on NIHSI-AA data take more time to report than indicators that use other data sources.</p>	

<b>Frequency of collection</b>	Analysis will be conducted twice during the evaluation: once to determine the baseline (July-December 2021) which will be included in the Midpoint Report and once with updated data for the Final Report in 2023.
<b>Scope</b>	Currently includes TAS, NSW, VIC, SA. NIHSI is expected to expand to further states and territories in 2021.

	ACQSC Complaints	Reported in: Midpoint Report Final Report
<b>Purpose and rationale</b>	ACQSC records data for the aged care sector, including RACFs. The performance information includes data on site visits, compliance issues and complaints. This data will provide jurisdictional-level information on the RACFs operating contexts, complaints in particular, to inform the evaluation. Any changes in frequency or severity of complaints will be monitored over the course of the evaluation.	
<b>Collection methodology</b>	Nous will collate the reports that ACQSC publicly releases each quarter.	
<b>Considerations</b>	ACQSC data is provided at the jurisdictional-level (e.g. RACFs are not identified). Nous will explore the value of individual facility accreditation reports in consultation with the ACQSC. Complaints data is likely to be biased towards negative input. Nous will be conscious of the negative bias when interpreting and using ACQSC data.	
<b>Frequency of collection</b>	Twice during the evaluation: in May 2022 and June 2023.	
<b>Scope</b>	All states and territories.	






OTHER  
DATA SETS


## Data collection method: Other datasets


Nous will use additional data sets, including:

- ELDAC
- Australian Healthcare and Hospitals Association (AHHA) progress reports
- Potential inclusion of Ambulance data has been explored but no funding source is available at the moment.

Each of these are detailed below.

	ELDAC	Reported in: Midpoint Report Final Report
<b>Purpose and rationale</b>	<p>ELDAC is a national palliative care and advance care planning advisory service that provides resources for palliative care.</p> <p>ELDAC has agreed to provide data/information to inform an understanding of training and education activities and outcomes. This includes information on the extent to which RACFs undertake an ELDAC After Death Audit, uptake of the ELDAC digital dashboards to monitor palliative care and training/education initiatives (limited to those undertaken as part of ELDAC).</p> <p>There are limitations, in that it is only collecting information about RACFs that use and report to ELDAC; however, it is helpful as there is no alternate national or comprehensive data on training and education activities in RACFs.</p>	
<b>Collection methodology</b>	<p>Nous will request the following data from ELDAC annually:</p> <ul style="list-style-type: none"> <li>• After Death Audit data (aggregate, pre and post data), which will provide information on the number of RACFs using the ELDAC After Death Audit and aggregate improvements over time.</li> <li>• Uptake of ELDAC digital dashboard data, which will provide aggregate information on the number of RACFs over time using the ELDAC tool to monitor palliative care activities in RACFs.</li> <li>• Any additional data such as learning needs assessment and organisational readiness (aggregate), which could provide a view of high-level training and education needs in RACFs regarding palliative care.</li> </ul>	
<b>Considerations</b>	<p>Access to ELDAC data is dependent on whether the ELDAC team receives ethics approval to share deidentified data with Nous.</p> <p>ELDAC's initiatives have varying uptake across the states and territories. Uptake is expected to increase during the evaluation.</p> <p>ELDAC is not the only palliative care education and training provider, nor the only After Death Audit tool. ELDAC provided data will be limited to RACFs that engage with and use ELDAC activities and tools. To supplement the ELDAC provided data, the survey of a sample of RACFs also asks more generally about their uptake of digital tools to monitor palliative care and any form of After Death Audit that may take place.</p>	
<b>Frequency of collection</b>	Twice during the evaluation: in May 2022 and June 2023.	
<b>Scope</b>	All states and territories that currently use ELDAC.	

	<b>AHHA progress reports</b>	Reported in: Progress Report 2 (baseline) Midpoint Report Final Report
<b>Purpose and rationale</b>	AHHA provides the Palliative Care Online Training Portal which provides free non-clinical interactive training for carers, community and aged care workers, students, volunteers, family members and clinicians. AHHA can provide reports on the number of people enrolling and outcome measures including change in level of confidence to provide palliative care support services before and after training.	
<b>Collection methodology</b>	Reports will be provided to Nous by AHHA for analysis.	
<b>Considerations</b>	There are a number of limitations including: <ul style="list-style-type: none"> <li>• linking changes in course enrolments and outcomes measures with the impact of the Measure. The level of disaggregation within the data is unclear.</li> <li>• RACFs may be using other training programs for palliative care training – the AHHA training will only be seen as one of a number of potential training avenues</li> <li>• AHHA modules are not RACF specific but we will coordinate with AHHA to implement an additional question on the settings in which survey respondents deliver palliative care (e.g. residential aged care, hospital, primary care, community).</li> </ul>	
<b>Frequency of collection</b>	Reports will be provided every six months with analysis for inclusion in the Midpoint and Final Reports.	
<b>Scope</b>	All jurisdictions participating in the Measure.	

	<b>Ambulance data pilot project</b> use of this data has been explored but funding has not been confirmed	<b>Reported in:</b> TBC
<b>Purpose and rationale</b>	<p>One of the key intended outcomes of the Measure is reducing the number of ambulance call-outs to RACFs and transfers from RACFs to hospital for palliative care when that treatment could be provided in the RACF. Currently there is limited national ambulance data particularly pertaining to palliative care in RACFs.</p> <p>Nous has proposed a pilot project working with researchers at Turning Point Population Health and Monash University who have developed methods to collate and code ambulance data. This project would involve coding existing ambulance records linked to RACFs with respect to palliative care. Once coded, the data can be used to measure the impact of the Measure on ambulance call outs and hospital transfer.</p> <p>This pilot project is still being discussed with the Department of Health to determine its viability as part of the evaluation.</p>	
<b>Collection methodology</b>	<p>The Turning Point Population Health Research Program will collate and code ambulance data to identify the number of ambulance call-outs to RACFs and transfers from RACFs to hospital. This data will be provided to Nous for analysis.</p>	
<b>Considerations</b>	<p>Turning Point Population Health will need to submit a modification to their existing ethics application to conduct the analysis and provide it to Nous. Nous will not need to submit a separate ethics application for this data.</p> <p>Analysis will be conducted as a pilot in one jurisdiction, Tasmania, due to the novel nature of this data set and the limitations in accessing suitable records from other jurisdictions.</p>	
<b>Frequency of collection</b>	<p>Analysis will be conducted yearly: Jan 2021-July 2021; Jan 2022-July 2022; Jan 2023-July 2023.</p>	
<b>Scope</b>	<p>Pilot project in one jurisdiction, Tasmania.</p>	

## 5.2 Data sources considered; however, not included in evaluation

Other data sources were considered, but excluded given limited value for the purpose of this evaluation:

- **Medicare Benefits Schedule (MBS):** MBS data will be included as part of the NIHSI-AA data set, although will not be incorporated as a standalone data set. MBS data does not have a flag to indicate that individuals are residents of RACFs. This severely limits the utility of MBS data to identify the impact of the Measure which is limited to RACFs. If NIHSI-AA data is not available for the evaluation, Nous will explore the possibility of performing limited linkage of MBS data with aged care data sets to identify individuals who are residents of RACFs.
- **Pharmaceutical Benefits Scheme (PBS):** As with MBS data, PBS data will be included as part of the NIHSI-AA data set, although will not be incorporated as a standalone data set. PBS data does not have a flag to indicate that individuals are residents of RACFs. This severely limits the utility of PBS data to identify the impact of the Measure which is limited to RACFs. If NIHSI-AA data is not available for the evaluation, Nous will explore the possibility of performing limited linkage of PBS data with aged care data sets to identify individuals who are residents of RACFs.
- **National admitted and non-admitted hospital data sets:** National hospital data sets will be included as part of the NIHSI-AA data set, although will not be incorporated as a standalone data set. National admitted and non-admitted hospital data sets do not contain a flag to indicate that individuals are residents of RACFs or address information. This removes the possibility of using these data sets to examine only residents of RACFs, the focus of the Measure.
- **Aged Care Funding Instrument (ACFI):** ACFI provides limited information related to the intended outcomes of the Measure including improved quality of palliative care in RACFs. The ACFI is used by aged care providers to claim subsidies for residents that permanently enter their care and contains little or no information about the type of care that is provided and resident outcomes. This limits the usefulness of ACFI data to the evaluation. Also, ACFI does not capture all individuals who are receiving palliative care and is likely undercounting the number of individuals who receive palliative care in RACFs. For example, if a resident is already on the maximum ACFI Complex Health Care claim, services may not claim for palliative care as it is not possible to increase the subsidy payable in this situation. The assessment of palliative care within the ACFI is also limited to the resident's last week or days. Nous will consider the usefulness of the Australian National Aged Care Classification (AN-ACC) if it is introduced during the evaluation. Nous understands that the timeframe for moving the AN-ACC from pilot use to full implementation is not currently known.
- **Consultations with residents and/or families and carers:** The national evaluation is seeking to observe system-wide and facility-level outcomes of the Measure over time. This includes understanding at the broad level whether the experience of residents, families and carers improves due to the Measure. However, there are complications for direct engagement with families and carers – for example, timing of engagement, their ability to comment on whether palliative care has changed over the life of the Measure (given most have a point in time experience) and the success of different models of care. Therefore, Nous will not directly consult with carers or families. Nous will use existing data sources to include the perspective of the families and carers, such as through PCA consumer representative groups, the ELDAC After Death Audit (a proxy) and information jurisdictions may be able to provide (see section 5.1).
- **PCOC:** PCOC aims to improve palliative care patient and carer outcomes through a framework and protocol for routine clinical assessment and response. Services that participate in PCOC collect palliative care outcomes data that could be valuable for evaluation purposes; however, Nous has been advised that PCOC data covering residents in RACFs is severely limited (less than 10 RACFs). PCOC is rolling out a new model that focussed on RACFs ("PCOC Wicking Model"), although it is not likely that this will reach maturity in time for this evaluation. Nous will continue to engage with PCOC and incorporate high-level information about the number of people in RACFs who are accessing specialist palliative care that is captured in PCOC.

