



Literature review summary report - National Evaluation of the Comprehensive Palliative Care in Aged Care Measure

Department of Health

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Executive summary

Introduction

Nous Group (Nous) has been engaged by the Australian Government Department of Health (the Department) to undertake a national evaluation of the *Comprehensive Palliative Care in Aged Care Measure* (the Measure). The national evaluation will determine the extent to which the aims and objectives of the Measure have been achieved.

This Literature Review Report summarises the outcomes of a review of peer-reviewed and grey literature on international and domestic approaches to palliative care in residential aged care facilities (RACFs). It draws on the principles of Rapid Evidence Assessment (REA) to provide a balanced assessment of what is known (and not known) in the literature by using a rapid but systematic methodology to search for empirical studies.

Summary of key findings

Four key questions guided the literature review and structure of this report:

1. What are the palliative care needs of residents, families/carers, staff and the system in RACFs?
2. What models of care exist that have proven successful?
3. What evidence exists on best practice approaches to funding and delivery arrangements?
4. How have palliative care in RACF initiatives sought to address health interface issues?

Below is a summary of key findings from the literature review, structured against these four questions.



What are the palliative care needs of residents, families/carers, staff and the system in RACFs?

Palliative care helps people live their life as fully and as comfortably as possible when living with a life-limiting or terminal illness, including the provision of general and specialist care to meet patient needs. It is distinct from end of life care, which is often described as a component of palliative care.

Evidence indicates that quality palliative care in RACFs is characterised by a respectful, person-centred and integrated approach. Direct measures of quality palliative care have been delivered by the Palliative Care Outcomes Collaboration (PCOC), while proxy markers of quality palliative care in RACFs include increased rates of advance care planning, decreased hospital admissions, reduced time spent in hospitals, and achieving a preferred place of death.

The literature review identified a consistent body of evidence describing the needs of residents, families, carers and staff in RACFs. Residents of RACFs need personalised, multidisciplinary palliative care that encompasses physical, spiritual and psychological care. Palliative care must be appropriate and flexible to their changing needs and preferences, including to medical comorbidities.

Evidence indicated that families and carers of RACF residents require access to information and appropriate resources and supports to maintain their own wellbeing. These supports include education and culturally respectful psychological support. They also need to be involved in and informed of care and decisions undertaken within the RACF.

Staff have varying needs based on their roles, but evidence notes that they need access to appropriate education, training and resources that enables them to identify palliative care needs, communicate about

palliative care with families and carers, and provide high quality care. RACFs need to recognise what skills each staff member requires to provide quality palliative care in RACFs, within their scope of practice.

The evidence indicates that system needs include appropriate funding, delivery and integration support to meet the needs of residents, families, carers and staff. Access and availability to high quality palliative care within the RACF is a challenge for many. Evidence indicated that identifying and communicating about palliative care needs is a key service gap and consistently indicates that workforce capacity and capability are significant contributors to service gaps.

The body of evidence describing the needs of residents, families, carers and staff in RACFs will be used to inform the national evaluation in the following ways:

- to describe the context within which RACFs participating in the Measure are operating;
- to understand the needs and operating context of systems involved in activities implemented under the Measure;
- to steer the discussion on service gaps in the national evaluation and support the articulation of the unmet needs that the Measure aims to meet; and
- to inform the selection of indicators that will guide data collection and analysis for the national evaluation.



What models of care exist that have proven successful?

Evidence suggested that changing population needs and health system policy and drivers have necessitated dynamic, integrative models of care for palliative care delivery in RACFs. There is significant variation in practice and availability of palliative care in RACFs in Australia and internationally. Relatively limited evidence has led to an absence of clear, evidenced-based models of care for providing efficient and quality palliative care services in RACFs.

Palliative care models of care in RACFs vary, but integrating specialist palliative care into RACFs is a common theme. Evidence identified six frequently cited components of palliative care models of care in RACFs: case management, capability building, specialist in-reach services, shared care, specialist out-reach services, and integrated care.

The literature review identified 12 separate models of delivering palliative care in RACFs in Australia. Of these, there was a high concentration of models of care identified in RACFs in New South Wales and Victoria. 25 per cent of the models of care identified were specialist in-reach services. Australian palliative care models of care in RACFs vary in terms of what they deliver, but the INSPIRED model is an effective, evidence-based approach.

The literature review identified seven international models of delivering palliative care in RACFs or equivalents. These models were concentrated in countries that provide universal health coverage, New Zealand, Canada, and the United Kingdom. There was no predominant model of care identified. Instead, the components of these models were spread across specialist in-reach services, capability building, and case management.

The success factors for palliative care models of care in RACFs are multi-dimensional but share a common theme of integrating specialist palliative knowledge and/or care into RACFs.

Evidence on existing and successful models of care for palliative care in RACFs will inform the national evaluation in the following ways:

- The domestic and international models identified in the literature review will answer the questions on successful models of care outside of the Measure; and

- The critical success factors for palliative care models of care will be used as a basis for further exploration.



What evidence exists on best practice approaches to funding and delivery arrangements?

There are multiple arrangements that can be used to support joint funding and delivery of activities between Commonwealth and state/territory governments. The type of funding arrangement is a key consideration in joint Commonwealth and state/territory projects; this literature review focused on National Partnership Payments (NPPs) in health or other sectors given they are most relevant to the Measure arrangements.

Of the four types of NPPs, the less onerous reporting requirements that characterise National Partnership Agreements (NPAs) and Project Agreements (PAs) have led to their increasing use in facilitating joint Commonwealth and state/territory projects. The literature indicates that there is very limited evidence on joint funding and delivery arrangements specific to palliative care in RACFs, so this report focuses on what the evaluation can learn about joint funding and delivery in health and other sectors more broadly.

Evidence showed that NPAs and PAs are commonly used for joint delivery of activities in the health sector. They allow states and territories to exercise their judgement as to where funding is allocated, yielding outcomes that address jurisdictional specific issues.

Pooled funding across state and territory jurisdictions has the potential to minimise service gaps and progress equitable health coverage. Co-commissioning between states/territories and Primary Health Networks (PHNs) has the potential to further integrate health system services. However, pooled funding and giving regions greater control and responsibility is supported in theory but not in practice. While many countries are exploring forms of funds pooling, there is little evidence of efficacy at scale. An international review of integrated funding for health and social care explored 38 schemes from eight countries and were unable to isolate elements such as funds pooling from care delivery.

Evidence on best practice approaches to joint funding and delivery is limited to large-scale agreements, but certain principles can apply to all agreements. Evidence suggests that funding models for palliative care should move toward activity-based, uncapped funding, and informed by performance metrics and reporting.

Evidence on best practice funding and delivery approaches will inform the national evaluation in the following ways:

- Best practice approaches to joint funding and delivery arrangements evidenced in the literature will be shared in the national evaluation and will contextualise the Measure's arrangement.
- Findings from examination of good practice funding and delivery arrangements will help identify areas of improvement for potential future joint activities/agreements.



How have palliative care in RACF initiatives sought to address health interface issues?

Health interface issues are made more complex by an increasing number of people in residential aged care, increasingly complex care needs, complex service delivery and funding arrangements and systems under pressure. People living in RACFs experience health interface issues related to access and coordination of services. Evidence suggested that the key health interface issues include access to primary

health care services and access to secondary and tertiary health care services, such as specialists or allied health professionals.¹

Initiatives have sought to address health system interface issues through the use of levers and models of care that influence policy, capability, networks and availability of expertise. Evidence-based models of care for the provision of palliative care in RACFs provide examples for what works well. For example, the INSPIRED Model uses a case management approach to aid the identification of palliative care needs and provision of clinical assessments.

The evidence points to a number of principles for successfully addressing health interface issues in RACFs. This includes timely access to health care providers, greater reliance on nurse practitioners and primary care nurses, improved advance care planning, and a standard information transfer tool between hospitals and RACFs. Successful initiatives must work in concert to have a meaningful impact on the bigger picture.

Evidence on how palliative care in RACF initiatives have sought to address health interface issues will inform the national evaluation in the following ways:

- Evidence based models of care outside of the Measure that address health interface issues will be used to inform the definition of good practice and will be explored further in the national evaluation.
- Success factors and enablers will be used to understand the factors that contribute to models that successfully address health interface issues and identify areas where activities under the Measure can improve.

Conclusions

Findings from this literature review provide a basis for understanding the context in which RACFs participating in the Measure operate and have implications for the evaluation as shown in Table 1.

Table 1 | Implications for the national evaluation

Key evaluation questions	Implications for the national evaluation
How appropriate is the Measure to meet the needs of residents, families and carers in the Residential Aged Care Facilities (RACF) setting?	<ul style="list-style-type: none">• The body of evidence describing the needs of residents, families, carers and staff in RACFs will be used to describe the context within which RACFs participating in the Measure are operating.• Evidence describing system needs will be explored further to understand the needs and operating context of systems involved in activities implemented under the Measure.• Evidence on service gaps, such as workforce capacity and capability, will steer the discussion on service gaps in the national evaluation and support the articulation of the unmet needs that the Measure aims to meet.
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?	<ul style="list-style-type: none">• Best practice approaches to joint funding and delivery arrangements evidenced in the literature will be shared in the national evaluation and will contextualise the Measure's arrangement.• Findings from examination of good practice funding and delivery arrangements will help identify areas of improvement for potential future joint activities/agreements.

¹ Information from the Department of Health indicates that this is a recognised key area, with work currently underway to address challenges for RACF residents accessing health services (as at November 2020).

To what extent has the Measure achieved its intended outcomes?	<ul style="list-style-type: none"> • Markers of quality palliative care in RACFs identified and outcomes measured by evaluations of evidence-based good practice models of care will inform the selection of indicators that will guide data collection and analysis for the national evaluation.
Is there a specific model of care that has been implemented that has proven to be more successful than others?	<ul style="list-style-type: none"> • The domestic and international models identified in the literature review will answer the questions on successful models of care outside of the Measure for the national evaluation. • The critical success factors for palliative care models of care will be used as a basis for further exploration in the national evaluation.
Does the Measure and the models adopted in each jurisdiction help to address health system interface issues?	<ul style="list-style-type: none"> • Evidence based models of care outside of the Measure that address health interface issues will be used to inform the definition of good practice and will be explored further in the national evaluation. • Success factors and enablers will be used to understand the factors that contribute to models that successfully address health interface issues and identify areas where activities under the Measure can improve.

1 Background and context

This section provides the background to the national evaluation of the *Comprehensive Palliative Care in Aged Care Measure* (the Measure) and the purpose of this document.

Background and context

The Measure provides \$57.2 million in Commonwealth funding over six years from 2018-2024, with funding to states and territories commencing from 2019-20. The Measure aims to help older Australians living in residential aged care who are nearing the end of their life. Its goals are to:

- improve palliative and end-of-life care for older people living in residential aged care; and
- further enable people to die where they want, supported by increased aged care services.

The Measure is provided through a cost-sharing model, meaning states and territories match Commonwealth funding. States and territories then implement initiatives suited to local needs and may evaluate initiatives implemented in their jurisdiction.

Purpose of the national evaluation of the Measure

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

The national evaluation will determine the extent to which the aims and objectives of the Measure have been achieved. The outcomes of the evaluation 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; and
- develop recommendations to inform palliative care policy development.

An Evaluation Framework will guide the national evaluation data collection, analysis and reporting, and is due for completion in late 2020.

Purpose of the Literature Review Report

This Literature Review Report summarises the outcomes of a review of peer-reviewed and grey literature on international and domestic approaches to palliative care in residential aged care facilities (RACFs). It supports the national evaluation by establishing a baseline of evidence on the need for palliative care in RACFs and successful models of care, funding and delivery arrangements and mechanisms to address interface issues.

2 Methodology

This section provides a summary of the approach and methodology for the literature review.

Nous' research approach drew on the principles of Rapid Evidence Assessment (REA). An REA provides a balanced assessment of what is known (and not known) in the literature about an intervention, problem or practical issues by using a systematic methodology to search for empirical studies; however, to be 'rapid', an REA makes concessions in relation to the breadth, depth and comprehensiveness of the search.

The literature review included peer-reviewed and grey literature on palliative care in RACFs (see Table 2).

Table 2 | Types of data sources for literature review

Type of data source	Description
Peer-reviewed literature	Peer-reviewed sources have been assessed for quality and importance by experts in the field. For example, articles published in academic journals, by professional scholarly societies, professional associations or university departments.
Grey literature	Grey literature sources are documents produced at all levels of government, academia, business and industry who are considered authorities on their content, however, are not controlled by commercial publishers. For example, reports, conferencing proceedings, doctoral theses/dissertations, newsletters, technical notes, working papers and white papers.

Four key questions guided the literature review and structure of this report, as shown in Figure 1. They are a subset of the broader key evaluation questions and research questions for the national evaluation.

Figure 1 | Key literature review questions and sub-questions

KEY LITERATURE REVIEW QUESTIONS	SUB-QUESTIONS
What are the palliative care needs of residents, families/carers, staff and the system in RACFs?	<ol style="list-style-type: none"> 1. What is the definition of quality palliative care in RACFs? 2. What are the needs of residents, families/carers, staff and the system? 3. What are the service gaps from the perspective of residents, families, carers staff?
What models of care exist that have proven successful?	<ol style="list-style-type: none"> 1. What examples exist of good practice palliative care in RACFs in Australia or internationally? 2. What is required for success?
What evidence exists on best practice approaches to funding and delivery arrangements?	<ol style="list-style-type: none"> 1. What evidence exists on best practice approaches to funding and delivery arrangements?
How have palliative care in RACF initiatives sought to address health interface issues?	<ol style="list-style-type: none"> 1. How have RACF initiatives addressed health system interface issues? 2. What has worked well and less well?

3 Findings

This section describes the findings of the literature review, structured by the four key questions.

Overall, evidence identified through the literature review showed that:

- There are relatively consistent descriptions in evidence on the needs of residents, families, carers and staff in RACFs and current service gaps. Much of this evidence was sourced from recent documents relating to the Royal Commission into Aged Care Quality and Safety and the Productivity Commission's Inquiry Report on Reforms to Human Services.
- Evidence on good practice in models of care for palliative care in RACFs is still emerging, but several key models of care with rigorous evidence bases were identified. A subset of these models of care also seeks to address health interface issues.
- Evidence on good practice funding and delivery arrangements was limited to large-scale National Agreements. Agreements in health and outside of health provided key principles for effective funding and delivery.

3.1 What are the palliative care needs of residents, families/carers, staff and the system in RACFs?

This sub-section summarises evidence from the literature on the:

- definition of quality palliative care in RACFs (see section 3.1.1)
- palliative care needs of residents in RACFs (see section 3.1.2)
- needs of families and carers (see section 3.1.3)
- needs of staff and the system (see section 3.1.4).



KEY FINDINGS

The literature review identified a consistent body of evidence describing the needs of residents, families, carers and staff and the ways in which their palliative care needs are commonly not met in RACFs:

- Palliative care treats patients with life-limiting illness. It is distinct from end of life care, which is often described as a subset of palliative care.
- Quality palliative care in RACFs is characterised by a respectful, person-centred and integrated approach.
- Residents need personalised, multidisciplinary palliative care that encompasses physical, spiritual and psychological care.
- Families and carers of RACF residents need education, information, and emotional and psychological support delivered in a respectful and appropriate way.
- Staff have varying needs based on their roles, but need access to appropriate education, training and resources that enables them to identify palliative care needs, communicate about palliative care with families and carers, provide high quality care and balance those roles with self-care.
- System needs include appropriate funding, delivery and integration support to meet the needs of residents, families, carers and staff.

- Access to high quality palliative care within RACFs is a challenge for many, with evidence indicating that there is highly variable availability of palliative care in RACFs.
- Evidence indicated that identifying and communicating about palliative care needs is a key service gap. From a system perspective, evidence also consistently indicates that workforce capacity and capability are significant contributors to service gaps.

3.1.1 What is the definition of quality palliative care in RACFs?

Palliative care treats patients with life-limiting illness and is distinct from end of life care

Palliative care helps people live their life as fully and as comfortably as possible when living with a life-limiting or terminal illness, including the provision of general and specialist care to meet patient needs.²

Numerous definitions for palliative care exist internationally and in the Australian context, as detailed below.

Palliative care in primary, acute and RACF settings is defined by the World Health Organisation (WHO) as an approach that:

improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, including physical, psychosocial and spiritual.³

The National Palliative Care Strategy 2018 defines palliative care as holistic care that helps people nearing the end of their life to live as well as possible for as long as possible.⁴ Palliative Care Australia defines palliative care as person and family-centred care provided for a person with an active, progressive, advanced disease, who has little or no prospect of cure and who is expected to die, and for whom the primary goal is to optimise the quality of life.⁵ The Palliative Care Outcomes Collaboration (PCOC) defines palliative care as the care in which the primary clinical purpose or treatment goal is to optimise of the quality of life of a patient or resident that has an active and advanced life-limiting illness.⁶

Palliative care can be further separated into 'specialist palliative care' and 'generalist palliative care'. The National Palliative Care Standards differentiates between specialist palliative care and generalist palliative care services as follows:

- Specialist palliative care services: comprising multidisciplinary teams with specialised skills, competencies, experience and training in palliative care, for people with more complex palliative care needs.
- Generalist palliative care services (also referred to as 'palliative care services'): care that is provided by other health professionals, including general practitioners, that have minimum core competencies in the provision of palliative care.⁷

There is no standard agreed definition of palliative care in different care settings (such as primary and acute care settings). As noted in Section 3.1.5, this may manifest in challenges in identification of palliative care needs and subsequent interface challenges (explored further in Section 3.4).

² Palliative Care Australia, "Palliative Care 2030." 2019.

³ World Health Organisation, "WHO Definition of Palliative Care" 2018.

⁴ Australian Government Department of Health, "National Palliative Care Strategy 2018", 2018.

⁵ Palliative Care Australia, "What is Palliative Care?", Date unknown.

⁶ Palliative Care Outcomes Collaboration, "Palliative Care Outcomes Collaboration", date unknown.

⁷ Palliative Care Australia, "National Palliative Care Standards", 2018.

Palliative care is closely related to, but stands distinct from, end of life care, which is defined as the last few weeks of life in which a patient with a life-limiting illness is rapidly approaching death.⁸ PCOC defines end of life care as taking place when a person is likely to die within the next 12 months.⁹ End of life care is often described as a component of palliative care.¹⁰

Quality palliative care in RACFs is characterised by a respectful, person-centred and integrated approach

High quality palliative and end of life care bring together health services, home care, personal support and support for carers, but always according to the preferences and circumstances of the dying person.¹¹ Literature indicated that key components of quality palliative care include a person and family centred approach;¹² effective patient identification and assessment;¹³ and high quality interdisciplinary care and care planning.¹⁴

The National Palliative Care Strategy 2018 provides guidance for Commonwealth, state and territory governments for the improvement of palliative care across Australia so that people affected by life-limiting illnesses get the care they need to live well.¹⁵ It notes six guiding principles that are identified as fundamental to ensure that all people experience the palliative care they need, summarised in Figure 2:

Figure 2 | Aspirational guiding principles of the National Palliative Care Strategy 2018¹⁶



In the aged care context, the Aged Care Quality Standards provide a resource that defines quality care in a residential aged care setting in respect to eight standards. Many of the standards are applicable to palliative care, but there is no standard that exclusively addresses palliative care. Guidance for the Standards reference palliative care in the following:

- **Standard 2 - Ongoing assessment and planning with consumers.** A series of palliative care resources and references are provided under this standard. Palliative care is referenced in respect to members of the workforce knowing how to access the relevant expertise to provide information on end of life planning and decision making.

⁸ Palliative Care Australia, "What is Palliative Care?", Date unknown.

⁹ Palliative Care Outcomes Collaboration, "Palliative Care Outcomes Collaboration", date unknown.

¹⁰ Department of Health, "What is palliative care?" 2019.

¹¹ Grattan Institute, "Dying Well." 2014.

¹² Palliative Care Australia, "Palliative Care 2030." 2019.

¹³ Highet, G, Crawford, D, Murray, S, Boyd, K, "Development and evaluation of the Supportive and Palliative Care Indicators Tool (SPICT): a mixed-methods study," British Medical Journal. 2018.

¹⁴ Liu, W-M, Koerner, J, Lawrence, L et al., 'Improved Quality of Death and Dying in Care Homes: A Palliative Care Stepped Wedge Randomized Control Trial in Australia,' The American Geriatrics Society. 2019.

¹⁵ Australian Government Department of Health, "National Palliative Care Strategy 2018", 2018.

¹⁶ Ibid

- **Standard 3 – Personal care and clinical care.** Palliative care is briefly mentioned in reference to how the organisation works with others external to the RACF, such as palliative care specialists, to improve end of life care.¹⁷

In the residential aged care setting, Palliative Care Australia in collaboration with other aged care peak bodies define the principles for the provision of quality palliative and end of life care as follows:

- “residents’ physical and mental needs at end-of-life are assessed and recognised;
- residents, families and carers are involved in end-of-life planning and decision making;
- residents receive equitable and timely access to appropriate end-of-life care within aged care facilities;
- end-of-life care is holistic, integrated and delivered by appropriately trained and skilled staff;
- the end-of-life care needs of residents with dementia or cognitive impairment are understood and met within residential aged care;
- residents, families and carers are treated with dignity and respect;
- residents have their spiritual, cultural and psychosocial needs respected and fulfilled; and
- families, carers, staff and residents are supported in bereavement.¹⁸

A key component of quality palliative care is the involvement of residents, families and carers in decision making. This is often achieved through the use advance care planning, which is a process of planning for future health and personal care whereby the person’s values, beliefs and preferences are documented in order to guide decision-making at a future time when that person cannot make or communicate their decisions. Advance care planning is formalised through the use of an advance care directive (ACD) or an advance care plan (ACP).¹⁹

Markers of quality palliative care in RACFs will be used as indicators for the national evaluation

Defining what good quality palliative care looks like in RACFs helps to determine specific indicators to measure its quality and availability across RACF settings.

For the evaluation, Nous will identify specific indicators linked to the outcomes being sought at the jurisdictional and national level. These will be informed by indicators identified in the evidence. The literature identified many proxy measures for quality palliative care including:

- increased rates of advance care planning;
- decreased hospital admissions;
- reduced time spent in hospitals; and
- achieving a preferred place of death.²⁰

Direct measures of the quality of palliative care delivered in RACFs have been developed by the Palliative Care Outcomes Collaboration (PCOC),²¹ which is the primary method for measuring palliative care outcomes in Australia. There are five assessments conducted as part of the PCOC program including:

¹⁷ Aged Care Quality and Safety Commission, “Guidance and resources for providers to support the Aged Care Quality Standards”. 2019.

¹⁸ Palliative Care Australia, “Principles for palliative and end-of-life care in residential aged care”. 2017. Note that for consistency in this report, references to consumers have been changed to residents.

¹⁹ Department of Health, “Advance care planning”, 2019.

²⁰ Chapman, M, Johnston, N, Lovell, C, et al., “Avoiding costly hospitalisation at end of life: findings from a specialist palliative care pilot in residential care for older adults,” British Medical Journal. 2015.

²¹ University of Wollongong Australia, “Palliative Care Outcomes Collaboration”, 2020.

- one rated by the resident (Symptom Assessment Scale); and
- four measured by a health care professional (Problem Severity Score Actions, Australia-modified Karnofsky Performance Status Scale, Resource Utilisation Group – Activities of Daily Living and Palliative Care Phase).²²

These provide a measure of whether residents' needs are being met. PCOC maintains a national longitudinal database of palliative care outcomes across settings including RACFs and types of providers.

Other administrative datasets provide indirect measures of quality palliative care. For example, the Aged Care Quality and Safety Commission collects data on complaints that have been received, which provides an indirect measure of instances in which residents' needs may not have been met.

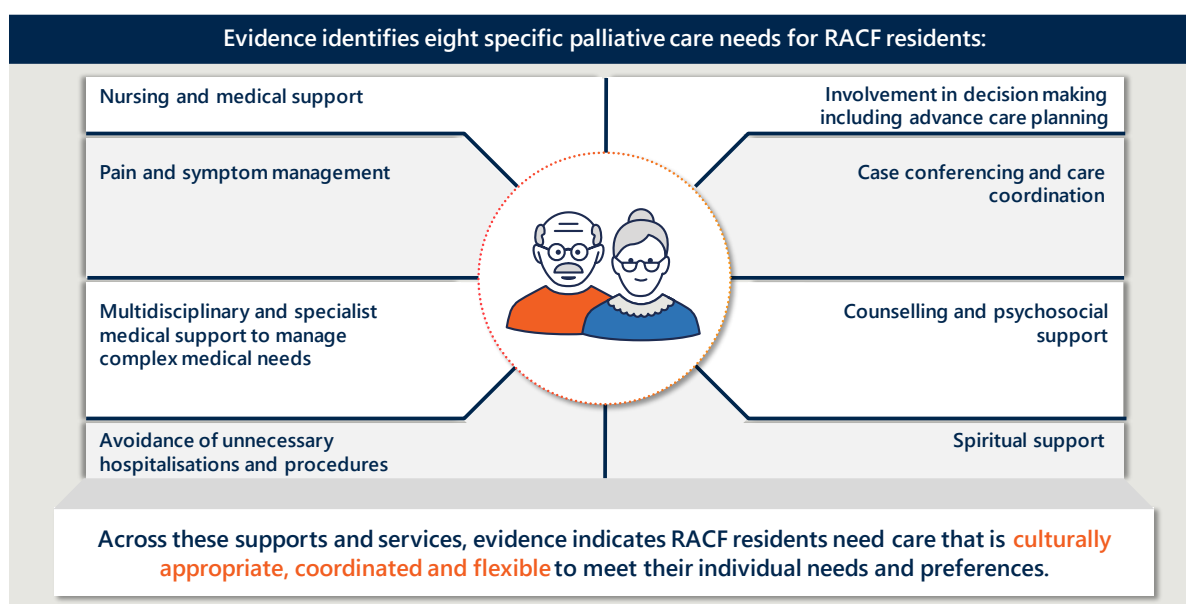
3.1.2 What are the needs of residents?

Residents need personalised, multidisciplinary palliative care that encompasses physical, spiritual and psychological care

Evidence consistently cited that the needs of residents are highly individual and dependent on the circumstances of the resident, which may change over time. Evidence indicated that ultimately, palliative care must be appropriate and flexible to these changing needs and preferences. It must also be respectful, culturally appropriate and designed around the preferences and values of the person receiving care.²³

The commonly reported needs of residents, as outlined in the literature, are shown in Figure 3.

Figure 3 | Evidence identified eight types of palliative care needs for RACF residents^{24,25,26}



Many residents have specific palliative needs, including (but not limited to):

²² University of Wollongong Australia, "Assessment forms", 2020.

²³ Department of Health, "National Palliative Care Strategy." 2018.

²⁴ KPMG & Palliative Care Australia, "Investing to save." 2020.

²⁵ Carlson, M, Lim, B, Meier, D, "Strategies and innovative models for delivering palliative care in nursing homes," Journal of American Medical Directors Association 12(2): 91-98. 2011.

²⁶ Luckett, T, Phillips, J, Agar, M et al., "Elements of effective palliative care models: a rapid review," BioMed Central, 14(36). 2014.