## 5.3 Analysis methods

The evaluation will use qualitative and quantitative analysis methods. Throughout the evaluation, Nous will take care to ensure that data is collated, stored, cleaned and analysed appropriately. This includes ensuring that the inferences drawn from data are robust and statistically valid where appropriate. See section 8 for Nous' approach to privacy and data management. As a general principle, where possible, we will examine data by socio-demographic or other cohorts to understand the different experiences and impacts of the Measure.

### 5.3.1 Qualitative analysis

Qualitative data sources will include consultations with the Department, state and territory representatives, peak bodies, providers and consumer representative groups. The KEQs will structure all qualitative analysis (see section 3.5).

The qualitative analysis will provide more detail and nuance that cannot be understood from quantitative data alone. Qualitative data will help to elicit insights on which models of care were successful and why.

Nous will conduct thematic analysis of documentation, evaluation reports/findings from jurisdictions and from consultations. Thematic analysis involves:

- **Initial review.** The evaluation will review the information from desktop research and consultations to develop a holistic understanding of the results.
- **Identify and code themes.** This involves recording or identifying similar, repeated content or patterns in the data that provide insights to the KEQs. Patterns are summarised and interpreted, then coded to develop an organised framework of thematic insights. Semantic (e.g. facts, statements) and latent (underlying ideas, concepts beyond the literal records) themes will be sought.
- **Review, modify and test themes.** This involves checking/testing the identified themes to ensure that, as far as possible, they are mutually exclusive and collectively exhaustive, and testing relevant emerging insights with key stakeholders in subsequent consultations. This allows the analysis team to test and modify codes in an iterative fashion. Themes may be refined, combined, split, weighted or discarded at this stage.
- **Define themes.** This involves developing a detailed analysis of each theme, determining the scope, focus and relationships between each theme and identifying key insights and findings from the consultations.
- **Triangulate with broader evaluation methods.** Nous will triangulate key findings from consultations with quantitative analysis to support, strengthen, balance, dilute or deviate overall evaluation findings.

### 5.3.2 Quantitative analysis

Nous will use quantitative analysis to provide a robust evidence base throughout the evaluation. KEQs will structure all analysis conducted as part of the evaluation, including quantitative analysis. Quantitative analysis will include descriptive and inferential statistics. Descriptive statistics describe what has happened. Inferential statistics, including regression modelling, helps to further understand circumstances where the Measure has been most effective (e.g. regions or types of interventions).

Nous will use best practices to manage and quality assure quantitative analysis. These include securely storing data, version controlling analysis code using git software and using the git workflow to ensure at least two analysts review any analysis that is produced. Quantitative analysis will be conducted using the R statistical programming language.

Nous will use two key quantitative analysis methods to assess the extent to which the Measure has achieved its intended outcomes and the cost-effectiveness of the Measure. These elements are described below.

## Outcome measurement

Nous will use indicators to measure progress against the national outcomes (see Table 6). Almost all indicators provide a quantitative basis to assess progress. Each indicator may provide information against multiple outcomes. Many outcomes are informed by more than one indicator. This list is being refined, as conversations about data availability continue. Appendix B provides detail on data sources and feasibility.

**Table 6 | Outcomes and indicators**

#	Outcome	Indicator(s)
<b>Understanding</b>		
1	More discussions focused on end-of-life care decision making between residents, families, carers, GPs and specialist palliative care services including use of Advance Care Plans.	<ul style="list-style-type: none"> <li>Increased proportion of RACF residents with advance care planning documents (e.g. Advance Care Plans or Advance Care Directives).</li> <li>Increased effectiveness and use of advance care planning documents (e.g. Advance Care Plans or Advance Care Directives) within RACFs.</li> <li>Increased number of Multidisciplinary Case Conferences by Medical Practitioners (Other Than Specialist or Consultant Physician) – (MBS items 735 to 758) in RACFs.</li> </ul>
2	Improved access to information that informs end-of-life care decisions for residents and families.	<ul style="list-style-type: none"> <li>Increased resident, family and carer access to information on end-of-life care.</li> </ul>
<b>Capability</b>		
3	A higher proportion of clinical and non-clinical staff in RACFs have skills and confidence appropriate to their roles to recognise and respond to the holistic palliative care needs of residents, in a culturally safe way.	<ul style="list-style-type: none"> <li>Increased number of residents who receive subcutaneous medicines associated with palliative care in RACFs.</li> <li>Decreased number of transfers from RACFs to acute care facilities.</li> <li>Decreased number of RACF residents admitted to an acute care facility for palliative care.</li> <li>Decreased number of inpatient bed days related to palliative care for residents of RACF.</li> <li>Increased completions of accredited courses related to palliative care.</li> </ul>
<b>Access and choice</b>		
4	Improved access to quality palliative care in RACFs including: <ul style="list-style-type: none"> <li>increased use of assessments to establish residents' palliative care needs</li> <li>decreased health service use including less futile or non-beneficial treatments and inpatient bed days</li> <li>decreased healthcare expenditure arising from decreased service use.</li> </ul>	<ul style="list-style-type: none"> <li>Increased number of RACFs that access palliative care provided by states/territory specialist services.</li> <li>Increased number of Multidisciplinary Case Conferences by Medical Practitioners (Other Than Specialist or Consultant Physician) – (MBS items 735 to 758) in RACFs.</li> <li>Increased number of residents who receive subcutaneous medicines associated with palliative care in RACFs.</li> <li>Increased number of individuals accessing palliative care in RACFs.</li> </ul>



#	Outcome	Indicator(s)
		<ul style="list-style-type: none"> <li>Decreased number of transfers from RACFs to acute care facilities.</li> <li>Decreased number of RACF residents admitted to an acute care facility for palliative care.</li> <li>Decreased number of inpatient bed days related to palliative care for residents of RACF.</li> <li>Increased number of RACF residents who receive palliative care through a service participating in PCOC.</li> </ul>
5	<p>Improved quality of palliative care provided in RACFs including:</p> <ul style="list-style-type: none"> <li>reduced symptom burden</li> <li>improved quality of life for residents during the period they access palliative care</li> <li>better experience of death and dying for residents, families/carers and staff, including meeting physical, psychosocial, cultural and spiritual needs.</li> </ul>	<ul style="list-style-type: none"> <li>Increased number of providers/RACFs participating in PCOC.</li> <li>Increased number of RACF residents who receive palliative care through a service participating in PCOC.</li> <li>Improved resident experience of dying reported by family/carers.</li> </ul>
6	<p>Greater patient choice in palliative care including:</p> <ul style="list-style-type: none"> <li>more people dying where they want</li> <li>increased person-centred care informed by an individual's choice.</li> </ul>	<ul style="list-style-type: none"> <li>Increased proportion of RACF residents with advance care planning documents (e.g. Advance Care Plans or Advance Care Directives).</li> <li>Increased effectiveness and use of advance care planning documents (e.g. Advance Care Plans or Advance Care Directives) within RACFs.</li> <li>Increased number of RACFs that access palliative care provided by states/territory specialist services.</li> <li>Decreased number of RACF residents dying in an acute care setting (e.g. hospital).</li> <li>Decreased number of RACF residents admitted to an acute care facility for palliative care.</li> </ul>
<b>Collaboration</b>		
7	Improved care coordination with GPs/primary care, acute care services and specialist palliative care services.	<ul style="list-style-type: none"> <li>Increased number of Multidisciplinary Case Conferences by Medical Practitioners (Other Than Specialist or Consultant Physician) – (MBS items 735 to 758) in RACFs.</li> </ul>
8	Improved integration between the health and aged care systems.	<ul style="list-style-type: none"> <li>Decreased number of transfers from RACFs to acute care facilities.</li> <li>Decreased number of RACF residents admitted to an acute care facility for palliative care.</li> </ul>
9	More palliative care services and health planners are informed by performance information on appropriateness, effectiveness, efficiency and outcomes.	<ul style="list-style-type: none"> <li>Increased number of providers/RACFs participating in PCOC.</li> </ul>
<b>Data and evidence</b>		

#	Outcome	Indicator(s)
10	Improved clinical governance to identify and implement quality improvement initiatives and evaluation of outcomes within RACFs.	<ul style="list-style-type: none"> <li>Increased number of RACFs that implement quality improvement activities to improve palliative care.</li> <li>Decreased number of complaints received by the Aged Care Quality and Safety Commission from residents and families related to palliative care.</li> <li>Increased number of RACFs that have a policy in place and monitored to ensure that all staff (including casuals) uptake available training/education opportunities to improve their understanding about palliative care.</li> </ul>

## Cost effectiveness analysis

Nous will use cost-effectiveness analysis to assess the broader cost implication of the Measure, including whether it has led to decreased expenditure in other parts of the health system. Nous has considered the following in designing the cost-effectiveness analysis described below:

- Each jurisdiction is taking substantially different approaches to implement the Measure. For example, South Australia is using funding in a limited set of RACFs while NSW is providing equal funding to all LHDs which are then developing their own initiatives. Aggregating and comparing the cost-effectiveness of the different implementations is challenging.
- Costs and cost savings associated with the Measure are spread over several health services including RACFs, hospitals, ambulances, medication and other medical services (e.g. GP visits). Given the available data, it is not possible to comprehensively collate costs across these services and attribute them to the Measure. This would require linking data from a variety of sources.
- Ultimately, the Measure seeks to improve the quality of death experienced by RACF residents. Nous does not believe it is possible to economically quantify the quality of death experienced by residents. This limits the ability to conduct analyses that account for the differential patient outcomes that are achieved under the Measure (e.g. using standard health economics methods such as Quality-Adjusted Life Years, which are not appropriate in this context).
- While “saving money” is not the primary aim of the Measure, a reduction in expensive, unnecessary interventions, or interventions that provide minimal improvement in outcomes, is an indicator that resources are being used more appropriately without significant impact on outcomes.

These considerations make clear that the results of the cost-effectiveness analysis need to be interpreted and communicated with care.

Nous is seeking to take two approaches to assess the cost-effectiveness of the Measure:

- comprehensive comparison of costs under the Measure compared with the “do nothing scenario”
- case study quantification of the cost implication of outcomes achieved.

Each are described below.