- People with dementia, who comprise approximately 52 per cent of people living in RACFs, are a population of particular need.^{27,28} The needs of people with dementia vary widely and vary over time, but may include the need for a tailored physical environment and additional support in communication, personal care and behaviour management.²⁹ The Royal Commission heard that there is a shortage of qualified staff experienced in caring for older people with complex conditions, such as dementia.³⁰
- Aboriginal and Torres Strait Islander people. The Royal Commission heard that it is important for providers to understand local practices around death and dying or ask for advice from local communities on appropriate practices.³¹
- People from CALD backgrounds. The Royal Commission heard that staff could benefit from increased understanding of peoples from diverse backgrounds in order to deliver personalised care.³²

3.1.3 What are the needs of families and carers?

Families and carers of RACF residents need education, information, and emotional and psychological support delivered in a respectful and appropriate way

Evidence suggested that families and carers need the appropriate resources and supports to provide support to the person receiving palliative care and to maintain their own health and wellbeing. Needs of families and carers identified in the evidence can be considered in the following three categories:

1. **Education and information:** Families and carers need to receive the information that allows them to best support the person receiving palliative care, and to understand what to expect.^{33,34} This includes information regarding and involvement in end of life planning and decision making.³⁵ They also need to understand the terminology around palliative care and what it entails.³⁶
2. **Emotional, spiritual and psychological support:** Families and carers need emotional, spiritual and psychological support throughout palliative care and during bereavement.³⁷
3. **Respectful support and involvement:** As for residents, families and carers need to be treated culturally appropriately and with respect, including support during bereavement.³⁸ Hearings from the Royal Commission into Aged Care Quality and Safety highlighted that families and carers need to be involved in palliative care planning and consulted regarding the resident's ongoing health.³⁹

²⁷ Chapman, M, Johnston, N, Lovell, C, et al., "Avoiding costly hospitalisation at end of life: findings from a specialist palliative care pilot in residential care for older adults," British Medical Journal. 2015.

²⁸ Dementia Australia, "Dementia statistics", 2020.

²⁹ Alzheimer's Australia, "Quality Dementia Care: Practice in residential aged care facilities for all staff", 2007.

³⁰ Royal Commission into Aged Care Quality and Safety, "Interim Report Volume 1." 2019.

³¹ Ibid.

³² Ibid.

³³ Nous Group, "Stocktake and analysis of activities at the interface between the aged care, health and disability systems." 2020.

³⁴ Johnston, N, Lovell, C, Liu-, W-M, et al., "Normalising and planning for death in residential care: findings from a qualitative focus group study of a specialist palliative care intervention," British Medical Journal. 2016.

³⁵ Palliative Care Australia, "Principles for palliative and end-of-life care in residential aged care". 2017.

³⁶ Royal Commission into Aged Care Quality and Safety, "Canberra Hearing - Interfaces between the aged care and the health care systems." 2019.

³⁷ KPMG & Palliative Care Australia, "Investing to save." 2020.

³⁸ Palliative Care Australia, "Principles for palliative and end-of-life care in residential aged care". 2017.

³⁹ Royal Commission into Aged Care Quality and Safety, "Interim report: Neglect, Volume 2", 2019.

3.1.4 What are the needs of RACF staff, other clinical personnel and the system?

Staff have varying needs based on their roles, but at a minimum need access to appropriate education, training and resources

The term 'staff' in the context of RACFs encompasses both non-clinical and clinical staff:

- **Non-clinical staff:** personal care workers and other employees of RACFs with caring duties, but that are not registered health practitioners.⁴⁰ RACF staff will generally have qualifications such as a Certificate III or Certificate IV, for example in Individual Support or Ageing Support. In 2016, personal care attendants and community care workers made up 70 per cent of direct care staff in RACFs.⁴¹ There is high turnover of personal care workers.⁴²
- **Clinical staff:** generalist staff such as registered nurses and staff with specialist palliative care qualifications, who are employed by the RACF.
- **Other clinical personnel,** including General Practitioners, Nurse Practitioners and gerontologists, who are unlikely to be employed by the facility but attend some days, or in response to a specific request.




Staff have differing involvement in palliative care, but evidence identified common needs (see Figure 4).

⁴⁰ This may also include staff that are not involved in personal care but interact with residents such as wardspeople, cleaners and cooks.

⁴¹ Australian Institute of Health and Welfare, "Australia's aged care workforce". 2017.

⁴² Productivity Commission, "Caring for older Australians, Report No. 53, Final Inquiry Report", 2011.

Figure 4 | Staff working in RACFs have different needs based on their skill set and role, but all require appropriate education and access to other services^{43,44,45,46,47,48,49}

NON-CLINICAL STAFF		CLINICAL PERSONNEL	
PERSONAL CARE WORKERS  <i>Personal care workers and other employees of RACFs with caring duties.</i>		CLINICAL STAFF  <i>Generalist clinical RACF staff such as registered nurses and staff with specialist palliative care qualifications.</i>	OTHER CLINICAL PERSONNEL  <i>Other clinical personally who are unlikely to be employed by a RACF but are involved in care, such as GPs.</i>
NEEDS <ul style="list-style-type: none"> • Access to clinical staff when needed • Training, support and supervision to identify palliative care needs and to recognise transition into end of life and terminal phases. • Appropriate referral pathways 		NEEDS <ul style="list-style-type: none"> • Education in symptom recognition and management • Support from specialist palliative care workforce when care requires it • Time and resources to deliver care • Training to engage with residents and families regarding end-of-life 	NEEDS <ul style="list-style-type: none"> • Specialist skills including communication and management of complex patients • Evidence-based models for specialist palliative care provision
COMMON (SYSTEM) NEEDS <ul style="list-style-type: none"> • Ability to communicate with patients, carers and families about palliative care needs, death and dying • Appropriate facilities, workforce and funding to provide care • Communication channels across the health system, including with other RACF staff and hospitals • Appropriate education and training options underpinned by competency and capability frameworks 			

A key component of staff needs identified in the literature is appropriate education and training. Appropriate workforce models in RACFs need to recognise a continuum of skills from basic care through to complex health care.⁵⁰ Staff working in RACFs report a need for palliative care education and improved access to specialist palliative care.⁵¹ Reported barriers to training and education in the aged care sector include time, money and access to qualified staff to act as trainers and assessors. For example, many staff are unable to travel off site or complete training after hours, making training difficult to access.⁵²

Training and education should enable staff to identify palliative care needs, communicate about palliative care with families and carers, and provide high quality care. Education and training needs to be consistent, quality and long enough to ensure that students gain the necessary skills and practical training.⁵³

⁴³ Lane, H, Philip, J, "Managing expectations: Providing palliative care in aged care facilities," Australasian Journal on Ageing. 2015.

⁴⁴ Forbat, L, Johnston, N, Mitchell, I, 'Defining 'specialist palliative care': findings from a Delphi study of clinicians,' Australian Health Review. 2019.

⁴⁵ Whittaker, E, Kernohan, W, Hasson, F, et al., "Palliative care in nursing homes: exploring care assistants' knowledge," International Journal of Older People Nursing 2: 36-44. 2007.

⁴⁶ Carlson, M, Lim, B, Meier, D, "Strategies and innovative models for delivering palliative care in nursing homes," Journal of American Medical Directors Association 12(2): 91-98. 2011.

⁴⁷ Chapman, M, Johnston, N, Lovell, C, et al., "Avoiding costly hospitalisation at end of life: findings from a specialist palliative care pilot in residential care for older adults," British Medical Journal. 2015.

⁴⁸ Palliative Care Australia, "Palliative Care 2030." 2019.

⁴⁹ Forbat, L, Chapman, M, Lovell, C, et al., 'Improving specialist palliative care in residential care for older people: a checklist to guide practice,' Supportive and Palliative Care. 2017.

⁵⁰ Aged Care Workforce Strategy Taskforce, "Health and Aged Care Interface Technical Advisory Group." 2018.

⁵¹ Lane, H, Philip, J, "Managing expectations: Providing palliative care in aged care facilities," Australasian Journal on Ageing. 2015.

⁵² Booth R et al, "Workplace training practices in the residential aged care sector", National Vocational Education and Training Research. 2005.

⁵³ Parliament of Australia, "Future of Australia's aged care sector workforce Chapter 3: Attracting, training, and retaining aged care workers", 2017.

System needs include appropriate funding, delivery and integration support to meet the needs of residents, families, carers and staff

System-level needs refer to needs at the Commonwealth (predominantly related to the aged care system and primary care system) and state/territory government level (predominantly related to health care systems). Across both levels, system needs largely relate to the need for support to overcome funding, delivery and interface issues, which are discussed in greater detail in Sections 3.3 and 3.4. Other system-level needs indicated in the evidence include:

- Effective clinical governance;⁵⁴
- Broad engagement from the health, disability and aged care systems⁵⁵ and integration of palliative care into primary health care and other systems;⁵⁶
- Organisational awareness and implementation of advance care planning;⁵⁷ and
- The resources and enablers for continuous learning and improvement.⁵⁸

There is limited evidence on the needs of state public health systems' in delivering palliative care in RACFs beyond the staffing, capacity, and workforce needs identified elsewhere in this report. This will be further explored in the evaluation.

3.1.5 What are the service gaps from the perspective of residents, families, carers and staff?

Evidence on service gaps and unmet needs from the perspective of residents, families, carers and staff was relatively consistent. Broadly, evidence indicated that access and availability of palliative care delivered by appropriately skilled staff with the RACF is a challenge for many, with evidence noting that there is highly variable availability of palliative care in RACFs.⁵⁹ Identified services gaps related to:

- the capacity and skill base of the workforce;
- the availability of education and training;
- the availability of information about available services or what should be available to support residents;⁶⁰
- the confidence of staff in identifying palliative care needs and communicating about palliative care; and
- the highly variable access to specialist palliative care support from health services.

The evidence did not tend to separate out the service gaps from the perspectives of residents, families, carers and staff. Instead, it often noted that the service gaps in the provision of palliative care in RACFs as a whole. Many of the same service gaps are observed through the different lenses of multiple stakeholders – for example, service gaps in the identification of palliative care needs are viewed by staff as a lack of appropriate education but is seen by residents, families and carers as a lack of timely care.

⁵⁴ Royal Commission into Aged Care Quality and Safety, "Interim report: Neglect, Volume 2", 2019.

⁵⁵ Palliative Care Australia, "Palliative Care 2030." 2019.

⁵⁶ World Health Organization, "Palliative Care", 2020.

⁵⁷ Palliative Care Australia, "Background report to the palliative care service development guidelines", 2018.

⁵⁸ Ibid.

⁵⁹ Productivity Commission, "Introducing competition and informed user choice into human services: Reforms to human services. Chapter 3: End-of-life care in Australia." 2017.

⁶⁰ Nous Group, "Stocktake and analysis of activities at the interface between the aged care, health and disability systems." 2020.

Access and availability to high quality palliative care within the RACF is a challenge for many

Evidence indicated that residents require greater access to services delivered by clinically qualified staff. Palliative Care Australia and the PCOC stated that:

“The greatest current barrier to patients receiving their preferred care is the availability and quality of palliative care services, including in the primary health sector”.⁶¹

It was also stated that in RACFs, staff ratios [of unregulated staff to qualified healthcare staff] can be weighted towards lower paid unregulated staff, with inadequate levels of qualified healthcare staff especially outside standard business hours.”⁶²

Evidence indicated that this is particularly relevant for groups of people with particular needs, for example those living in rural and remote areas, Aboriginal and Torres Strait Islander people, people from culturally and linguistically diverse backgrounds, LGBTQI people and people with disabilities.⁶³ For example, the Royal Commission heard that it is important for providers to understand local practices or ask for advice from local communities on appropriate practices.⁶⁴

Evidence indicated that identifying and communicating about palliative care needs is a key service gap

Evidence identified the early identification of palliative care needs as a critical prerequisite for effective palliative care, and as a service gap.⁶⁵ Another service gap identified was the lack of clear communication about palliative and end-of-life care from the perspectives of residents, families/carers and staff. In one study, RACF staff were noted to appear confident in providing end of life care but were not confident in discussing goals of care or effecting a transition to a palliative approach.⁶⁶

Evidence also indicated that residents rely on clinicians to initiate end of life care conversations, but many are inadequately trained to hold these conversations.⁶⁷

From a system perspective, evidence consistently indicates that workforce capacity and capability are significant contributors to service gaps

Workforce capacity and capability were consistently identified in the literature as key contributors to service gaps. Evidence indicated that limited medical or nursing cover and heavy workloads for RACF staff result in increased emergency department presentations and impacts on end of life care.⁶⁸

Workforce capacity challenges span from personal care workers through to clinical staff, with evidence indicating that a shortage of available GPs and specialist after-hours care impacts on the quality of care.^{69,70}

A study of barriers to the provision of palliative care in long-term care facilities in Canada identified a number of barriers relating to education and support, including:

⁶¹ Productivity Commission, "Introducing competition and informed user choice into human services: Reforms to human services. Chapter 3: End-of-life care in Australia." 2017.

⁶² Palliative Care Australia, "Submission to the Productivity Commission Future of Australia's aged care sector workforce", 2016.

⁶³ Productivity Commission, "Introducing competition and informed user choice into human services: Reforms to human services. Chapter 3: End-of-life care in Australia." 2017.

⁶⁴ Royal Commission into Aged Care Quality and Safety, "Interim report: Volume 1", 2019.

⁶⁵ Highet, G, Crawford, D, Murray, S, Boyd, K, "Development and evaluation of the Supportive and Palliative Care Indicators Tool (SPICT): a mixed-methods study," British Medical Journal. 2018.

⁶⁶ Lane, H, Philip, J, "Managing expectations: Providing palliative care in aged care facilities," Australasian Journal on Ageing. 2015.

⁶⁷ Productivity Commission, "Introducing competition and informed user choice into human services: Reforms to human services. Chapter 3: End-of-life care in Australia." 2017.

⁶⁸ Lane, H, Philip, J, "Managing expectations: Providing palliative care in aged care facilities," Australasian Journal on Ageing. 2015.

⁶⁹ Lane, H, Philip, J, "Managing expectations: Providing palliative care in aged care facilities," Australasian Journal on Ageing. 2015.

⁷⁰ Palliative Care Australia, "Response to the Royal Commission into Aged Care Quality and Safety consultation paper - Aged care program redesign: services for the future." 2019.

- lack of pain assessment and monitoring protocols;
- lack of practice guidelines related to assessing and managing palliative patients;
- lack of knowledge and specialized skills in palliative care; and
- lack of access to literature on palliative care.⁷¹

These workforce challenges are similar to evidence on challenges domestically. In addition, the Royal Commission noted that more could be done to train and upskill Aboriginal and Torres Strait Islander staff in palliative care in aged care.⁷²

Evidence indicated that quality education and training in Australia is also made challenging as there are no national minimum standardised training requirements for aged care.⁷³

THE ROYAL COMMISSION INTO AGED CARE QUALITY AND SAFETY

Insights from the Royal Commission into Aged Care Quality and Safety have identified that 'the availability and standard of palliative care provided in RACFs is highly variable'. It found that inadequate palliative care provision is a major feature of safety and quality issues.⁷⁴

⁷¹ Brazil, K, Bedard, M, Krueger, P, et al., "Barriers to providing palliative care in long-term care facilities. "Canadian Family Physician, 52. 2006.

⁷² Royal Commission into Aged Care Quality and Safety, "Interim report: Volume 3", 2019.

⁷³ Parliament of Australia, "Future of Australia's aged care sector workforce", 2017.

⁷⁴ Royal Commission into Aged Care Quality and Safety, "Interim report: Volume 1", 2019.



3.2 What models of care exist that have proven successful?

This sub-section summarises evidence from the literature on the:

- evidence on domestic and international examples of models of care in RACFs (see section 3.2.2)
- critical enablers in successful models of care in RACFs (see section 3.2.3).



KEY FINDINGS

- Evidence suggested that changing population needs and health system policy and drivers have necessitated dynamic, integrative models of care for palliative care delivery in RACFs.⁷⁵
- There is significant variation in practice and availability of palliative care in RACFs in Australia and internationally. Relatively limited evidence has led to an absence of clear, evidenced-based models of care for providing efficient and quality palliative care services in RACFs.⁷⁶
- Palliative care models of care in RACFs vary, but integrating specialist palliative care into RACFs is a common theme. Evidence identified six frequently cited components of palliative care models of care in RACFs: case management, capability building, specialist in-reach services, shared care, specialist out-reach services, and integrated care.

Australia

- The literature review identified 12 separate models of delivering palliative care in RACFs in Australia.
- Of these, there was a high concentration of models of care identified in RACFs in New South Wales and Victoria. 25 per cent of the models of care identified were specialist in-reach services.
- Australian palliative care models of care in RACFs vary in terms of what they deliver, but the INSPIRED model is an effective, evidence-based approach.

International

- The literature review identified seven international models of delivering palliative care in RACFs or equivalents. These models were concentrated in countries that provide universal health coverage, New Zealand, Canada, and the United Kingdom.
- There was no predominant model of care identified. Instead, the components of these models were spread across specialist in-reach services, capability building, and case management.

Success factors

- The success factors for palliative care models of care in RACFs are multi-dimensional but share a common theme of integrating specialist palliative knowledge and/or care into RACFs.

⁷⁵ Luckett, T, Phillips, J, Agar, M et al., "Elements of effective palliative care models: a rapid review," BioMed Central, 14(36). 2014.

⁷⁶ Chapman, M, Johnston, N, Lovell, C, et al., "Avoiding costly hospitalisation at end of life: findings from a specialist palliative care pilot in residential care for older adults," British Medical Journal. 2015.

Evidence showed that palliative care models of care in RACFs vary but integrating specialist palliative care is a common theme

The NSW Agency for Clinical Innovation defines a Model of Care (MOC) as the way in which health services are delivered.⁷⁷ A MOC outlines best practice principles of care and service delivery for a patient cohort to ensure “people get the right care, at the right time, by the right team and in the right place”. A model of care can provide a framework or system for the organisation of care, distinct from practices that contribute to a model of care.⁷⁸

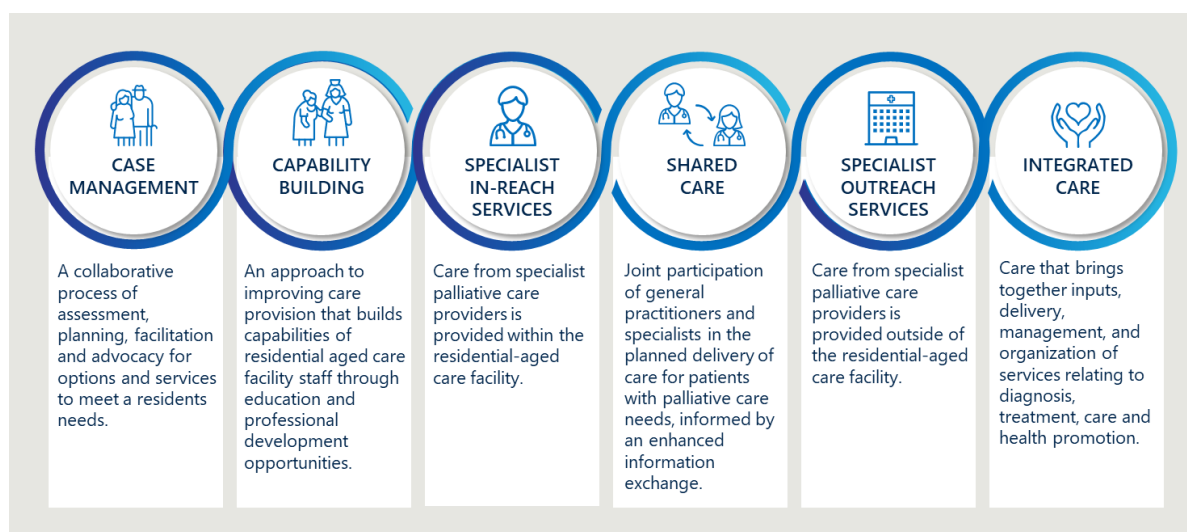
The evidence suggested that changing population needs and health system policy and drivers have necessitated dynamic, integrative models of care.⁷⁹ Unfortunately, there is significant variation in practice and availability of palliative care in RACFs in Australia and internationally. Limited evidence internationally and domestically has led to an absence of clear, evidenced-based models of care for providing efficient and quality palliative care services in RACFs.⁸⁰

A review by Lockett and colleagues suggests that models of care integrating specialist palliative care into RACFs are effective ways to address the needs of residents towards the end-of-life.⁸¹ For palliative care to be effectively integrated into residential aged care facilities, it must be needs-led, with particular attention paid to care coordination and transitions across care settings. In addition, RACFs and staff must be able to detect and adapt to the changing needs of residents.

Evidence identified six frequently cited components of palliative care models of care in RACFs.

Successful models of palliative care are often multi-component models that seek specialist input, care, and/or training from specialist palliative care providers (e.g. palliative care nurses, geriatricians).⁸² Figure 5 illustrates frequently cited components of palliative care models of care in RACFs, which are:

Figure 5 | Forms of palliative care models of care in RACFs⁸³



⁷⁷ NSW Agency for Clinical Innovation, “Process Flow Chart for developing a Model of Care (MoC).” 2013.

⁷⁸ Lockett, T, Phillips, J, Agar, M et al., “Elements of effective palliative care models: a rapid review,” BioMed Central, 14(36). 2014.

⁷⁹ Ibid

⁸⁰ Chapman, M, Johnston, N, Lovell, C, et al., “Avoiding costly hospitalisation at end of life: findings from a specialist palliative care pilot in residential care for older adults,” British Medical Journal. 2015.

⁸¹ Lockett, T, Phillips, J, Agar, M et al., “Elements of effective palliative care models: a rapid review,” BioMed Central, 14(36). 2014.

⁸² Ibid.

⁸³ Ibid

3.2.2 What examples exist of good practice palliative care in RACFs in Australia or internationally?

Australian palliative care models of care in RACFs are variable but the INSPIRED model is an effective, evidence-based approach

The literature review identified 14 models of delivering palliative care in RACFs across Australia (see Appendix A for full details).

Of these, there was a high concentration of models of care in New South Wales (5 or 36 per cent) and Victoria (4 or 29 per cent). 21 per cent of the models of care identified were specialist in-reach services.

A quarter of the models of care included palliative care as a component of a broader range of services. 13 of 14 models were concerned with delivering clinical care in particular, except for the Indigenous Palliative Care Service Delivery model, which was concerned with delivering respectful and culturally appropriate care.

See Figure 6 and Table 3 for a summary of key Australian models identified.

THE COST EFFECTIVENESS OF IMPROVED PALLIATIVE CARE

Examining the cost effectiveness of palliative care delivery in RACFs is complicated by several factors: difficulty quantifying savings, data limitations, and issues with attribution.

Given the complicated context in which palliative care is delivered, in RACFs and in acute care, certain savings are difficult to quantify. For example, while costs from bed days are well quantified in literature, there are second order savings, such as bereavement support, that are difficult to measure and may result in inaccurate analyses.⁸⁴

In addition, data limitations exist both within RACFs and at the interface of aged care and acute care. Aged Care Funding Instrument (ACFI) appraisals to receive palliative care are limited in RACFs and point to underreporting of palliative care.⁸⁵ Further, while PCOC takes a comprehensive and detailed approach to measuring quality of palliative care delivery, it too has limited rollout in RACFs.⁸⁶

Lastly, attributing costs and savings incurred to palliative care interventions is difficult to ascertain due to the nature of care delivery. Many factors contribute to palliative care, leading to a range of potential areas to intervene.⁸⁷ Interventions have the potential to overlap with each other, complicating the ability to attribute certain outcomes to certain interventions.

One recent comprehensive economic analysis undertook a pragmatic evaluation on the return on investment on key palliative care interventions. The analysis found that a \$1 investment in improving uptake of advance care planning can return an average between \$0.47 and \$2.99 from reduced hospitalisation costs. Based on the INSPIRED Model, implementing a Nurse Practitioner in RACFs is estimated to return \$1.68 to \$4.14 for every \$1 spent. Costs saved result from reduced bed days, ICU admissions, and ED transport costs.⁸⁸

⁸⁴ Carter. H et al., "Incidence, duration, and cost of futile treatment in end-of-life hospital admissions to three Australian public-sector tertiary hospitals: a retrospective multicentre cohort study. *BMJ Open*, 7(10). 2017.

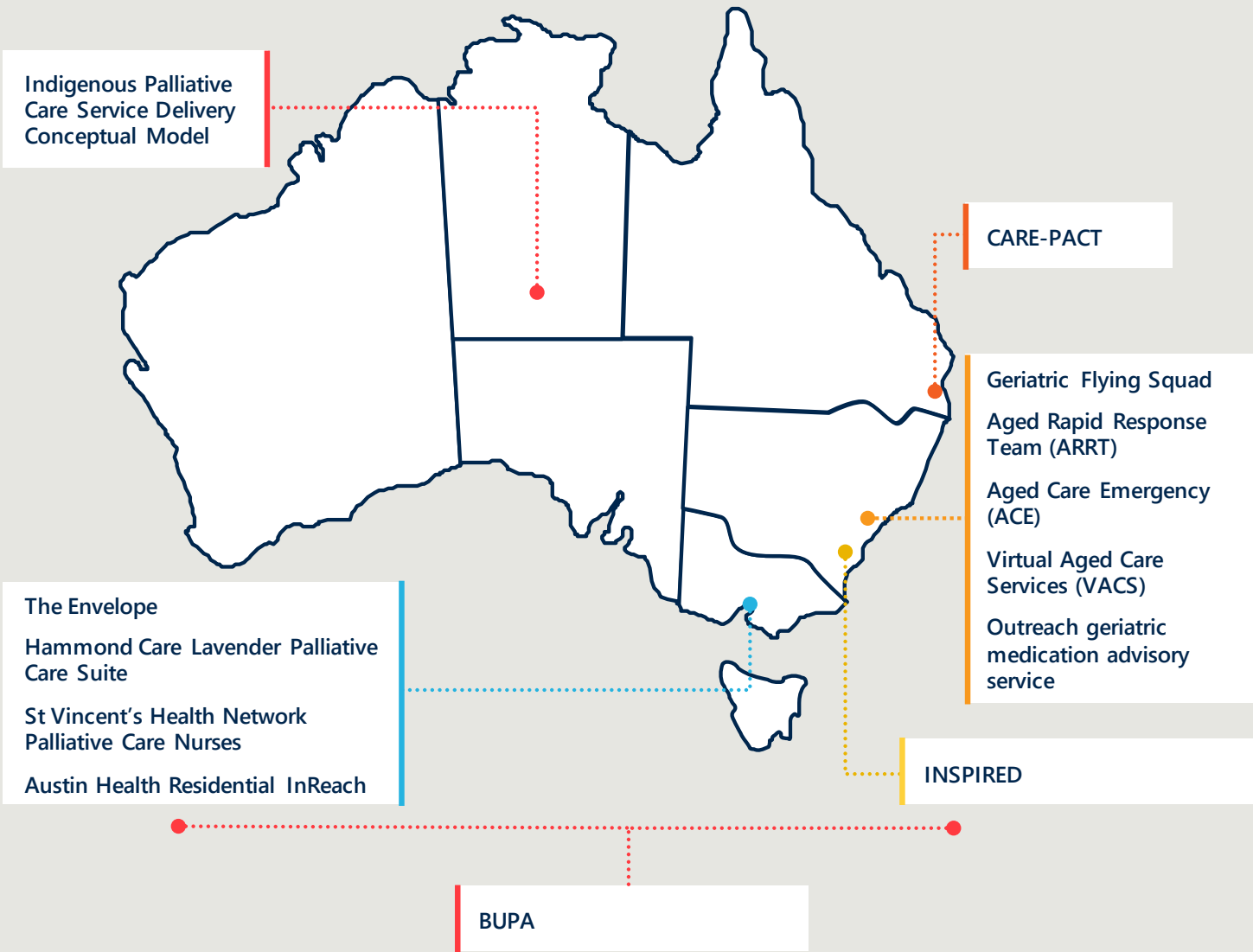
⁸⁵ Australian Institute of Health and Welfare, "Palliative care for people living in residential aged care." 2018.