### Approach 1: Comprehensive comparison of costs under the Measure compared with the “do nothing scenario”

Cost-effectiveness analysis will be used to assess whether the Measure leads to more or less expenditure overall. Nous will conduct this analysis by comparing the costs of the “do nothing” scenario in which the Measure is not implemented with the costs under the Measure. Nous intends to conduct this analysis in partnership with AIHW using the NIHSI-AA linked dataset. This will allow for a wide variety of costs to be included under both scenarios including transfers and time spent in hospital, items under the MBS and PBS and services in RACFs. Comparisons will also be undertaken to determine if particular activities or processes for implementing the Measure were more cost-efficient.

The cost-effectiveness analysis will *not* quantify the value of the patient outcomes that may be achieved through the Measure. For example, the analysis will not estimate the monetary value of reduced symptom burden for residents receiving palliative care nor the lack of benefit or minimal benefit from expensive interventions near the end-of-life. These costs will be captured indirectly through the changes in hospital attendances and PBS scripts.

#### **Approach 2: Case study quantification of the cost savings associated with outcomes achieved**

Nous will also estimate cost savings associated with outcomes achieved under the Measure. For example, if the evaluation identifies fewer transfers from RACFs to acute care facilities under the Measure (potentially in one or more jurisdictions), the evaluation will estimate approximate cost savings associated with fewer transfers using standard assumptions and cost estimates from AIHW and the National Hospital Cost Data Collection (NHCDC) released by the Independent Hospital Pricing Authority. This approach will provide quantification of the cost savings associated with the Measure while also capturing the diversity of implementations and outcomes across the country. It will also enable quantification of cost-savings during the period where NIHSI-AA data is not yet available (approximately one-year lag).

## **5.4 Data synthesis and triangulation**

Nous will collect a large volume of data from multiple sources during the evaluation. In each progress reporting period, Nous will present and, where possible, triangulate the latest data, with preliminary insights against KEQs. In the Midpoint, Interim and Final Report, Nous will use all data available to present a full consideration against the KEQs.

A key consideration in the synthesis of data sources is how to determine contribution of activities in each jurisdiction to national outcomes and/or identify whether changes can be attributed to the Measure.

This is not experimental or quasi-experimental research, nor jurisdictional-level outcome evaluations. Nous will not determine what would have occurred without the Measure (except in relation to the cost effectiveness analysis). Attribution or contribution is complicated by variable service delivery contexts and activities in each jurisdiction, and the complex drivers of improved palliative care in RACFs and carer/families experiences of death and dying.

Therefore, the focus will be on understanding the extent to which the aims of the Measure have been achieved – in terms of implementation success and challenges, progress on national outcomes over the period, cost-effectiveness and alignment to the National Palliative Care Strategy. Nous will remain across major national and jurisdictional policy reforms and local service contexts in order to accurately caveat or interpret findings as needed.

## 6 Stakeholder communication plan

### THIS SECTION

This section outlines the purpose and provides a plan for stakeholder engagement over the course of the evaluation. It includes:

- principles for stakeholder engagement
- a description of who will be consulted, when and how.

### 6.1 Principles for engagement

Engagement is a critical component of the evaluation. It will provide insights from the Australian Government, state and territory governments, RACFs, palliative care clinicians, GPs, PHNs, families and carers, peak bodies and others on the success of the Measure in achieving its stated aims. The objectives of engagement are to:

- understand how the Measure is implemented in practice, from a range of perspectives
- contextualise and validate insights from other qualitative and quantitative data sources
- inform the KEQs and identify areas for improvement.

Six principles will underpin the design and conduct of engagements:

- **Confidential** – Stakeholders may have a vested interest in the outcome of the review. Communication will maintain confidentiality and not disclose sensitive information.
- **Consistent** – Nous will engage with many RACFs over the course of the review. Communications and engagement will have a consistent format and brand so that there is a single source of truth.
- **Purposeful** – It is important to begin every engagement with a clear sense of what Nous wants to achieve. Outlining a purpose in advance allows stakeholders to contribute meaningfully.
- **Respectful** – Stakeholders' expertise and experiences are critical. Nous will always listen first and be respectful where opinions may differ.
- **Culturally appropriate** – Nous will ensure all engagements are culturally appropriate and that diverse perspectives are included in the evaluation. This includes understanding and respecting differing viewpoints and ideas.
- **Sensitive** – Nous will undertake engagement that is sensitive and compassionate, particularly for engagement with families and carers who may have recently lost a loved one.







Many of the principles above – including sensitive and cultural appropriate engagement – are key tenets of ethical consultations. Refer to section 8 for information on ethics.







### 6.2 Stakeholder communication plan

Nous will engage with a range of stakeholders over the course of the evaluation. Engagements will inform comprehensive findings and help to ensure that Nous interprets information accurately.

Table 7 lists stakeholders Nous will engage, including the purpose, frequency and method. See section 8 for ethical considerations and Appendix B for data collection tools.

Table 7 | Stakeholder communication plan

Stakeholder	Purpose of engagement	Frequency			Quantum	Method	Considerations
		2021	2022	2023			
Aged care and palliative care representatives from state and territory health departments		●	●	●	8 consultations (1 per jurisdiction) x5 rounds (six monthly).	60-minute interview/teleconference	Ongoing and close collaboration is critical to the success of the evaluation. Also ad hoc as needed.
Representative sample of RACFs		●		●	N/A	Online survey	Nous will coordinate with jurisdictions to determine a representative sample of RACFs.
Staff within representative sample of RACFs			●	●	Per jurisdiction: 1 focus group x2 rounds For larger jurisdictions, up to 2-3 each round	60-minute focus group	Staff to be consulted will be determined using the approach defined in section 5. Numbers consulted will be dependent on response rates and nominations.
Service providers such as GPs, specialist palliative care providers and other clinicians			●	●	Per jurisdiction: 1 focus group with specialist providers 1 focus group with generalist providers x2 rounds	60-minute focus group, grouped by type of provider	Focus groups will be grouped by: specialist providers, generalist providers (including GPs) and one PHN group if required. We may do slightly more in larger jurisdictions and combine focus groups in small jurisdictions.
PHNs – representative sample			●	●	1 focus group (national) x2 rounds	60-minute focus group	
Existing PCA consumer representative forums			●	●	1 with national PCA consumer group x2 Up to 3 more with state chapter consumer groups x2	60-90 minute focus group	Consumer groups from PCA national and chapter bodies will be engaged where available.

Stakeholder	Purpose of engagement	Frequency			Quantum	Method	Considerations
		2021	2022	2023			
<b>Peak bodies</b> <i>Examples include PCA, LASA, Aged and Community Services Australia (ACSA) and COTA.</i>			●	●	Up to 5 consultations x2 rounds	30-60 minute interview/teleconference	N/A
<b>National data organisations</b> <i>Examples include the AIHW and the Australian Commission on Safety and Quality in Health Care (ACSQHC).</i>			●	●	Ad hoc as needed – likely 3 consultations x2 rounds	30-60 minute interview/teleconference	Also ad hoc as needed.
<b>Other national programs or initiatives</b> <i>Examples include PCOC and ELDAC.</i>		●	●	●	4 or as required x2 rounds	30-60 minute interview/teleconference	Also ad hoc as needed.
 = Inform evaluation findings  = Inform interpretation of results  = Provide data advice							

Note: All consultations are assumed to be virtual. Where Nous team members are based in the same city as stakeholders, we can conduct consultations face-to-face if COVID-19 restrictions allow and Nous and stakeholders agree.



## 7 Dependencies, challenges and risks

### THIS SECTION

This section describes the potential challenges, limitations and risks of the evaluation. It includes:

- the boundaries and dependencies
- challenges and risks
- the risk management approach and risk management plan.

### 7.1 Boundaries and dependencies of the evaluation

The evaluation scope is limited to the implementation of the Measure and activities undertaken under the Measure. The following are not within the scope of the evaluation:

- **Palliative care activities and service delivery by states and territories in residential aged care settings which are not part of the Measure.** For example, if an in-reach service is expanded under the Measure, then expansion activities only will be considered in this evaluation.
- **The evaluation of individual measures implemented by the states/territories.** Individual activities implemented by states and territories will not be evaluated; however, models of care may be compared to identify successful models.

Dependencies are described below and in the Risk Management Plan (see section 7.3 and Appendix D):

- **Establishment of strong relationships with participating states and territories.** Timeframes, activities, funding and local operating environments differ in each jurisdiction. To understand the variation and the impact upon the evaluation, a strong relationship with jurisdictions is critical. This will support information sharing, collaboration and ongoing learning.
- **Access to quality data and availability of stakeholders.** Consistent quality data in the aged care sector – and from palliative care within aged care – is challenging. Nous will be practical about access to data sources to ensure the evaluation is rigorous. Where data is not available, Nous will consider proxies, workarounds and/or engage with stakeholders to gather supplementary qualitative information.

### 7.2 Key challenges and risks for the evaluation

Several challenges, limitations and risks exist. Three key challenges are outlined below (with all risks detailed in Appendix D):

#### 1. Variability of activities implemented under the Measure over time and across jurisdictions raises challenges in the evaluation

There is variation that will influence implementation of activities and the evaluation including:

- Each jurisdiction has a unique population and operating environment that defines the context in which the Measure is implemented.
- Each jurisdiction has implemented different initiatives to support palliative care in RACFs prior to and outside of the Measure.

- Jurisdictions are implementing a range of different activities under the Measure and will do so under varying timeframes and with varying amounts of funding.
- Each individual RACF will vary in their implementation of activities under the Measure.

The evaluation will remain aware of jurisdictional variations; however, will bring a national perspective to the evaluation.

## **2. There are significant data limitations in residential aged care and palliative care**

Access to high quality and comprehensive data in RACFs – particularly relating to the provision of palliative care – presents many challenges. Jurisdictions collect different data, which in turn each have different limitations. Some of the challenges that may arise relating to data limitations include:

- Jurisdictions may not have specific data collections for state-based palliative care services or be able to identify when these services are provided in RACFs.
- ACFI data captures only permanent residents who have been appraised as requiring palliative care and may therefore underrepresent the number of residents receiving palliative care.
- Jurisdictions may not be able to identify when a patient is from a RACF in admitted or non-admitted patient data sets.

These challenges mean that the evaluation approach will have to be flexible. Qualitative data collection will be used to fill any gaps in unavailable quantitative data – for example through the use of a RACF survey to identify a baseline. See section 5 for further detail on how data limitation challenges will be addressed.

## **3. Gaining input from RACFs, families and carers will hold challenges**

A critical input to the evaluation is the views of families/carers of residents. Clinicians and practitioners are well placed to observe the impact of the Measure as they engage with palliative care in RACFs over time. In contrast, families/carers will have input about service delivery at a specific point in time and at the jurisdictional-level. It is out-of-scope for the national evaluation to conduct jurisdictional-level evaluations or reviews.

Further, directly engaging with families and carers comes with substantial risks and may provide little valuable information directly relevant for the purpose of this evaluation. Risks include causing survey fatigue and additional distress to the family/carer for re-experiencing the death of a loved one. In addition, it is difficult to obtain accurate and relevant responses when the family/carer is currently experiencing grief. Researchers must balance survey time delicately: providing families/carers an appropriate grieving period, while administering surveys or interviews soon after a residents' death in order to reduce the risk of recall bias.<sup>10</sup>

Nous understands the importance of providing the residents' family/carer perspective to inform the evaluation. We will use the following data sources to understand the needs of residents, families and carers:

- clinician/practitioner input via consultations with GPs/PHNs and/or the ELDAC After Death Audit
- PCA consumer representative groups (see section 5.1 for details).

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<sup>10</sup> Recall bias is where participants erroneously provide responses based on their (in)ability to accurately recall past events. Recall bias is more common in epidemiologic and medical research. Althubaiti, 4 May 2016. Information bias in health research: definition, pitfalls, and adjustment methods. *Journal of Multidisciplinary Healthcare*, Online.

#### **4. Initiatives outside of the Measure will impact upon the Measure and how it is evaluated**

Programs and initiatives implemented prior to and alongside the Measure will impact upon activities under the Measure and their evaluation in two ways:

- Activities undertaken prior to the Measure will form a foundation for what is implemented under the Measure. For example, a jurisdiction that has made significant progress on implementation of specialist in-reach palliative care services may choose to build on that progress through expanding the service or using it as a basis for the introduction of other activities such as education and training.
- Initiatives established outside of the Measure may also be implemented under the Measure. For example, initiatives such as ELDAC provided training and education resources that might be implemented under the Measure. Attribution may become a challenge in this scenario. Evaluation of such activities may also involve metrics that are recorded by the pre-existing initiative, such as uptake or usage statistics.

It may be challenging to separate the impact of activities under the Measure from those that existed prior to the Measure – particularly where activities build on or utilise pre-existing programs or initiatives.

### **7.3 Risk management approach**

Nous employs a risk matrix approach to determine overall risk rating and mitigation strategies. Appendix D provides a thorough risk assessment. It includes a risk rating, mitigation strategies and residual risk. Nous will continue to assess risks through the use of a risk register.

## 8 Ethics considerations

### THIS SECTION

This section details how the evaluation will be conducted in an ethical manner, including the approach to seeking formal ethical approval from a Human Research Ethics Committee (HREC) where needed.

### 8.1 Ethics management

Nous is committed to ensuring that the evaluation is conducted to the highest standard of ethical conduct. Nous' methodology has been developed in a way that ensures design and implementation of the evaluation is consistent with the relevant ethical requirements outlined within the following codes of practice:

- The Australian Code for the Responsible Conduct of Research (2018), published by the National Health and Medical Research Council (NHMRC), the Australian Research Council and Universities Australia.
- National Statement on Ethical Conduct in Human Research (2018), published by the NHMRC.
- Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders (2018), published by the NHMRC.
- AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research (2020), published by the Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS).

Based on the evaluation methodology described above, Nous assesses that this evaluation **does not require ethics approval**.

NIHSI-AA will be a significant data source for the evaluation that does include personal data and therefore requires ethics considerations. Analysis of NIHSI-AA will be conducted in partnership with AIHW and Nous will not have direct access to NIHSI-AA. Nous understands existing ethics approvals within AIHW cover use of NIHSI-AA for this purpose and a new ethics application is not necessary. AIHW's head of Ethics, Privacy and Legal will conduct a review of the project proposal to ensure that further ethics approvals are not required.

If an additional data source is required to inform the evaluation, Nous will reassess the need for ethics approval at that time.

Nous will conduct all activities ethically. Of particular relevance for this evaluation is:

- **Ethical engagement.** Nous is intending to engage with families and carers through PCA consumer representative bodies, and with other relevant stakeholders including clinicians and RACF staff. Nous will ensure that all stakeholder engagement is completed in an ethical fashion, in accordance with the principles for stakeholder engagement detailed in section 6.1.
- **Privacy and data management.** While not intending to collect personal data except through other data projects such as NIHSI-AA, the evaluation will still require the use and handling of sensitive data. Nous' approach to privacy and data management is described in section 8.1.1 and in Appendix D.

### 8.1.1 Privacy and data management

Nous manages all information in accordance with relevant privacy and data security legislation, regulations and public sector policies and procedures for data storage and retention. Nous has a comprehensive suite of Information Security and Privacy policies and educates its staff on the importance of designating and managing sensitive information.

Nous will implement the following regime to ensure the highest levels of privacy and confidentiality of the collected evaluation data:

- only data relevant to the evaluation will be collected
- the volume of personal or identifying information will be minimised as far as possible
- all electronic information will be stored on private network servers protected by firewalls
- document management and collaboration systems will be hosted on a secure private cloud in Australia
- receipt of key documents and datasets will be tracked in central project registers
- any stored data will be destroyed at the conclusion of the evaluation and all personal information that is no longer required will be deleted.

# Appendix A Stakeholders consulted in development of this Framework

This appendix provides the list of stakeholders consulted in development of the Evaluation Framework.

Name	Position	Organisation
<b>Australian Department of Health</b>		
Cathy Moore	Assistant Director	Department of Health
Donna Acs	Project Officer	Department of Health
Georgia Phillips	Acting Director	Department of Health
Jacky Lacey	Program Manager	Department of Health
<b>ACT Department of Health</b>		
Nikki Johnston	OAM, Palliative Care Nurse Practitioner	Clare Holland House Hospice, Calvary Public Hospital Bruce
Peter Matwijw	Manager	Health Policy Unit, Health Policy and Strategy, ACT Health Directorate
<b>NSW Department of Health</b>		
Gemma Rafferty	Principal Policy Officer	Palliative Care, Primary and Community Care and Priority Programs, Health and Social Policy Branch, NSW Health
Isabella Dillon Savage	Policy Officer	Health Policy Unit, Health Policy and Strategy, NSW Health
<b>NT Department of Health</b>		
Amy Jean Burrows	Clinical Nurse Manager	NT Health, Top End
Anthony Burton	Principal Policy Advisor	Strategy, Policy and Planning Branch, NT Health, Central
Christine Sanderson	Palliative Care Consultant	NT Health, Central
Natalie Anderson	Nurse Management Consultant	NT Health, Central
Philomena Smith	Policy Officer	Intergovernmental Relations and Ageing, NT Health
Precious Mapendere	Nurse Practitioner	NT Health, Top End
Rachel Flavell	Acting Chief Finance Officer	NT Health, Central
<b>Queensland Department of Health</b>		
Laureen Hines	Director	Healthcare Improvement Unit, clinical Excellence, Queensland Health
Michelle Lucas	Manager	Social Policy and Legislation Branch, Queensland Health
Caitlin Lock	Principal Project Officer	Care at End-of-life, Queensland Health
Allison Lovell	Project Manager	Care at End-of-life, Queensland Health
<b>SA Department of Health</b>		

Name	Position	Organisation
Elizabeth Lithgow	Senior Policy Officer	Inter-government Relations, SA Health
Kate Swetenham	Clinical Lead	Comprehensive Palliative Care in Aged Care Project, SA Health
Kathy Williams	Principal Policy Officer	Office for Ageing Well, SA Health
Tasmania Department of Health and Human Services		
Flora Dean	Principal Project Officer	Tasmania Health
Ian Bell	Manager	Primary, Rural and Palliative Care, Tasmania Health
Victoria Department of Health and Human Services		
Jackie Kearney	Assistant Director	Person Directed Care and Worker Wellbeing, Health and Wellbeing Division, VIC Health
Theresa Williamson	Manager	Palliative Care, Person Directed Care and Worker Wellbeing, VIC Health
WA Department of Health		
Andrew Jones	(Former) Manager	Cancer and Palliative Care, WA Health
Christie Sorenti	Senior Policy Officer	End-of-Life Care, WA Health
Danielle Vanpraag		WA Health
Frances Arthur	Project Officer	End-of-Life Care, WA Health
Gabriella Jerrat	Program Manager	Palliative Care and Advance Care Planning, WA Health
Palliative care and/or aged care peak bodies		
Katie Snell	Acting National Policy Manager and Aged Care Policy Advisor	Palliative Care Australia
Coleen Johnstone	CEO	Palliative Care Tasmania
Tracy Gillard	CEO	Palliative Care ACT
Janeane Harlum	President	Palliative Care Nurses Australia
Julianne Brisbane	Supportive and Palliative Care Nurse Practitioner	Nepean Blue Mountains Local Health District (NBMLHD), Palliative Care Nurses Australia
Beverley Malone	Residential Services Advisory Group	Leading Age Services Australia
Troy Speirs	Senior Policy Advisor	Leading Age Services Australia
ELDAC		
Deborah Parker	Professor of Nursing Aged Care (Dementia)	University of Technology Sydney, ELDAC
Jennifer Tieman	CareSearch, Palliative and Supportive Services	Flinders University, ELDAC
Patsy Yates	QUT Lead and Project Director	Queensland University of Technology, ELDAC
PCOC		
Barb Daveson	Director and Senior Research Fellow	University of Wollongong, PCOC
Claire Johnson	Professorial Fellow	University of Wollongong, PCOC
Kathy Eager	Chief Investigator	University of Wollongong, PCOC
Other stakeholders		



Name	Position	Organisation
Cathy Thomas	Group Executive, Executive Director	Blue Care, ARRCs
Chris Hall	Chief Executive Officer	Juniper
Felicity Reid	Program Director	Australian Digital Health Agency
Ian Thompson	Principal	Nous Group
James Eynstone-Hinkins	Director of Health and Vital Statistics	Australian Bureau of Statistics
Paula Trood	Chief Operating Officer	RSL LifeCare
Richard Jukes		AIHW
Sandra Hills	Chief Executive Officer	Benetas
Saviour Buhagiar	Director of Aged Care	Uniting NSW and ACT
Stephen Teulan	Principal	Nous Group

# Appendix B Data collection tools

This appendix provides data collection tools for the collection of primary data. This includes the:

- RACF survey (B.1)
- state/territory biannual reporting template (B.2)
- PCA consumer representative interview guide (B.3)

## B.1 RACF survey

This section provides a draft survey for RACFs to collect data for the national evaluation of the Measure.