⁸⁶ University of Wollongong Australia, "Palliative Care Outcomes Collaboration", 2020.

⁸⁷ KPMG, Palliative Care Australia, "The economics of increased investment in palliative care in Australia." 2020.

⁸⁸ Ibid

Figure 6 provides a high-level description of the domestic models of care identified in the literature review.



NT

Indigenous Palliative Care Service Delivery - Model that outlines Indigenous palliative care service delivery.

QLD

CARE-PACT - Consultative service for GPs regarding their resident's acute issues.

NSW

Geriatric Flying Squad- Palliative care rapid response team to RACFs.

ARRT - Rapid medical outreach service.

(ACE) - Capability building to reduce unnecessary hospital presentations.

(VACS) - Virtual care in-reach.

Outreach geriatric medication advisory service - Multi-disciplinary case conferencing for medication prescription.

ACT

INSPIRED - Palliative care specialists conduct 'needs rounds' for residents.

VIC

The Envelope - Tool to transfer clinical information during ED transfers.

Hammond Care Lavender Palliative Care Suite - Palliative care unit operating with access to in-house acute care and pharmacy.

St Vincent's Health Network Palliative Care Nurses - Network of palliative care providers.

Austin Health Residential InReach - A geriatrician-led telephone advice service.

NATIONAL

BUPA - GPs delivering preventative healthcare in RACFs.

Of the 14 domestic models of care identified, seven models were supported by evidence that demonstrated their efficacy through their study design and/or via review or evaluation. The variety of approaches to palliative care models of care in RACFs suggest that there are multiple ways to address current service gaps, but that integrating specialist care into RACFs is a consistent theme.⁸⁹ The majority of models are not solely focused on palliative care but programs or initiatives that will contribute to improved palliative care alongside broader care improvement. Models were predominantly rolled out in one or two facilities but were not done at a regional or national scale. The INSPIRED Model was the only model that was rolled out at scale, done so in the region of ACT (over 1000 participants and in 12 sites across the region). The key features of each model that is supported by evidence, including why the model is considered good practice, are described in Table 3. See Appendix A for the detailed list of all models.

Table 3 | Australian examples of palliative care activities or initiatives in RACFs

Model of care	Key component	Description	Rationale for why the model is good practice
ACT			
INSPIRED Model ⁹⁰	Case management	INSPIRED model consists of placing a palliative care nurse practitioner in RACFs. Nurse practitioners conduct 'Needs rounds' to assess residents' palliative care needs and deterioration. Palliative care nurse practitioners provide direct support through clinical assessments and indirect support through needs rounds, which serve to uplift staff capability uplift through care plan discussions.	<ul style="list-style-type: none"> • Normalised death and dying in RACFs • Provided timely access to palliative care specialist • Reduced unnecessary hospitalisations • Improved decision making and planned care for residents, meaning staff and relatives were better informed on resident trajectory • Developed capabilities of RACF staff indirectly through needs rounds
NSW			
Outreach geriatric medication advisory service ⁹¹	Case management	The outreach geriatric medication advisory service consists of multidisciplinary case conferences involving GP, geriatrician and pharmacists and residential care staff held for each resident. The aim of the service is to improve medication prescribing for residents, so they are receiving the appropriate care.	<ul style="list-style-type: none"> • Provided holistic, person-centred care through the multidisciplinary team • Improved appropriate medication prescribing to residents

⁸⁹ Luckett, T, Phillips, J, Agar, M et al., "Elements of effective palliative care models: a rapid review," BioMed Central, 14(36). 2014.

⁹⁰ Chapman, M, Johnston, N, Lovell, C, et al., "Avoiding costly hospitalisation at end of life: findings from a specialist palliative care pilot in residential care for older adults," British Medical Journal. 2015.; Johnston, N, Lovell, C, Liu-, W-M, et al., "Normalising and planning for death in residential care: findings from a qualitative focus group study of a specialist palliative care intervention," British Medical Journal. 2016.

⁹¹ Crotty, M, Halbert, J, Rowett, D, et al., "An outreach geriatric medication advisory service in residential aged care: a randomised controlled trial of case conferencing," British Geriatrics Society, 33(6). 2004.

Model of care	Key component	Description	Rationale for why the model is good practice
Aged Care emergency (ACE) program ⁹²	Capability building	ACE supports staff in RACFs to facilitate residents' acute care needs being met within the facility and avoiding an ED presentation. Aim to reduce the need for residents of RACFs to present to an ED for acute care, or where ED presentation is required, to proactively manage the visit. Enhance integration of a range of services for older people.	<ul style="list-style-type: none"> Increased respect for knowledge and skills of RACF staff Provided RACF staff access to a network of specialist palliative care providers Developed collaborative relationships and trust to enable appropriate decision making Established clear patient goals of care prior to transferring to an ED Provided proactive case management within the ED
Virtual Aged Care Services (VACS) ⁹³	Specialist in-reach service	VACS aims to reduce unnecessary hospital presentations and admissions for older people, facilitate early discharge from hospital (reducing length of stay) and streamline older patients' entry points to hospital. VACS was piloted in two RACFs to trial telehealth strategies for delivery.	<ul style="list-style-type: none"> Improved care coordination and collaborative care plan development Provided access to a network of specialist care providers Developed capabilities of RACF staff through education Increased resource utilisation through telehealth strategies
VIC			
The Envelope ⁹⁴	Shared care	A simple tool to transfer clinical information during ED transfers. The Envelope maintained privacy of the resident, was succinct and simple, and kept costs to a minimum.	<ul style="list-style-type: none"> Improved clinical handover, as perceived by staff Raised staff awareness of the importance of clinical handover
NATIONAL			
BUPA Model of Care ⁹⁵	Integrated care	A program where GPs deliver preventative healthcare and immediate medical treatment in residential aged care facilities.	<ul style="list-style-type: none"> Provided individual services in RACFs, including delivery of palliative care Trained and educated GPs as required

⁹² NSW Agency for Clinical Innovation, "ACI Clinical Innovation Program – Specialised geriatric outreach for residential aged care." 2014.


⁹³ Ibid

⁹⁴ Belfrage, M, Chiminello, C, Cooper, D, et al., "Pushing the envelope: clinical handover from the aged-care home to the emergency department." 2009.

⁹⁵ Reed, R, "Models of general practitioner services in residential aged care facilities." Australian Family Physician. 2015.

A case study of the INSPIRED trial demonstrates an example of a model of care with demonstrated success through evaluation.

Figure 7 | Case study of the INSPIRED model



CASE STUDY
INSPIRED Model

The literature review identified the INSPIRED Model as a high-quality example of good practice palliative care in RACFs. Large scale, multi-facility interventions and repeated evaluations in both metropolitan and rural settings demonstrate that ‘needs rounds’ conducted by palliative care specialists (palliative care nurse practitioners, palliative medicine specialist) are an effective method to deliver quality palliative care to residents’, reduce residents’ hospital admissions, and improve staff confidence in managing end-of-life care.

The INSPIRED Model was first trialled in 2015 in four RACFs in the Australian Capital Territory. In this model, palliative care nurse practitioners worked with RACFs to conduct needs rounds. Needs rounds assessed residents’ palliative care needs and stratified specialist provision of care based on deterioration. Needs rounds served to uplift staff capability and confidence in delivering palliative care through care plan discussions. The INSPIRED model resulted in substantially reduced overall hospital admissions and reduced length of stay in hospital.

In 2019, the INSPIRED Model was trialled in two rural RACFs in New South Wales. In rural settings, palliative care is typically provided by RACF staff

and GPs. This intervention consisted of a palliative medicine specialist who conducted needs rounds to identify dying residents. Staff reported a strengthened awareness of the end of life, strengthened decision making, and improved confidence in managing pain at the end of life.

The INSPIRED model used a variety of data including specially collected data like the Quality of Dying and Death (QODD) Questionnaire during its randomised control trial to measure outcomes. The QODD Questionnaire was completed by health care professionals and provides information on symptom control, preparation, connectedness and transcendence. Family perspectives were also collected during the INSPIRED trial using the Brief Assessment Scale for Caregivers of the Medically Ill. These measures provide both direct and indirect measures of the extent to which residents needs are being met. Chapman, M, Johnston, N, Lovell, C, et al., "Avoiding costly hospitalisation at end of life: findings from a specialist palliative care pilot in residential care for older adults," British Medical Journal. 2015.

Rainsford, S, Johnston, N, Liu, W-M, 'Palliative care Needs Rounds in rural residential aged care: A mixed-methods study exploring experiences and perceptions of staff and general practitioners,' Progress in Palliative Care. 2019.

Evidence of international models of care are concentrated in countries with universal health systems

The literature review identified seven international models of delivering palliative care in RACFs or equivalents (see Appendix A for details). These models were concentrated in countries that provide universal health coverage, New Zealand, Canada, and the United Kingdom (see Figure 8). There was no predominant model of care identified. Instead, the components of these models were spread across specialist in-reach services, capability building, and case management. Table 4 provides detail on models with demonstrated efficacy through their study design and/or via review or evaluation. Six of seven models were clinically focused, palliative care or end-of-life models of care,⁹⁶ except for the United States social worker model focused on improving advance care planning and end-of-life discussions.

⁹⁶ International models of care identified were observed to use varying definitions of palliative and end-of-life care.

Figure 6 provides a high-level description of the international models of care identified in the literature review.



Of the seven international models of care identified, five models were supported by evidence that demonstrated their efficacy through their study design and/or via review or evaluation. Similar to what the evidence revealed for domestic models, integrating specialist care into RACFs is a theme across the variety of approaches to delivering care.⁹⁷ The Gold Standards Framework, ARCHUS, and RACIP were models that was rolled out at scale regionally but not nationally (over 1000 participants and in multiple sites across their respective region). The key features of each of the five models supported by evidence, including why the model is considered good practice, are described in Table 4. See Appendix A for details of all models.

Table 4 | International examples of palliative care activities in RACFs

Model of care	Key elements	Description	Rationale for why the model is good practice
NEW ZEALAND			
Residential Aged Care Integration Program (RACIP) ⁹⁸	Specialist outreach service	RACIP is a quality improvement intervention to support residential aged care staff and includes on-site support, education, clinical coaching, and care coordination provided by gerontology nurse specialists (GNSs) employed by a large district health board.	<ul style="list-style-type: none"> • Developed capabilities of RACF staff through education and clinical coaching • Developed a collaborative relationship between GNS and facility staff • Established quality initiatives and indicators • Improved care coordination for high-risk residents • Provided access to a network of specialist care providers
Aged Residential Care Health Utilisation Study (ARCHUS) ⁹⁹	Case management	A complex multi-disciplinary team intervention in long-term care facilities. A gerontology nurse specialist (GNS) conducted baseline facility needs assessment and quality indicator benchmarking. Multi-disciplinary team (MDT) meetings were held involving a geriatrician, facility GP, pharmacist, GNS and senior nursing staff.	<ul style="list-style-type: none"> • Improved integration of RACF with geriatricians and with emergency/acute services • Developed capabilities of RACF staff through education • Improved RACF palliative care practices • Provided alternative residential aged care models to target care for high risk groups, e.g.: those with end-stage dementia
UNITED KINGDOM			

⁹⁷ Luckett, T, Phillips, J, Agar, M et al., "Elements of effective palliative care models: a rapid review," BioMed Central, 14(36). 2014.

⁹⁸ Boyd, M, Armstrong, D, Parker, J, et al., "Do Gerontology Nurse Specialists Make a Difference in Hospitalization of Long-Term Care Residents? Results of a Randomized Comparison Trial." American Geriatrics Society. 2014.

⁹⁹ Foster, S, Boyd, M, Broad, J, et al., "Aged Residential Care Health Utilisation Study (ARCHUS): a randomised controlled trial to reduce acute hospitalisations from residential aged care," BMC Geriatrics, 12. 2012.; Connolly, M, Broad, J, Boyd, M, et al., "The 'Big Five'. Hypothesis generation: a multidisciplinary intervention package reduces disease-specific hospitalisations from long-term care: a post hoc analysis of the ARCHUS cluster-randomised controlled trial," Age and Ageing, 45: 415-420. 2016.

Model of care	Key elements	Description	Rationale for why the model is good practice
Gold Standards Framework (GSF) ¹⁰⁰	Case management	A model of end-of-life care, in nursing homes in England. The GSF helps practitioners to identify individuals in need of supportive end-of-life care, to assess their needs, symptoms, preferences and other concerns important to them.	<ul style="list-style-type: none"> Increased discussion with residents and families about care towards the end-of-life Improved communication with GP out-of-hours services Introduced procedures for anticipatory medication and greater staff confidence in caring for people at the end-of-life
The Supportive and Palliative Care Indicators Tool (SPICT) ¹⁰¹		SPICT is designed to provide practical, evidence-informed guidance to help clinicians working in primary and secondary care recognise when their patients might be at risk of dying and likely to benefit from supportive and palliative care in parallel with appropriate ongoing management of their advanced conditions.	<ul style="list-style-type: none"> Provided holistic, person-centred care through the multidisciplinary team Identified patients who would benefit from a review of care goals and anticipatory care planning Established quality initiatives and indicators to initiate end-of-life discussions and care planning Promoted effective communication and coordination between primary and secondary care teams
UNITED STATES			
Social workers to enhance advance care planning ¹⁰²	Specialist in-reach services	Nursing home social workers were given a baseline education in advance care planning that incorporated small-group workshops and role play/practice sessions for intervention social workers. Social workers then continued care planning with residents of nursing homes, discussing goals of care at team meetings, and “flagged” advance directives on nursing home charts.	<ul style="list-style-type: none"> Improved documentation of and adherence to residents’ preferred resuscitation orders and other medical interventions Developed capabilities of RACF staff indirectly through team meetings

¹⁰⁰ Badger, F, Clifford, C, Hewison, A, & Thomas, K, "An evaluation of the implementation of a programme to improve end-of-life care in nursing homes," Palliative Medicine, 23. 2009.