The survey (All questions will be voluntary so if a respondent is unsure, RACFs will be able to leave the response blank. This reduces response burden and the level of inaccurate responses.

Table 8) captures information about the delivery, access and quality of palliative care available in RACFs. The questions in the survey have been aligned with the aims of the Measure:

1. Support the delivery of projects that expand existing models of care or new approaches to the way care is delivered or commissioned, to improve palliative and end of life care coordination for older Australians living in RACFs.
2. Strengthen national efforts to improve access to quality palliative care as a key component of an integrated health-aged care system.

Nous intends that the survey is distributed at the start of the evaluation to provide an understanding of the delivery of palliative care in RACFs as the Measure is in the early stages of implementation. The survey will be re-administered at the end of the evaluation to assess the impact of the Measure.

Distribution of the survey will involve working with the Australian Government and state and territory representatives. Please see definitions at the end of the survey before proceeding.

All questions will be voluntary so if a respondent is unsure, RACFs will be able to leave the response blank. This reduces response burden and the level of inaccurate responses.

Table 8 | Draft RACF survey items

#	Question	Response type
RACF palliative care processes		
1	Does the RACF have routine processes in place to discuss and record the end-of-life care wishes of each resident? For example, running multidisciplinary case conferences, or discussions between a resident and their family/informal carer, RACF staff, specialist care services and General Practitioner (GP).	Yes/No
2	Does the facility use an audit process to look at end of life care? For example, the End of Life Directions for Aged Care (ELDAC) After Death Audit.	Yes/No
3	Does the facility use a digital dashboard or other digital tool to monitor palliative care within the RACF? For example, the ELDAC digital dashboard.	Yes/No
4	Has the RACF implemented quality improvement initiatives to improve palliative care outcomes over the past 12 months? If yes, please provide a brief description of the activity	Yes/No

	Does the RACF have processes in place (e.g. clear steps for staff) that:	
5	<ul style="list-style-type: none"> <li>Assist staff to recognise when a resident is close to end-of-life?</li> <li>Ensure residents' emotional, spiritual and cultural needs are met at end-of-life?</li> <li>Ensure residents can access appropriate medication if their condition changes suddenly at end-of-life?</li> </ul>	Yes/No for each item
Access to palliative care		
6	<p>Are residents at the RACF able to access palliative care provided by a state or territory health service? This could be nurses, specialist doctors, allied health or private services.</p> <p>If yes, please select modes through which specialist palliative care (from any provider) can be accessed:</p> <ul style="list-style-type: none"> <li>In person</li> <li>Telephone</li> <li>Video call</li> </ul>	Yes/No for overall and then checkbox for each item
7	Does the RACF have access to palliative care services from General Practitioners (GPs)? If yes, please describe access from GPs to the RACF.	Yes/No. If yes, free text.
8	How many Registered Nurses (or other staff if any) with specialised palliative care knowledge work at the RACF?	Number
Advance care planning documents		
9	<p>What proportion of current residents have advance care planning documents (ACPDs)?</p> <ul style="list-style-type: none"> <li>For example, an Advance Care Plan or Advanced Care Directive.</li> <li>On entry to the RACF</li> <li>Within the first 3 months of entry</li> <li>Currently</li> </ul>	Proportion of residents
10	Please describe any process used within the RACF for residents and their families and carers to update ACPDs	Free text
11	How often are ACPDs reviewed to ensure that they are up to date and complete?	Likert scale response from 0 (Never) to 5 (more than once a month)
12	<p>Are ACPDs readily able to be accessed across the:</p> <ul style="list-style-type: none"> <li>The RACF</li> <li>Specialist palliative care services</li> <li>Hospitals</li> <li>GPs</li> </ul>	Yes/No for each item
13	Does the RACF record preferred place of death for all residents?	Yes/No
Education and training		
14	<p>Does the facility have a policy or requirement in place, and monitored, to ensure that the following staff (including casuals) uptake available training/education opportunities to improve their understanding about palliative care:</p> <ul style="list-style-type: none"> <li>Registered Nurses</li> <li>Team Leaders/Enrolled Nurses</li> <li>Allied Health</li> <li>Direct care staff (e.g. Personal care worker)</li> <li>Pastoral care staff</li> <li>Other staff</li> </ul>	Yes/No for each staff group

15	Does the facility use a preferred training/education package? If yes, please identify the preferred package.	Yes/No Free text
16	How regularly is palliative/end-of-life training and education taken up by those staff who are responsible for end-of-life discussions and care provision?	Likert scale response from 0 (Never), 3 (Once a year) and 5 (More than twice a year)
Focus group participation		
17	Would you like to participate in a focus group conversation to discuss palliative care in RACFs?	Yes/No

## Glossary of terminology and acronyms

Term	Definition
Advance care directive (ACD) <sup>11</sup>	Advance Care Directives is a catch-all term to refer to the instruments which are recognised in each jurisdiction under advance care directive legislation or common law. They are voluntary, person-led documents completed and signed by a competent person that focus on an individual's values and preferences for future care decisions, including their preferred outcomes and care. Advance Care Directives are recognised by specific legislation (statutory) or under common law (non-statutory). They come into effect when an individual loses decision-making capacity. Advance Care Directives can also appoint substitute decision-makers who can make decisions about health or personal care on the individual's behalf. Advance Care Directives are focused on the future care of a person, not on the management of his or her assets.
Advance care plan (ACP) <sup>12</sup>	Documents that capture an individual's beliefs, values and preferences in relation to future care decisions, but which do not meet the requirements for statutory or common law recognition due to the person's lack of competency, insufficient decision-making capacity or lack of formalities (such as inadequate person identification, signature and date). An Advance Care Plan for a non-competent person are often very helpful in providing information for substitute decision-makers and health practitioners and may guide care decisions but are not legally binding. An Advance Care Plan may be oral or written, with written being preferred. A substitute decision-maker named in an Advance Care Plan is not a statutory appointment.
Advance care planning <sup>13</sup>	A process of planning for future health and personal care whereby the person's values, beliefs and preferences are made known to guide decision-making at a future time when that person cannot make or communicate their decisions. Registered and non-registered health practitioners have a role in advance care planning and require capability to facilitate these conversations effectively. The National Quality Standards for aged care, general practice and health services all promote advance care planning. Individuals can also choose to engage in advance care planning with other non-health practitioners, such as friends or family.
Advance health directive (AHD) <sup>14</sup>	A document that records possible treatment decisions for a competent adult. Treatment includes medical, surgical and dental treatment and other health care.

<sup>11</sup> Department of Health, Nous Group, "National framework for advance care planning documents." June 2020.

<sup>12</sup> Department of Health, Nous Group, "National framework for advance care planning documents." June 2020.

<sup>13</sup> Department of Health, Nous Group, "National framework for advance care planning documents." June 2020.

<sup>14</sup> Department of Health, Western Australia, "Preparing an Advance Health Directive." 2018.

Term	Definition
	These decisions must be followed in the event that the adult can no longer communicate or make decisions themselves.
Advance care planning documents (ACPDs) <sup>15</sup>	A catch all term to include documents that result from advance care planning. This includes Advance Care Directives and Advance Care Plans.
End of Life Care	End-of-life care is care delivered to a patient who is living with a fatal condition, even if the exact trajectory is unknown. The end-of-life period may be days, months, or years depending on the diagnosis or disease. The Aged Care Funding Instrument (ACFI) definition for end of life is more specific as follows: ACFI 12 item 14 enables a claim for a palliative care program involving end of life care.
Specialist palliative care <sup>16</sup>	<p>A specialist palliative care provider is a health professional who has had extra training to provide specialist care to those with a life-limiting illness, including in residential aged care facilities. These providers can provide that care in many settings including hospices. Specialist palliative care providers can include:</p> <ul style="list-style-type: none"> <li>• cancer doctors (oncologists)</li> <li>• palliative care nurses, including Nurse Practitioners</li> <li>• clinical nurse specialists/consultants</li> </ul> <p>counsellors</p>
Specialist palliative care knowledge <sup>17</sup>	Specialist palliative care knowledge includes expert knowledge on the pathophysiology of diseases, advanced pain and symptom assessment and management, counselling and communication skills, and advance care planning. It includes advanced knowledge about caring for individuals with serious, life-threatening illness, as well as those who are imminently dying.

## B.2 State and territory biannual reporting template

This section provides a draft reporting template for states and territories to provide information at six-month intervals for the national evaluation of the Measure.

Nous designed the template, shown in Table 9, based on the service mapping exercise conducted in October 2020. It groups activities in line with the Project Agreement i.e. by in-reach/out-reach, education and training, and end-of-life decision making.

Jurisdictional-level evaluations are out-of-scope for the evaluation, but states and territories may provide some additional information to the national evaluation. Jurisdictions will be asked to provide a detailed report (due April each year) and minor update (due October each year). Jurisdictions will also participate in a subsequent one-hour consultation with Nous to discuss responses.

All responses will be free text. Maximum word count is 500 words per question.

Nous has tested the draft template with states and territories during January 2021 consultations.

<sup>15</sup> Department of Health, Nous Group, "National framework for advance care planning documents." June 2020.

<sup>16</sup> Department of Health, "Palliative Care - Find a palliative care provider." July 2019.