¹⁰¹ Highet, G, Crawford, D, Murray, S, Boyd, K, "Development and evaluation of the Supportive and Palliative Care Indicators Tool (SPICT): a mixed-methods study," British Medical Journal. 2018.

¹⁰² Morrison, R, Chichin, E, Carter, J, *et al.*, 'The effect of a social work intervention to enhance advance care planning documentation in the nursing home,' American Geriatrics Society, 52: 290-294. 2005.

3.2.3 What is required for success?

The success factors for delivery of palliative care models of care in RACFs are multi-dimensional but share the theme of ensuring access to palliative knowledge and/or care.

The evidence showed that approaches to delivering palliative care in RACFs vary both domestically and internationally. Of the models identified in the literature, common success factors include:

- **Evidence-based activities or outcomes.** While approaches to palliative care models of care in RACFs are variable, a robust evidence base is growing. Palliative care activities conducted in RACFs should be guided by up-to-date evidence. Outcomes that the RACFs endeavour to achieve should be guided by quality indicators and informed by data collected at the facility.¹⁰³ This will enable high-quality provision of palliative care in RACFs and/or signal where improvements need to be made.
- **Address residents' physical, spiritual, and psychological needs.** Residents' benefit from care that is respectful, culturally appropriate, and person-centred.¹⁰⁴ The RACF will need to work with the resident, their family and carer to document their needs and deliver care that meets those needs as best as possible.
- **Engage in advance care planning.** There may come a time where a resident cannot make or communicate their decisions.¹⁰⁵ Documenting the resident's values, beliefs and preferences through an advance care plan will guide decision-making in the future. Making difficult decisions in advance has the potential to reduce the emotional burden on the family.
- **Flexible to changing needs of residents.** Residents' needs will change as the population ages.¹⁰⁶ This will require RACFs to look out for and adapt to trends in medical needs (e.g. comorbidities) and other needs (e.g. LGBTIQ+).
- **Engage closely with RACFs, staff, residents, families and carers.** If staff know their residents, and residents, carers and family members are listened to and engaged in care, and good communication exists within and outside the facility, the chances of good palliative care is dramatically increased.¹⁰⁷ RACFs should enable effective communication pathways among staff, residents, families and carers, and aim to deliver person-centred care. To support this, RACFs must ensure staff have the requisite skills and are engaged and empowered to support the delivery of quality palliative care.
- **Guided by principles of culturally safe palliative care delivery.** Some residents may not have their personal needs and preferences met as a result of spiritual, cultural or linguistic differences.¹⁰⁸ Identifying residents' needs and preferences at admission, or early on in their stay at the RACF, will enable the provision of care suited to their individual needs.

¹⁰³ Boyd, M, Armstrong, D, Parker, J, et al., "Do Gerontology Nurse Specialists Make a Difference in Hospitalization of Long-Term Care Residents? Results of a Randomized Comparison Trial." American Geriatrics Society. 2014.

¹⁰⁴ Department of Health, "National Palliative Care Strategy." 2018.

¹⁰⁵ Amadoru, S, Rayner, J, Joseph, R, et al., "Factors influencing decision-making processes for unwell residents in residential aged care: Hospital transfer or Residential InReach referral?" Australasian Journal on Ageing, 37 (2). 2016.

¹⁰⁶ Boyd, M, Armstrong, D, Parker, J, et al., "Do Gerontology Nurse Specialists Make a Difference in Hospitalization of Long-Term Care Residents? Results of a Randomized Comparison Trial." American Geriatrics Society. 2014.

¹⁰⁷ Department of Health, "National Palliative Care Strategy." 2018.

¹⁰⁸ Hibbert, P, Wiles, L, Cameron, I, et al., "CareTrack Aged: The appropriateness of care delivered to Australians living in residential aged care facilities: a study protocol," British Medical Journal. 2019.

- **Educate all staff (both clinical and non-clinical) about palliative care.** RACF staff need to be trained on identifying residents' palliative care needs and delivering appropriate care within their abilities.¹⁰⁹ Staff should be upskilled within their scope of practice, as the specialist palliative care provider is there to provide support and deliver care when residents' palliative needs become too complex. Staff can be trained either directly (e.g. palliative care training) or indirectly (e.g. staff attending palliative care needs rounds conducted by specialists). With high turnover in RACFs, educating staff needs to be continual.
- **Focus on facilitating smooth transitions across care settings.** Transitions to and from RACFs can be difficult physically and emotionally for older Australians and their families.¹¹⁰ RACFs should aim to minimise transitions where possible. Where transitions are required, RACFs should aim to communicate advance care directives when residents are transferred out and seek out relevant information when residents are transferred in. This will ensure residents' needs and their families wishes are being met.
- **Provide timely access to health professionals.** Residents' medical and psychological needs should be promptly met.¹¹¹ RACFs should aim to establish working relationships with relevant medical and other health professionals and/or facilities (e.g. GP, emergency department) so that their residents' medical and psychological needs are prioritised.
- **Provide access to a network of palliative care specialists.** This can be achieved either informally, through a specialist palliative care provider doing in-reach or outreach, or formally, through shared care or an integrated care network.¹¹² Access to specialist palliative care knowledge will ensure residents' palliative care needs are being met in a timely and appropriate manner.
- **Work collaboratively with stakeholders.** Effective working arrangements between service providers, state/territory and Commonwealth governments is a key enabler for delivery of care in health and aged care.¹¹³ Sharing knowledge, performance indicators and data and successful models of care as well as prioritising the needs of residents above all can drive collaborative working arrangements between RACFs and funding and regulatory stakeholders.

¹⁰⁹ Lockett, T, Phillips, J, Agar, M et al., "Elements of effective palliative care models: a rapid review," BioMed Central, 14(36). 2014.; Chapman, M, Johnston, N, Lovell, C, et al., "Avoiding costly hospitalisation at end of life: findings from a specialist palliative care pilot in residential care for older adults," British Medical Journal. 2015.

¹¹⁰ Chapman, M, Johnston, N, Lovell, C, et al., "Avoiding costly hospitalisation at end of life: findings from a specialist palliative care pilot in residential care for older adults," British Medical Journal. 2015.

¹¹¹ Johnston, N, Lovell, C, Liu-, W-M, et al., "Normalising and planning for death in residential care: findings from a qualitative focus group study of a specialist palliative care intervention," British Medical Journal. 2016.

¹¹² Nous Group, "Stocktake and analysis of activities at the interface between the aged care, health and disability systems." 2020.

¹¹³ Productivity Commission, '5 year productivity review: Commonwealth-State relations.' 2017.



3.3 What evidence exists on best practice approaches to funding and delivery arrangements?

This sub-section summarises evidence from the literature on Commonwealth and state/territory joint funding and delivery arrangements.



KEY FINDINGS

- There are multiple arrangements that can be used to support joint funding and delivery of activities between Commonwealth and State/territory governments.
- The type of funding arrangement is a key consideration in joint Commonwealth and state/territory projects; this literature review focused on National Partnership Payments (NPPs) in health or other sectors given they are most relevant to the Measure arrangements.
- Of the four types of NPPs, the less onerous reporting requirements that characterise National Partnership Agreements (NPAs) and Project Agreements (PAs) have led to their increasing use in facilitating joint Commonwealth and state/territory projects. Project Agreements are a simpler form of NPAs, used largely for low value and/or low risk projects.
- The literature indicates that there is very limited evidence on joint funding and delivery arrangements specific to palliative care in RACFs, so this report focuses on what the evaluation can learn about joint funding and delivery in health and other sectors more broadly.
- Evidence showed that NPAs and PAs are commonly used for joint delivery of activities in the health sector. They allow states and territories to exercise their judgement as to where funding is allocated, yielding outcomes that address jurisdictional specific issues.
- Pooled funding across state and territory jurisdictions has the potential to minimise service gaps and progress equitable health coverage. Co-commissioning between states/territories and Primary Health Networks (PHNs) has the potential to further integrate health system services.
- However, pooled funding and giving regions greater control and responsibility is supported in theory but not in practice. While many countries are exploring forms of funds pooling, there is little evidence of efficacy at scale. An international review of integrated funding for health and social care explored 38 schemes from eight countries and was unable to isolate elements such as funds pooling from care delivery.
- Evidence on best practice approaches to joint funding and delivery is limited to large-scale agreements, but certain principles can apply to all agreements.
- Evidence suggests that funding models for palliative care should move toward activity-based, uncapped funding, and informed by performance metrics and reporting.

There are multiple arrangements that can be used to support joint funding and delivery of activities between Commonwealth and state/territory governments

Joint Commonwealth and states/territories arrangements span funding, delivery, and regulatory obligations in sectors such as health, education, and infrastructure. All funding arrangements, excluding Commonwealth own-purpose expenses, are governed by the Intergovernmental Agreement on Federal Financial Relations (IGA) (see Appendix B).¹¹⁴

The IGA aims to ensure fair and sustainable financial arrangements that recognise the primary role of the states and territories in delivering services in key sectors. The IGA has sought to foster collaborative working arrangements, with more clearly defined roles and responsibilities.¹¹⁵

The type of funding arrangement is a key consideration in joint Commonwealth and state/territory projects; this literature review focused on national partnership payments (NPPs) in health or other sectors as they are most relevant to Measure arrangements.

Two forms of funding arrangements governed by the IGA are Commonwealth and state/territory level funding agreements such as NPPs (which are about the circumstances in which the Commonwealth makes money available to the states/territories), and specific purpose payments (SPPs) (which direct payments to particular services, typically with tied conditions) (see Appendix B for detail).

The health sector is increasingly consolidating SPPs under NPPs or National Agreements.¹¹⁶ NPPs support the delivery of projects, facilitate reforms or reward states and territories that deliver on nationally significant reforms.¹¹⁷

The four types of NPPs are shown in Figure 9.

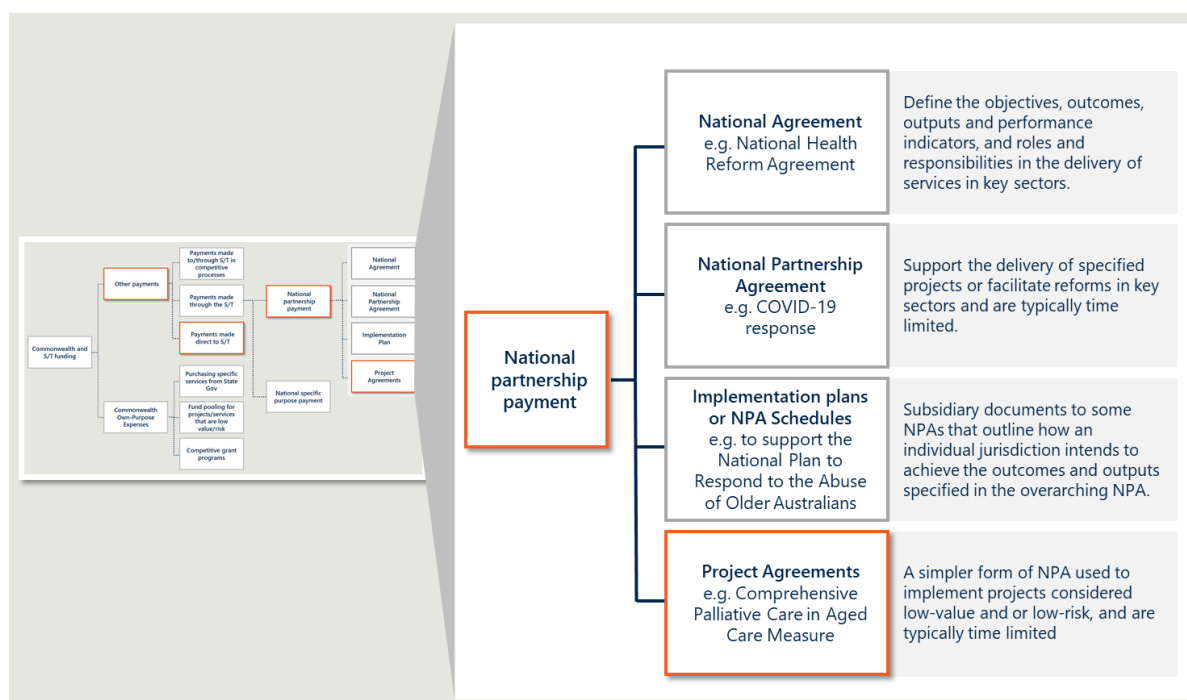
¹¹⁴ Northern Territory, 'Guidance document on Commonwealth funding agreements.'

¹¹⁵ Productivity Commission, '5 year productivity review: Commonwealth-State relations.' 2017.

¹¹⁶ Ibid.

¹¹⁷ Council on Federal Financial Relations, 'Agreements.' Website. Date unknown.

Figure 9 | Joint funding and delivery pathways



Evidence showed that National Partnership Agreements and Project Agreements are commonly used for joint Commonwealth and state/territory delivery of activities in the health sector

The literature indicates that there is very limited evidence on joint funding and delivery arrangements specific to palliative care in RACFs.¹¹⁸ Therefore, this report focuses on what the evaluation can learn about joint funding and delivery in health and other sectors more broadly.

The less onerous reporting requirements that characterise National Partnership Agreements (NPAs) and Project Agreements (PAs) have led to their increasing use in facilitating joint Commonwealth and state/territory projects.¹¹⁹ PAs are a simpler form of NPAs, used largely for low value and/or low risk projects. A review of structural barriers to Australian health policy reform reflected this finding in the health sector specifically.¹²⁰ This is further evidenced by the fact that NPAs and PAs in the health sector consist of 43 per cent (44 of 149) of all ongoing agreements (see Appendix C for details).

Evidence indicated that allowing states and territories to exercise their judgement as to where funding is allocated yields outcomes that address jurisdictional specific issues.¹²¹ Agreements under the IGA recognise the primary role states and territories play in delivering services in their jurisdictions. Unlike tied or conditional payments, NPAs and PAs typically do not require pre-set outcomes or requirements be reached before funding is released.¹²²

¹¹⁸ Duckett, Stephen, "Aligning policy objectives and payment design in palliative care." BMC Palliative Care (17). 2018.

¹¹⁹ Productivity Commission, '5 year productivity review: Commonwealth-State relations.' 2017.

¹²⁰ Australian Centre for Health Research and TPG International, 'Structural Barriers to Reform of the Australian Health and Public Hospital System,' 2010.

¹²¹ Productivity Commission, '5 year productivity review: Commonwealth-State relations.' 2017.

¹²² Ibid.

Other mechanisms include pooled funding and co-commissioning, for which there are variable levels of evidence

Pooled funding

Pooled funding between Commonwealth Primary Health Networks (PHNs) and state and territory Local Hospital Networks (LHNs) has the potential to minimise service gaps and progress equitable health coverage.¹²³ Pooling funding from different health-related agreements and establishing regional commissioning authorities could support major reforms to the health system. Evidence from the Productivity Commission's report on mental health suggests that pooled funding could serve to improve care continuity and create incentives for more efficient and effective use of taxpayer money.¹²⁴

However, whilst evidenced in theory, it lacks a robust evidence-base in practice. Many countries are exploring pooled funding yet there is little evidence of efficacy at scale.¹²⁵ An international review of integrated funding for health and social care explored 38 schemes from eight countries and was unable to isolate elements such as funds pooling from care delivery.¹²⁶ It is therefore yet to be established whether the implied additional level of bureaucracy may outweigh the benefits.

Co-commissioning

Co-commissioning by LHNs and PHNs has the potential to integrate health system services and reduce fragmentation or siloing of programs.¹²⁷ In response to the National Mental Health Commission, the Commonwealth committed to strengthening the roles of PHNs to provide a regional approach to delivering services, acknowledging the PHNs' community knowledge and improved commissioning abilities. As a result of increased regional commissioning, evidence from the PHN advisory panel on mental health suggests that states/territories need to balance regional autonomy and national consistency.¹²⁸ Where the evidence base is strong, PHNs are expected to adhere to established models of care.

The Productivity Commission identified two priorities in funding arrangements to support efficient and equitable service provision in their Mental Health Inquiry Report.¹²⁹ Firstly, they recommended strengthening cooperation between PHNs and LHNs so they are able to effectively meet consumer needs. Joint regional planning will clarify roles and responsibilities between PHNs and LHNs and enable governments to hold the LHN-PHN accountable for commissioning and service delivery. Minimum standards and annual reports are necessary to guide monitoring and accountability of PHN-LHN cooperation.

Secondly, the report noted that recommendations above will serve to increase cooperation between PHNs and LHNs and provide a foundation on which to transition to regional commissioning authorities (RCAs). The Productivity Commission recommended state/territory governments to transition to RCAs to administer mental health funding, as an alternative to PHN-LHN pooling. The Productivity Commission noted that RCAs should be separate from LHNs to prevent conflicts of interest. The governing state or territory government can hold the RCA accountable but provide enough independence so as to reduce influence over decision-making—noting the additional burden of monitoring, reporting, and compliance that this arrangement may bring.

¹²³ Deeble Institute for Health Policy Research, "Funds pooling in Australia: could alliance contracting hold the key?" 2018.

¹²⁴ Productivity Commission, "Mental Health – interim report." 2020.

¹²⁵ Deeble Institute for Health Policy Research, "Funds pooling in Australia: could alliance contracting hold the key?" 2018.

¹²⁶ Mason A, Goddard M, Weatherly H and Chalkley M, "Integrating funds for health and social care: an evidence review." *Journal of Health Services Research & Policy*, 20 (3): 177-188. 2015.

¹²⁷ National Mental Health Commission, "Contributing Lives, Thriving Communities: Review of Mental Health Programs and Services." 2014.; Primary Health Network Advisory Panel on Mental Health, "Report on the PHN Advisory Panel on Mental Health." 2019.

¹²⁸ Primary Health Network Advisory Panel on Mental Health, "Report on the PHN Advisory Panel on Mental Health." 2019.

¹²⁹ Productivity Commission, "Mental Health."

Where the evidence base is growing, PHNs have the opportunity to add to the evidence base through innovative approaches. Irrespective of commissioning methodology, PHNs must ensure transparent, accountable and robust commissioning processes.¹³⁰ Monitoring and evaluation of commissioned services, co-designed with residents, families, and carers, are supported in the evidence.¹³¹

Evidence on best practice approaches to joint funding and delivery is limited to large-scale agreements, but certain principles can apply to all agreements

There is limited evidence to suggest which approach is best for specific circumstances. Recent Productivity Commission reports on the National Disability Agreement (NDA) and the Skills and Workforce Development Agreements (NASWD) provide insights on what has worked well and what has not.¹³² While the evidence base is limited to reporting on fairly large-scale agreements and/or reforms, certain principles of funding and delivery can still apply.

These agreements are both National Agreements. Both agreements provide baseline roles and responsibility and data collection principles. Lessons from the NDA are particularly applicable, given that this agreement is occurring in a sector with significant reform and complex interface issues.

Available evidence demonstrated that there are some commonalities in good practice funding and delivery arrangements, which included:

- **Agreements should set out aspirational objectives for the project.** Evidence suggests that agreements should articulate aspirational objectives for the project, particularly if the agreement is made in the context of significant reforms to the sector. Outlining long-term objectives will guide project activities to address service and systemic gaps, in turn affecting policymaking.
- **Agreements should clarify roles and responsibilities.** For cooperation to be effective, there needs to be a recognition of 'who is responsible for what' to ensure the necessary structural and regulatory changes can occur.¹³³ Clear roles and responsibilities in progressing project objectives will enable the Commonwealth and states/territories to address that which is within their control.
- **Agreements should acknowledge and address interface issues.** If the agreement is operating in a sector with interface issues, such as mental health and acute care,¹³⁴ the agreement should seek to improve and integrate services to ensure a better response to meet the needs of people. This includes amending interface issues for residents and the workforce. A clearer division of responsibilities between the Commonwealth and states/territories will reduce interface problems.
- **Agreements should articulate the importance of data to inform performance and accountability.** An absence of adequate data weakens the basis for performance reporting and can adversely affect policy making. While agreements should aim to specify what data need to be captured, there is significant variability in the ability to capture high-quality data across sectors, organisations, and facilities.
- **Agreements should be viewed as living documents.** Ensuring that agreements are independently reviewed at appropriate intervals (e.g. 5 years), updating clarified roles and responsibilities and performance targets, will allow states and territories to reach their overarching policy goals.

¹³⁰ Ibid.

¹³¹ Nous Group, "Stocktake and analysis of activities at the interface between the aged care, health and disability systems." 2020.

¹³² Productivity Commission, 'National Agreement for Skills and Workforce Development Review.' 2020; Productivity Commission, 'National Disability Agreement Review.' 2019.

¹³³ Council of Australian Governments, "National Partnership Agreement supporting national mental health reform." 2011.

¹³⁴ Productivity Commission, "Mental Health – interim report." 2020.

- Agreements should align intent of the agreement with funding and delivery arrangements. If agreements are seeking large-scale reform in certain sectors with difficult to achieve outcomes, then time-limitations or other conditions have the potential to de-incentivise systemic service improvements.¹³⁵

Evidence suggests that funding models for palliative care should move toward activity-based, uncapped funding, and informed by performance metrics and reporting

As noted above, the literature specifically related to palliative care funding arrangements is relatively sparse.¹³⁶ The literature is even more limited on funding arrangements specific to palliative care in RACFs. The following desirable features of funding models for palliative care services are based on international models of palliative care funding. These features are more applicable to the funding of the state-based palliative care services themselves than to an extension of those services into RACFs through the Commonwealth/state joint funding arrangement, but nonetheless may inform the evaluation.

Duckett (2018) argues for new approaches to palliative care funding altogether, ensuring the appropriate design fosters the expansion of quality, appropriate palliative care. A critical aspect of funding system design is ensuring that funding of the different components of the palliative care system is consistent with palliative care policy.

Features of desirable palliative care funding models:

- **Reduce fee-for-service payments in favour of activity-based funding.** Evidence from the literature review suggested that funding models should reduce fee-for-service payments, where providers are reimbursed for each additional service, and increase activity-based funding, where payments are made according to an agreed classification, such as the Australian National Sub-acute and Non-acute Patient (AN-SNAP).¹³⁷ This would incentivise palliative care providers to reduce unnecessary service activities. However, classification systems often assume homogenous quality of care, which is not the case in practice.
- **Reduce capped funding in favour of uncapped funding with performance monitoring.** There is evidence for palliative care providers should be paid on the basis of capitation payments, calculated by population served and the expected number of deaths in that population.¹³⁸ While uncapped funding could risk inappropriate over-subscription of palliative care providers, this could be mitigated with performance monitoring. However, the capitation-based model involves a risk of underservicing, as there is no incentive to improve take-up of palliative care across underserved populations.
- **Align funding arrangements with policy objectives to achieve a preferred place of death.** Many health systems use bonus payments to reward improved performance on policy-relevant metrics.¹³⁹ Payment models could reward the achievement of preferred place of death, which would improve providers choosing the appropriate site of care. This may have limited generalisability to RACFs.
- **Reduce out-of-pocket payments.** The literature showed that out-of-pocket payments can perversely encourage hospital rather than community-based palliative care options.¹⁴⁰ Ensuring public financing of health care and palliative care specifically could mitigate out-of-pocket expenses for residents of RACFs and their families.¹⁴¹

¹³⁵ Productivity Commission, '5 year productivity review: Commonwealth-State relations.' 2017.

¹³⁶ Duckett, Stephen, "Aligning policy objectives and payment design in palliative care." BMC Palliative Care (17). 2018.

¹³⁷ Kimberly, JR, de Pouvourville, G, D'Aunno, T. "The Globalization of Managerial Innovation in Health Care." 2008.

¹³⁸ Bernheim, JL, Distelmans, W, Mullie, A, Ashby, MA. "Questions and Answers on the Belgian Model of Integral End-of-Life Care: Experiment? Prototype?" Journal of Bioethical Inquiry, 11(4):507–29. 2014.

¹³⁹ Srivastava, D, Mueller, M, Hewlett, E, "Better Ways to Pay for Health Care." OECD. 2016.

¹⁴⁰ Orlovic, M, Marti, J, Mossialos, E, "Analysis Of End-Of-Life Care, Out-Of-Pocket Spending, And Place Of Death In 16 European Countries And Israel." Health Affiliated, 36(7). 2017.

¹⁴¹ Hurley, J, "Ethics, economics, and public financing of health care." J Med Ethics, ;27(4):234–9. 2001.

3.4 How have palliative care in RACF initiatives sought to address health interface issues?



KEY FINDINGS

- Health interface issues are made more complex by an increasing number of people in residential aged care, increasingly complex care needs, complex service delivery and funding arrangements and systems under pressure.
- People living in RACFs experience health interface issues related to access and coordination of services.
- Initiatives have sought to address health system interface issues through the use of levers and models of care that influence policy, capability, networks and availability of expertise.
- Evidence-based models of care for the provision of palliative care in RACFs provide examples for what works well.
- In addition, the evidence points to a number of principles for successfully addressing health interface issues in RACFs.

The term 'health interface' is used in this context to refer to the intersection between the health and aged care systems. It describes how people with palliative care needs living in RACFs access the health system while in the RACF, or as they transition between systems (see Figure 10).

Figure 10 | The interface between health and residential aged care



Health interface issues are made more complex by an increasing number of people in residential aged care, increasingly complex care needs, and systems under pressure

Health interface issues for people living in residential aged care with palliative care needs are made more complex by the following:

- The population requiring residential aged care is increasing. The proportion of people aged 65 and older in Australia is expected to increase from 15 per cent in 2016 to 22 per cent by 2056, placing

increasing pressure on the health and aged care systems.¹⁴² In 2018-19, there were 242,774 people who were permanent residents of a residential aged care facility, of which 4,341 had an Aged Care Funding Instrument (ACFI) appraisal indicating the need for palliative care.¹⁴³

- There is an increasing prevalence of complex health needs among people living in residential aged care. Over time the morbidity of the cohort of people living in RACFs has become increasingly complex. Permanent residents of RACFs increasingly have dementia and/or communication difficulties and complex care needs, and there is a greater prevalence of chronic disease and comorbidity.¹⁴⁴ In addition, disadvantaged groups of older people (for example those affected by remoteness, cognitive impairment, mental health conditions, cultural isolation, low financial capacity, homelessness, limited technology access/literacy, or fear of discrimination or abuse), face additional hurdles in engaging with complex health and aged care systems.
- The Commonwealth and state/territory funding and delivery arrangements are complex. The evidence indicates that the overlapping responsibilities of Commonwealth and state/territory governments lead to conflict over responsibilities and uncertainty regarding coordination of service provision.¹⁴⁵ Funding arrangements vary across states and territories, leading to regional variation and a lack of national consistency in services delivered, which is further complicated at the interface of aged care and health systems.
- The aged care and health systems are interconnected, complex and facing multiple pressures. The aged care and health care systems are fragmented. Both health and aged care have their own distinct governance arrangements, funding mechanisms, eligibility criteria and entry processes. As a result, the ecosystem is difficult for older people, families and carers to navigate.