<sup>17</sup> American Nurses' Association (ANA). Position Statement: Registered Nurses' Roles and Responsibilities in Providing Expert Care and Counselling at the End of Life. 2010.

Table 9 | Proposed questions for state/territory reporting<sup>18</sup>

#	Question
1	Approximately how many RACFs are impacted by the Measure or its components as at <b>date</b> ?
2	Have your implementation plans changed over the six months to <b>date</b> ? If yes, please describe.
3	What progress has your jurisdiction made in implementing the Measure in the six months to <b>date</b> ?
4	In the six months to <b>date</b> , has your state/territory delivered in-reach or out-reach models of care? If yes, please describe.
5	In the six months to <b>date</b> , has your state/territory facilitated or delivered education and training initiatives? If yes, please describe.
6	In the six months to <b>date</b> , what other initiatives have you undertaken, that are not covered above, that enhance end-of-life decision-making?
7	What other activities have been implemented under the Measure in the six months to <b>date</b> ?
8	To what extent have activities under the Measure supported RACFs, GPs and state/territory palliative care providers/clinicians to work together to meet the palliative care needs of residents? (incl. reducing silos) Please provide specific examples or evidence.
9	To what extent has the combination of Commonwealth and state/territory funding in a single pool helped to address challenges at the interface of health/aged care? Please provide specific examples or evidence.
10	What are the other key learnings from the six months to <b>date</b> ?
11	Have any barriers to implementation become apparent in the six months to <b>date</b> ?
12	Do you have any internal outputs and/or data to share with the national evaluation?
<p><i>If not already provided:</i> Nous would like to speak with a mix of clinicians from various jurisdictions during the evaluation to understand their perspectives. Can you nominate one or two clinicians (e.g. GP, nurse, nurse practitioner, hospital outreach staff) who would be willing to have a 30 min interview with Nous?</p>	

## B.3 PCA consumer representative group interview guide

### Background and context

Nous Group has been engaged by the Australian Government Department of Health to conduct an evaluation of the Comprehensive Palliative Care in Aged Care Measure (the Measure). The Measure is funded by the Australian and state/territory governments and seeks to improve palliative care in RACFs with each jurisdiction implementing their own initiatives. The aims of the Measure are to:

- Support the delivery of projects that expand existing models of care or new approaches to the way care is delivered or commissioned, to improve palliative and end-of-life care coordination for older Australians living in Residential Aged Care Facilities (RACFs).

<sup>18</sup> Questions 4-6 reflect the three categories of activities suggested in the Project Agreement, with Question 7 serving to capture any other initiatives jurisdictions may have implemented.

- Strengthen national efforts to improve access to quality palliative care as a key component of an integrated health-aged care system.
- Under the Measure, states and territories can choose to undertake activities suited to local needs. It may include activities such as in-reach from specialist palliative providers into RACFs, education and training and activities to improve end-of-life care decision making.

As part of the evaluation, Nous is seeking input from families and carers to understand delivery of palliative care in RACFs. We plan to do these interviews in early 2021 and again at the end of the evaluation in 2023.

### **Purpose of this focus group**

The purpose of this group interview is to explore consumer, family, and carer perspectives on the delivery of palliative care in RACFs. The interview will take 60 minutes.

If you have any questions, please contact Simone Schulz, Project Manager for the project on (02) 8281 8030 or [simone.schulz@nousgroup.com.au](mailto:simone.schulz@nousgroup.com.au).



## Discussion questions

#	Question
1	What processes are in place to involve families and carers in treatment and end of life care decisions? <i>Prompt participants to comment on the use and effectiveness of Advance Care Plans or Directives and family/carer/resident access to information.</i>
2	How responsive/attentive are RACF staff and other palliative care providers to the needs of residents of RACFs? Palliative care providers include General Practitioners, palliative care nurses and other specialist providers.
3	How do RACFs meet the spiritual, cultural, and psychological needs of residents? How well are they met?
4	Do RACFs strive to understand and achieve residents' preferred place of death?
5	Are complaints to RACFs typically met promptly?
6	What emotional support and/or bereavement procedures are in place in RACFs?
7	Do you have any questions for Nous regarding the national evaluation of the Measure?

## Appendix C Evaluation indicators

Table 10 presents the potential indicators to measure national outcomes. It outlines the feasibility, limitations, data source and outcomes each indicator measures. The table is ordered by feasibility:

- **"Good"** indicates that data is expected to be available and will cover all jurisdictions.
- **"Intermediate"** indicates that data is expected to be available but will only cover some jurisdictions or time periods.
- **"Poor"** indicates that it is unlikely that a substantial amount of data will be available.

**Table 10 | Potential indicators to assess progress against national outcomes**

Potential indicator(s)	Data source(s)	Feasibility	Limitations	Outcome
Increased proportion of RACF residents with advance care planning documents (e.g. Advance Care Plans or Advance Care Directives)	<ul style="list-style-type: none"> <li>Survey of sample of RACFs</li> </ul>	Good	Many RACFs facilitate residents having Advance Care Plans and so there may be little change in this indicator. Needs to be considered alongside qualitative assessment of Advance Care Plans.	1,6
Increased effectiveness and use of advance care planning documents (e.g. Advance Care Plans or Advance Care Directives) within RACFs	<ul style="list-style-type: none"> <li>Qualitative assessment through consultation with sample of RACFs</li> </ul>	Good	Sample of RACFs will be relatively small. Care will be taken to ensure that it is representative of the RACFs across the country who receive support through the Measure.	1, 6
Increased number of RACFs that implement quality improvement activities to improve palliative care	<ul style="list-style-type: none"> <li>Survey of sample of RACFs</li> </ul>	Good	This measure will be self-reported by RACFs and will allow identification of the improvement activities	10
Increased number of providers/RACFs participating in the Palliative Care Outcomes Collaboration (PCOC)	<ul style="list-style-type: none"> <li>PCOC</li> </ul>	Good		5, 9
Increased number of RACF residents who receive palliative care through a service participating in the Palliative Care Outcomes Collaboration (PCOC)	<ul style="list-style-type: none"> <li>PCOC</li> </ul>	Good	PCOC currently has limited collection of data related to RACFs. (see section 0). This is expected to expand as more services participate in PCOC and engage with RACFs to provide palliative care.	4, 5
Increased resident, family and carer access to information on end-of-life care	<ul style="list-style-type: none"> <li>Qualitative assessment through consultation (PCA<sup>19</sup> and state/territory health departments)</li> <li>Desktop research</li> </ul>	Good	Will not involve direct measures of access from residents, families or carers.	2
Decreased number of complaints received by the Aged Care Quality and Safety Commission from residents and families related to palliative care	<ul style="list-style-type: none"> <li>Aged Care Quality and Safety Commission</li> </ul>	Good	Complaints data will need to be interpreted with caution due because of the potential for a skewed sample.	10

<sup>19</sup> PCA: Palliative Care Australia

	through the Department			
Increased number of RACFs that have a policy in place and monitored to ensure that all staff (including casuals) uptake available training/education opportunities to improve their understanding about palliative care	<ul style="list-style-type: none"> <li>Survey of sample of RACFs</li> </ul>	Good		3
Increased number of RACFs that access palliative care provided by states/territory specialist services	<ul style="list-style-type: none"> <li>Survey of sample of RACFs</li> <li>State/territory government data</li> </ul>	Good/Intermediate	The extent of state/territory data on the location of specialist palliative care services is still unclear.	4, 6
Improved resident experience of dying reported by family/carers	<ul style="list-style-type: none"> <li>PCA consumer representative group</li> </ul>	Intermediate	PCA consumer representative group may not contain all perspectives regarding resident experience of dying.	5
Increased number of Multidisciplinary Case Conferences by Medical Practitioners (Other Than Specialist or Consultant Physician) - (MBS items 735 to 758) in RACFs	<ul style="list-style-type: none"> <li>NIHSI-AA<sup>20</sup></li> <li>MBS<sup>21</sup></li> </ul>	Intermediate	NIHSI-AA is not available in all jurisdictions and has a time-lag of approximate 1 year (i.e. 2018-19 will be released in 2020-21). Standalone MBS data may provide an alternative where NIHSI-AA is not available.	1, 4, 7
Decreased number of RACF residents dying in an acute care setting (e.g. hospital)	<ul style="list-style-type: none"> <li>NIHSI-AA</li> </ul>	Intermediate	NIHSI-AA is not available in all jurisdictions and has a time-lag of approximate 1 year (i.e. 2018-19 will be released in 2020-21).	6
Increased number of residents who receive subcutaneous medicines associated with palliative care in RACFs	<ul style="list-style-type: none"> <li>NIHSI-AA</li> </ul>	Intermediate	NIHSI-AA is not available in all jurisdictions and has a time-lag of approximate 1 year (i.e. 2018-19 will be released in 2020-21). Expert clinical advice will be needed to identify medicines associated with palliative care from the PBS.	3, 4
Increased number of individuals accessing palliative care in RACFs	<ul style="list-style-type: none"> <li>NIHSI-AA</li> </ul>	Intermediate	NIHSI-AA is not available in all jurisdictions and has a time-lag of approximate 1 year (i.e. 2018-19 will be released in 2020-21). Expert guidance will be needed to develop a marker of palliative care from the treatment information included in NIHSI-AA. ACFI assessments involving palliative care are inherently lower than the total number of residential aged care requiring palliative care. <sup>22</sup>	4
Decreased number of transfers from RACFs to acute care facilities	<ul style="list-style-type: none"> <li>NIHSI-AA</li> <li>Ambulance data pilot</li> </ul>	Intermediate	NIHSI-AA is not available in all jurisdictions and has a time-lag of approximate 1 year (i.e. 2018-19 will be released in 2020-21). Ambulance data will be a pilot of one jurisdiction (likely Tasmania).	3, 4, 8
Decreased number of RACF residents admitted to an acute care facility for palliative care	<ul style="list-style-type: none"> <li>NIHSI-AA</li> </ul>	Intermediate	NIHSI-AA is not available in all jurisdictions and has a time-lag of approximate 1 year (i.e. 2018-19 will be released in 2020-21). Expert clinical advice will be needed to develop a market of admissions related to palliative care within the NIHSI-AA data set.	3, 4, 6, 8

<sup>20</sup> NIHSI-AA: National Integrated Health Services Information Analysis Asset

<sup>21</sup> MBS: Medicare Benefits Schedules

<sup>22</sup> AIHW, Palliative care services in Australia: Palliative care for people living in residential aged care, 2020

Decreased number of inpatient bed days related to palliative care for residents of RACF	<ul style="list-style-type: none"> <li>NIHSI-AA</li> </ul>	Intermediate	<p>NIHSI-AA is not available in all jurisdictions and has a time-lag of approximate 1 year (i.e. 2018-19 will be released in 2020-21). Expert clinical advice will be needed to develop a market of inpatient bed days related to palliative care within the NIHSI-AA data set.</p>	3, 4
Increased completions of accredited courses related to palliative care	<ul style="list-style-type: none"> <li>AHHA<sup>23</sup></li> <li>ELDAC<sup>24</sup></li> </ul>	Intermediate / Poor	<p>There are limited Vocational Education and Training courses focussed on palliative care. AHHA will have data on the number of participants on their Palliative Care Online Training Courses. ELDAC may also be able to provide relevant data.</p>	3

<sup>23</sup> AHHA: Australian Healthcare and Hospitals Association

<sup>24</sup> ELDAC: End-of-life Directions for Aged Care

## Appendix D Risk management plan

This appendix provides the risk management plan for the evaluation.

Risk	Consequence	Likelihood	Impact	Risk rating	Mitigation strategy	Residual risk
DATA RISKS						
<b>Quantitative data is difficult to access, or quality and consistency is low</b>	The evaluation cannot draw meaningful conclusions from the quantitative data.	High	High	High	<p>There is an ongoing risk that quantitative data will be incomplete, inaccurate, challenging to access, or nationally inconsistent. Nous will work with the Department and jurisdictions to identify possible data quality and coverage issues. In addition, Nous will:</p> <ol style="list-style-type: none"> <li>1. Work with the Department to identify data requirements and availability and shape the evaluation accordingly.</li> <li>2. Identify where it is possible to supplement existing information with data to be collected, including through states and territories, Primary Health Networks (PHNs), MBS and PBS.</li> <li>3. Where data quality is low, undertake a quality assurance process, (through state and territory representatives or assistance from the Department project team) and identify proxy sources/measures. Where there are gaps, Nous will attempt to source alternative data. Nous will be clear about data limitations that may impact results in all reporting.</li> </ol>	High
<b>Sensitive data is mismanaged</b>	Participant confidentiality is breached.	Low	High	Medium	<p>There is potential that some data obtained during the evaluation will be sensitive. To ensure it is handled appropriately, we will:</p> <ol style="list-style-type: none"> <li>1. Adhere to Nous' strict privacy protocols and ensure all project team members are current in their training for managing sensitive information.</li> <li>2. Conduct a Privacy Impact Assessment and only access identifiable data where required by the research design.</li> <li>3. Define which Nous employees can access relevant files and data.</li> </ol>	Low

Risk	Consequence	Likelihood	Impact	Risk rating	Mitigation strategy	Residual risk
					4. Ensure all outputs meet the project objectives and that all data released is non-disclosive.	
<b>Ethics approval is not granted rapidly or fully</b>	The start of the evaluation is delayed, or components of the evaluation cannot be completed.	Low	High	Medium	At this stage, it has been assessed that this evaluation will not require ethics approval. If circumstances should change and ethics approval should be required in the future, Nous has experience developing successful ethics applications and will draw on this experience, along with close liaison with the Department, to develop well-considered ethics applications for an appropriate HREC(s). This process will build in time contingencies where possible, to account for possible revisions.	Low
<b>Data is not effectively shared between states/territories, RACFs and the evaluation</b>	Data and information for the evaluation is limited or delayed.	Low	High	Medium	The evaluation is dependent upon regular information sharing between Nous, states/territories participating in the Measure and participating RACFs. To ensure a timely flow of information, Nous will: 1. Establish regular channels of communication with all states/territories signed up to the Measure and with their evaluators where appropriate. Nous will engage with all participating jurisdictions early in the project and establish regular lines of communication. 2. Communicate potential issues with the Department in a timely manner and develop an adapted approach. Nous will keep the Department informed of any data collection challenges so that issues can be resolved in a timely fashion.	Low
<b>Jurisdictions do not consult with residents, families and carers in the course of their evaluations</b>	The perspectives of residents, families and carers are not collected, particularly in the COVID-19 environment.	Medium	Medium	Medium	Nous will engage early with all jurisdictions to understand the intended evaluation approach. Nous will seek to shape jurisdictional evaluation approaches to ensure that required data is collected to inform the evaluation.  In the circumstance that the views of residents, carers and families are not collected in jurisdictional evaluations, Nous will seek to gain additional feedback through our planned consultations with the relevant peak bodies at state and national-levels and through jurisdictional PCA groups.	Low

#### TIMEFRAME RISKS

Risk	Consequence	Likelihood	Impact	Risk rating	Mitigation strategy	Residual risk
Roll out of the Measure in some states/territories is delayed	Evaluation timeframes cannot be maintained as implementation of parts of the Measure are delayed.	High	Medium	High	<p>There is a risk that, due to unforeseen circumstances such as COVID-19, roll-out of the Measure is delayed in some locations (e.g. Victoria). In this case, components of the evaluation would also be delayed. Nous will mitigate risk as far as possible by:</p> <ol style="list-style-type: none"> <li>1. Maintaining regular contact with state/territory departments to understand any changes to proposed schedules.</li> <li>2. Communicating any changes to the Department in a timely manner and develop an adapted approach. Where required, Nous will take a flexible approach to the timeframes of the evaluation and/or reporting (within budget).</li> </ol>	High
STAKEHOLDER ENAGEMENT RISKS						
COVID-19 restrictions are unpredictable and prevent face-to-face consultation	Implementation of the activities is delayed or compromised and stakeholder engagement is delayed or not possible.	Medium	Medium	Medium	<p>The current environment is unpredictable and implementation of the state/territory activities may be delayed or only implemented virtually for some RACFs. In addition, many or all stakeholder consultations may need to be completed virtually. Nous is experienced in conducting virtual stakeholder engagements using a range of online tools (e.g. Skype for Business and Microsoft Teams). We will adapt our approach to meet stakeholder needs and preferences, and respond to circumstances during the evaluation. We will consult with the Department about the need for any changes to deliverable dates as a result of delays in the jurisdictions.</p>	Medium
Stakeholders are difficult to engage	Data for the evaluation is limited or key stakeholders do not buy-in to evaluation findings and/or recommendations.	Low	Medium	Low	<p>Nous will ensure adequate engagement of all stakeholders through the following:</p> <ol style="list-style-type: none"> <li>3. Development of a Stakeholder Communication Plan that identifies the purpose, principles and approach for engagement that best meets the needs of each type of stakeholder.</li> <li>4. Provision of clear communications of the purpose, nature, scope and confidentiality of all consultations.</li> <li>5. Provision of multiple timeslot options for stakeholders to engage.</li> <li>6. Drawing on the Department, jurisdictions and service providers to identify participants and connect them to the evaluation.</li> <li>7. Design and implement engaging consultations.</li> <li>1. Adherence to relevant COVID-19 restrictions in each jurisdiction, through the use of platforms such as Skype and Microsoft Teams.</li> </ol>	Low



Risk	Consequence	Likelihood	Impact	Risk rating	Mitigation strategy	Residual risk
QUALITY RISKS						
The evaluation does not meet the quality expectations of the Department	The Department does not receive the information it requires from the evaluation and/or loses confidence in the robustness of the evaluation.	Low	High	Medium	<p>Nous has several quality assurance processes to ensure we deliver quality work, every time. For this evaluation, we will:</p> <ol style="list-style-type: none"> <li>2. Agree the KEQs and evaluation scope and approach early, through the Evaluation Framework.</li> <li>1. Ensure the research design is valid and appropriate through a carefully designed methodology.</li> <li>2. Develop and test draft report outlines with the Department to ensure the scope and detail meets requirements.</li> <li>3. Draw on experts within the team to test our findings and assumptions. This includes Professor David Currow and Stephen Teulan for expertise in aged care and palliative care.</li> <li>4. Test findings with the Department in monthly meetings and Progress Reports.</li> </ol> <p>Nous will keep the Department informed as to achievements, progress, key activities, issues, risks and suggested solutions through the regular updates proposed in this plan. This will help to ensure the Department is aware of progress, without compromising the independence of the evaluation.</p>	Low

## Appendix E Glossary

Item	Definition
Advance Care Directive (ACD) <sup>25</sup>	Advance Care Directive is a catch-all term to refer to the instruments which are recognised in each jurisdiction under Advance Care Directive legislation or common law. They are voluntary, person-led documents completed and signed by a competent person that focus on an individual's values and preferences for future care decisions, including their preferred outcomes and care. Advance Care Directives are recognised by specific legislation (statutory) or under common law (non-statutory). They come into effect when an individual loses decision-making capacity. Advance Care Directives can also appoint substitute decision-makers who can make decisions about health or personal care on the individual's behalf. Advance Care Directives are focused on the future care of a person, not on the management of his or her assets.
Advance Care Plan (ACP) <sup>26</sup>	Documents that capture an individual's beliefs, values and preferences in relation to future care decisions, but which do not meet the requirements for statutory or common law recognition due to the person's lack of competency, insufficient decision-making capacity or lack of formalities (such as inadequate person identification, signature and date). An Advance Care Plan for a non-competent person are often very helpful in providing information for substitute decision-makers and health practitioners and may guide care decisions, though are not legally binding. An Advance Care Plan may be oral or written, with written being preferred. A substitute decision-maker named in an Advance Care Plan is not a statutory appointment.
Advance care planning <sup>27</sup>	A process of planning for future health and personal care whereby the person's values, beliefs and preferences are made known to guide decision-making at a future time when that person cannot make or communicate their decisions. Registered and non-registered health practitioners have a role in advance care planning and require capability to facilitate these conversations effectively. The National Quality Standards for aged care, general practice and health services all promote advance care planning. Individuals can also choose to engage in advance care planning with other non-health practitioners, such as friends or family.
Advance care planning documents (ACPDs) <sup>28</sup>	A catch all term to include documents that result from advance care planning. This includes Advance Care Directives and Advance Care Plans.
Aged Care Quality and Safety Commission (ACQSC)	An independent Statutory Agency, with responsibility for regulating aged care services including accreditation, monitoring, education and support for providers and resolving complaints. The role of the Aged Care Quality and Safety Commission seeks to protect and enhance the safety, health, wellbeing and quality of life of people receiving aged care.
Australian Commission on Safety and Quality	An Australian Government entity that works with patients, consumers, clinicians, managers, policy makers and healthcare organisations to achieve a sustainable, safe and high-quality health system.

<sup>25</sup> Department of Health, Nous Group, "National framework for advance care planning documents." June 2020.

<sup>26</sup> Ibid.

<sup>27</sup> Ibid.

<sup>28</sup> Ibid.

Item	Definition
in Health Care (ACSQHC)	
Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS)	An independent Australian Government statutory authority that promotes knowledge and understanding of Aboriginal and Torres Strait Islander cultures, traditions, languages and stories, past and present.
Aged Care Funding Instrument (ACFI)	The Aged Care Funding Instrument is managed by the Department of Health. The Aged Care Funding Instrument assesses the degree of care each aged care resident needs and allocates funding accordingly.
Australian Healthcare and Hospitals Association (AHHA)	An independent peak membership body and advocate for the Australian healthcare system and a national voice for universally accessible, high quality healthcare in Australia.
Australian Institute of Health and Welfare (AIHW)	An independent statutory agency that provides reliable and relevant information and statistics on Australia's health and welfare.
Carer	A person who provides personal care to someone with a disability, medical condition, or mental illness, or are frail and/or aged. A carer typically volunteers to provide personal assistance to a person (e.g. a resident of a RACF).
Council on the Ageing Australia (COTA)	Council on the Ageing Australia is an advocacy organisation which lobbies for action at a national-level on issues affecting seniors.
Dying	The terminal phase of life, where death is imminent and likely to occur within hours or days, or occasionally weeks. This is sometimes referred to as "actively dying".
End-of-life Directions for Aged Care (ELDAC)	A resource hub that provides information, guidance and resources to health professionals and aged care workers to support palliative care and advance care planning to improve the care of older Australians.
End-of-life care <sup>29</sup>	End-of-life care is care delivered to a patient who is living with a fatal condition, even if the exact trajectory is unknown. The end-of-life period may be days, months, or years depending on the diagnosis or disease. The Aged Care Funding Instrument definition for end-of-life is more specific as follows: Aged Care Funding Instrument 12 item 14 enables a claim for a palliative care program involving end-of-life care.
Futile or non-beneficial treatment <sup>30</sup>	<p>Futile or non-beneficial treatment includes treatment which:</p> <ul style="list-style-type: none"> <li>• is of no benefit</li> <li>• cannot achieve its purpose, or</li> <li>• is not in the person's best interests.</li> </ul>

<sup>29</sup> ELDAC, "Terminology." Accessed Dec 2020; Palliative Care Australia. Palliative Care Service Development Guidelines (2018) Canberra: Palliative Care Australia, 2018.

<sup>30</sup> ELDAC, "Factsheet: Futile or Non-Beneficial Treatment." Accessed 14 December 2020.

Item	Definition
	<p>An example of futile treatment is providing cardiopulmonary resuscitation to someone who will not respond to it.</p> <p>Futile or non-beneficial treatment is not formally defined in law.</p>
General Practitioner (GP)	A doctor who is also qualified in general medical practice. General Practitioners are often the first point of contact for someone, of any age, who feels sick or has a health concern. They treat a wide range of medical conditions and health issues.
Hospital and Health Service (HHS)	Queensland Health consists of the Department of Health and 16 Health and Hospital Services. The Health and Hospital Services are independent statutory bodies which are responsible for delivering public health services in their areas.
Leading Age Services Australia (LASA)	A national peak body representing all providers of age services across residential care, home care and retirement living.
Local Health District (LHD)	NSW Health consists of the Department of Health and 18 Local Health Districts. The Local Health Districts are independent statutory bodies which are responsible for delivering public health services in their areas.
Jurisdictional evaluation and monitoring	Jurisdictions are implementing activities unique to their own state or territory. As a result, some jurisdictions are evaluating and/or monitoring said activities. It is out-of-scope for the national evaluation to be conducting jurisdictional-level evaluations.
The Measure	Comprehensive Palliative Care in Aged Care Measure.
Medicare Benefits Schedule (MBS)	A listing of the Medicare services subsidised by the Australian Government.
National evaluation	An independent evaluation to determine to what extent the aims and objectives of the Measure have been achieved. Findings will inform national policy decisions about palliative care delivery in aged care. The outcomes of the evaluation will contribute to the national evidence base and inform implementation and models of care in future years.
National Health and Medical Research Council (NHMRC)	A statutory authority and the primary agency of the Australian Government responsible for medical and public health research.
National Integrated Health Services Information Analysis Asset (NIHSI-AA)	A dataset owned by the Australian Institute of Health and Welfare as well as the Department of Health, and state and territory health authorities. It contains anonymised data from participating states and territories from 2010-2011 onwards.
Not-for-profit	Organisations that do not operate for the profit or gain of their members, including charities and religious organisations.
Other clinicians	Other clinicians refer to professionals from allied health disciplines, including but not limited to occupational therapy, psychology, speech pathology and social work. These clinicians may be part of a multi-disciplinary team at the RACF.

Item	Definition
Palliative care <sup>31</sup>	An approach that seeks to improve the quality of life of patients and their families facing a life-limiting illness. Palliative care aims to reduce pain and suffering at the end-of-life, such as through early identification and assessment of symptoms. Palliative care should be holistic, attending to the patients' physical, psychosocial and spiritual needs.
Pharmaceutical Benefits Schedule (PBS)	A list of the medicines available to be dispensed to patients at a government-subsidised price.
Palliative Care Australia (PCA)	The national peak body for palliative care in Australia.
Palliative Care Outcomes Collaboration (PCOC)	The national evidence hub on patients' daily pain and symptom outcomes in Australia. The purpose of the Palliative Care Outcomes Collaboration is to drive continuous improvement by providing outcome information to clinicians and local, state and national providers of palliative care.
Primary Health Network (PHN)	<p>The Australian Government established 31 Primary Health Networks across Australia in 2015. They aim to:</p> <ul style="list-style-type: none"> <li>• improve medical services for patients, particularly those at risk of poor health outcomes</li> <li>• make sure government money is directed to where it's needed and is spent on health programs that will be most effective</li> <li>• improve the links between local health services and hospitals, so that patients receive the right care, in the right place, at the right time.</li> </ul>
Project Implementation Group	The Project Implementation Group consists of members from the Department of Health and from states and territories.
National Palliative Care and End-of-life Project Reference Group	<p>The Reference Group will:</p> <ul style="list-style-type: none"> <li>• share information among jurisdictions, particularly in the COVID environment.</li> <li>• discuss progress against the Implementation Plan for the National Palliative Care Strategy.</li> <li>• collaborate on related work and provide a forum to discuss opportunities, issues and linkages.</li> </ul>
Quality improvement initiatives <sup>32</sup>	<p>Quality improvement initiatives are consumer-focused, achieve improvement through planned steps, driven by involvement and accountability of key stakeholders (consumers, families and carers, staff and volunteers, advocates), and involve regular monitoring and evaluation of progress.</p> <p>This may include assessing and monitoring the quality of care and services against the Aged Care Quality and Safety Commission Quality Standards, the End-of-life Directions for Aged Care Palliative Care and Advance Care Planning Organisational Audit, or other initiatives.</p>
Residential aged care facility (RACF)	Residential aged care is for older people who can no longer live at home. These services are funded and regulated by the Australian Government.

<sup>31</sup> ELDAC, "Terminology." Accessed Dec 2020; Palliative Care Australia. Palliative Care Service Development Guidelines (2018) Canberra: Palliative Care Australia, 2018.

<sup>32</sup> Aged Care Quality and Safety Commission, "Continuous Improvement." December 2019.

Item	Definition
Specialist palliative care <sup>33</sup>	People with more complex needs should be able to access care provided by specialist palliative care services comprising multidisciplinary teams with specialised skills, competencies, experience and training in palliative care.

**Table 11 | Acronyms**

Acronym	Description
ACQSC	Aged Care Quality and Safety Commission
ACSQHC	Australian Commission on Safety and Quality in Health Care
AIATSIS	Australian Institute of Aboriginal and Torres Strait Islander Studies
ACD	Advance Care Directive
ACP	Advance Care Plan
ACFI	Aged Care Funding Instrument
ACT	Australian Capital Territory
AHHA	Australian Healthcare and Hospitals Association
AIHW	Australian Institute of Health and Welfare
COTA	Council on the Ageing Australia
ELDAC	End-of-life Directions for Aged Care
GP	General practitioner
HHS	Hospital and Health Service
LASA	Leading Age Services Australia
LHD	Local Health District
MBS	Medicare Benefits Schedule
NIHSI-AA	National Integrated Health Services Information Analysis Asset
NHMRC	National Health and Medical Research Council
NSW	New South Wales
NT	Northern Territory
PBS	Pharmaceutical Benefits Schedule

<sup>33</sup> ELDAC, "Terminology." Accessed Dec 2020; Palliative Care Australia. Palliative Care Service Development Guidelines (2018) Canberra: Palliative Care Australia, 2018.

Acronym	Description
PCA	Palliative Care Australia
PCOC	Palliative Care Outcomes Collaboration
PHN	Primary Health Network
RACF	Residential aged care facility
SA	South Australia
WA	Western Australia





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## ABOUT NOUS

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**Nous Group** is an international management consultancy operating in 11 locations across Australia, the UK and Canada. For over 20 years we have been partnering with leaders to shape world-class businesses, effective governments and empowered communities.

A dark blue world map graphic with white dots representing cities, located in the bottom left corner of the page.

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performance & influence  
engaging

400

PEOPLE

11

LOCATIONS

3

COUNTRIES

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