Older people living in RACFs experience health interface issues related to access and coordination of services

Evidence indicated that access to and coordination of health services is challenging for many people living in RACFs.¹⁴⁶ These issues apply to all older people living in RACFs, but are of particular relevance for people with palliative care needs who often have more complex health and aged care needs and a greater need to interact with both systems.

Evidence suggested that the following are key health interface issues that RACFs, primary care and acute care sectors are seeking to address:

- access to primary health care services;¹⁴⁷
- access to secondary and tertiary health care services, such as specialists or allied health professionals;¹⁴⁸
- avoiding unnecessary transfers to hospital emergency departments, which are often due to challenges accessing appropriate health services from within the RACF;¹⁴⁹

¹⁴² Australian Institute of Health and Welfare, "Older Australia at a glance." 2018.

¹⁴³ Australian Institute of Health and Welfare, "Palliative care for people living in residential aged care." 2018.

¹⁴⁴ Ibid.

¹⁴⁵ Productivity Commission, "Introducing competition and informed user choice into human services: Reforms to human services. Chapter 3: End-of-life care in Australia." 2017.

¹⁴⁶ Shahid, S, Taylor, E, Cheetham, S, et al., "Key features of palliative care service delivery to Indigenous peoples in Australia, New Zealand, Canada and the United States: a comprehensive review," *BMC Palliative Care*, 17(72). 2018.

¹⁴⁷ Royal Commission into Aged Care Quality and Safety, "Canberra Hearing - Interfaces between the aged care and the health care systems." 2019.

¹⁴⁸ Ibid.

¹⁴⁹ Arendts G, Howard K 2010, The interface between residential aged care and the emergency department: a systematic review, *Age and Ageing* 39:306-312.

- poor clinical handovers that occur when residents are required to transition between RACFs and the health system;¹⁵⁰
- coordination of the various health and aged care services that a person is accessing;¹⁵¹
- continuity of care when transitioning into a RACF and communication between hospitals and RACF when transitioning between health and aged care services¹⁵² which includes poor clinical handovers that occur when residents are required to transition between RACFs and the health system;¹⁵³ and
- a lack of support to navigate the complex health and aged care systems.¹⁵⁴

Access to health services is a particular challenge for people living in RACFs. This is particularly true for allied health services, which form an important part of multidisciplinary palliative care teams.

THE ROYAL COMMISSION INTO AGED CARE QUALITY AND SAFETY

Hearings for the Royal Commission into Aged Care Quality and Safety have highlighted health system interface issues in the provision of palliative care in RACFs, noting that the aged care system should be integrated with the disability care system, the general healthcare system and the public oral healthcare system. Some also demonstrated the need to delineate what is within the scope of RACFs to manage, and what is not. The Royal Commission heard that:

“Residential care and the services for older people tend to be planned as if it’s a completely separate part of your life and that there’s an expectation if you’re in aged care that every single need that you have will be met by aged care and, in fact, that’s not the case.”¹⁵⁵

3.4.2 How have RACF initiatives addressed health system interface issues?

Initiatives have sought to address health system interface issues through approaches that influence policy, capability, networks and availability of expertise

Initiatives have access to a number of ‘levers’ through which to improve health interface issues in RACFs. These levers can focus on policy and governance; funding; capability; networks and relationships; availability of expertise and others. Key approaches to overcome health interface issues in the RACF setting identified in this literature review and accompanying examples are described in Table 5. Many models of care act to address the health system interface; where examples are noted below, greater detail is provided in Appendix A.

Table 5 | RACF initiatives address health system interface issues using a number of levers

Lever	Description	Examples
Policy	Strategy or other policy documents issued by	Although no national strategy for palliative care in residential aged care exists, the National Palliative Care

¹⁵⁰ Belfrage, M, Chiminello, C, Cooper, D, et al., "Pushing the envelope: clinical handover from the aged-care home to the emergency department." 2009.

¹⁵¹ Grattan Institute, "Dying Well." 2014.

¹⁵² Testa, L, Seah, R, Ludlow, K, et al., "Models of care that avoid or improve transitions to hospital services for residential aged care facility residents: An integrative review," *Geriatric Nursing*, 41:360-372. 2020.

¹⁵³ Belfrage, M, Chiminello, C, Cooper, D, et al., "Pushing the envelope: clinical handover from the aged-care home to the emergency department." 2009.

¹⁵⁴ Grattan Institute, "Dying Well." 2014.

¹⁵⁵ Royal Commission into Aged Care Quality and Safety, "Interim report: Neglect, Volume 2", 2019.

	governments, peak bodies and other influencers that set out the key elements and priorities of an approach to address health interface issues.	Strategy (2018) broadly encompasses provision of palliative care in RACFs. This includes goals and priorities to increase understanding, capability, and collaboration among others. ¹⁵⁶ The Principles for Palliative and End-of-Life Care in Residential Aged Care were developed collaboratively by seven peak bodies and organisations. It describes the key principles for the provision of palliative and end of life care in RACFs. ¹⁵⁷
Funding models	Funding models that promote actions to address health interface issues.	The literature indicates that suboptimal funding structures contribute to health interface issues. ^{158,159,160} A proposition to improve the health interface in residential aged care is the introduction of funding models that incentivise proactive coordination and delivery of care. ¹⁶¹
Building capability	Approaches that aim to overcome health interface issues by building capability through education, information and resources.	The Residential Aged Care Palliative Approach Toolkit (the PA Toolkit) was a set of clinical, educational and management resources designed to guide and support residential aged care facilities to implement a comprehensive, evidence-based and person-centred approach to palliative care. The PA Toolkit was developed in 2009 but was retired in 2020 and replaced by other general and specific palliative care and aged care resources and information. ¹⁶² The Indigenous Palliative Care Service Delivery Conceptual Model is a conceptual model that outlines key principles for Indigenous palliative care service delivery. ¹⁶³ End of Life Directions for Aged Care (ELDAC) is not specific to RACFs, but provides a national advisory service for specialist palliative care and advance care planning. It provides resources to equip care providers with skills and information to help older Australians receive high-quality end of life care. ¹⁶⁴
Building relationships and integrating care	Approaches that aim to overcome health interface issues by promoting integrated care and building networks of professionals to provide care.	As noted in Section 3.2, integrating specialist care into RACFs is a consistent theme in models of care. This approach addresses health interface issues by ensuring that medical services are available in the RAC. Hammond Care's Lavender Palliative Care Suite provides residents with

¹⁵⁶ Department of Health, "National Palliative Care Strategy." 2018.

¹⁵⁷ Palliative Care Australia, "Principles for palliative and end-of-life care in residential aged care". 2017.

¹⁵⁸ Royal Commission into Aged Care Quality and Safety, "Canberra Hearing - Interfaces between the aged care and the health care systems." 2019.

¹⁵⁹ Oliver-Baxter, J, Brown, L, Bywood, P, "Integrated care: What policies support and influence integration in health care in Australia?" 2013.

¹⁶⁰ Productivity Commission, "Introducing competition and informed user choice into human services: Reforms to human services. Chapter 3: End-of-life care in Australia." 2017.

¹⁶¹ Royal Commission into Aged Care Quality and Safety, "Canberra Hearing – Propositions under consideration by Counsel Assisting." 2019.

¹⁶² PalliAged, "PA Toolkit Closure", 2020.

¹⁶³ Shahid, S, Taylor, E, Cheetham, S, et al., "Key features of palliative care service delivery to Indigenous peoples in Australia, New Zealand, Canada and the United States: a comprehensive review," BMC Palliative Care, 17(72). 2018.

¹⁶⁴ ELDAC, "About the Project", 2019.

Improving transfer of information		access to acute care, clinical training service, and in-house pharmacy within the RACF. ¹⁶⁵
	Approaches that aim to overcome health interface issues by promoting the effective transfer of information between RACFs and hospitals.	The Envelope model of care employed a simple tool to transfer a resident's clinical information during ED transfers. Evidence indicated that it improves the transfer of clinical information between the RACF and the hospital. ¹⁶⁶

RACF initiatives to address health system interface issues often apply a combination of the elements/components described above; for example, by using policy and good practice guidelines to develop a model of care that seeks to address a specific health interface challenge.

3.4.3 What has worked well and not as well?

Evidence-based models of care for the provision of palliative care in RACFs provide examples for what works well

Section 3.2 describes a number of models of care for the provision of palliative care for which there is evidence to suggest that the model is successful. A select subset of the models of care that address health interface issues that have a strong evidence base supporting their success are highlighted below, alongside the reported reasons the approach worked well:

- The INSPIRED Model uses a case management approach to aid the identification of palliative care needs and provision of clinical assessments. Proactive identification of palliative care needs in a systematic assessment framework and the integration of specialist palliative care with a palliative approach delivered by the RACF were noted as reasons for success.¹⁶⁷
- The NSW outreach geriatric medication advisory service employs multidisciplinary case conferences involving GPs, geriatricians, pharmacists and residential aged care staff to improve medication management for residents. The evidence indicated that the use of a case conferencing approach is more effective than an individual health provider, and that success may be driven by the presence of the resident's GP and a focus on individual residents with agreed, time-based goals and approaches.¹⁶⁸
- The Envelope model which is used to ensure effective transfer of information during ED transfers. Its ease of use, low cost, and ability to increase awareness of the importance of clinical handovers were noted as reasons for success.¹⁶⁹

¹⁶⁵ Productivity Commission, "Introducing competition and informed user choice into human services: Reforms to human services. Chapter 3: End-of-life care in Australia." 2017.; HammondCare, "Reforms to Human Services submission." 2017.

¹⁶⁶ Belfrage, M, Chiminello, C, Cooper, D, et al., "Pushing the envelope: clinical handover from the aged-care home to the emergency department." 2009.

¹⁶⁷ Chapman, M, Johnston, N, Lovell, C, et al., "Avoiding costly hospitalisation at end of life: findings from a specialist palliative care pilot in residential care for older adults," British Medical Journal. 2015.; Johnston, N, Lovell, C, Liu-, W-M, et al., "Normalising and planning for death in residential care: findings from a qualitative focus group study of a specialist palliative care intervention," British Medical Journal. 2016.

¹⁶⁸ Crotty, M, Halbert, J, Rowett, D, et al., "An outreach geriatric medication advisory service in residential aged care: a randomised controlled trial of case conferencing," British Geriatrics Society, 33(6). 2004.

¹⁶⁹ Belfrage, M, Chiminello, C, Cooper, D, et al., "Pushing the envelope: clinical handover from the aged-care home to the emergency department." 2009.

The evidence points to a number of principles for successfully addressing health interface issues in RACFs

The evidence described a number of principles for overcoming health interface issues for people receiving palliative care in RACFs, including:

- Promoting timely access to GPs which allows for earlier identification of issues requiring intervention and avoidance of unnecessary hospitalisation;¹⁷⁰
- Ensuring greater availability of nurse practitioners and primary care nurses to reduce reliance on GPs and provide education and more immediately available support to residents at a lower cost;^{171,172,173}
- Promoting greater availability of care plans, family communication and advance care directives when transitions between an RACF and a health care provider are required;¹⁷⁴
- Effective clinical governance and leadership in practice;^{175,176} and
- Introduction of a standard information transfer tool between hospitals and RACFs.¹⁷⁷

These principles are by no means comprehensive but highlight the principles most frequently identified in this review. Often, these approaches address only one facet of the health interface challenge. Successful initiatives must work in concert to have a meaningful impact on the bigger picture – particularly due to the fractured and individualistic nature of RACFs and health care services.

¹⁷⁰ Finn, J, Flicker, L, Mackenzie, E, et al., "Interface between residential aged care facilities and a teaching hospital emergency department in Western Australia," Medical Journal of Australia. 2006.

¹⁷¹ Forbat, L, Chapman, M, Lovell, C, et al., 'Improving specialist palliative care in residential care for older people: a checklist to guide practice,' Supportive and Palliative Care. 2017.

¹⁷² KPMG, "Cost benefit analysis of nurse practitioner models of care, prepared for the Department of Health." 2018.

¹⁷³ Davey R. et al., "National Evaluation of the Nurse Practitioner — Aged Care Models of Practice Initiative: Summary of Findings", Centre for Research & Action in Public Health, UC Health Research Institute. 2015.

¹⁷⁴ Aged Care Workforce Strategy Taskforce, "Health and Aged Care Interface Technical Advisory Group." 2018.

¹⁷⁵ Royal Commission into Aged Care Quality and Safety, "Interim report: Neglect, Volume 2", 2019.

¹⁷⁶ Royal Commission into Aged Care Quality and Safety, "Interim report: Neglect, Volume 3", 2019.

¹⁷⁷ Nous Group, "Stocktake and analysis of activities at the interface between the aged care, health and disability systems." 2020.

4 Conclusions

This section describes how findings from the literature review will inform the national evaluation.

Findings from this literature review detail the context in which RACFs participating in the Measure are operating. Further, domestic and international evidence of palliative care in RACFs will serve as comparators against the RACFs participating in the Measure.

Table 6 summarises how the literature review will help address the key evaluation questions for the national evaluation.

Table 6 | Implications for the national evaluation

Key evaluation questions	Implications for the national evaluation
How appropriate is the Measure to meet the needs of residents, families and carers in the Residential Aged Care Facilities (RACF) setting?	<ul style="list-style-type: none">• The body of evidence describing the needs of residents, families, carers and staff in RACFs will be used to describe the context within which RACFs participating in the Measure are operating.• Evidence describing system needs will be explored further to understand the needs and operating context of systems involved in activities implemented under the Measure.• Evidence on service gaps, such as workforce capacity and capability, will steer the discussion on service gaps in the national evaluation and support the articulation of the unmet needs that the Measure aims to meet.
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?	<ul style="list-style-type: none">• Best practice approaches to joint funding and delivery arrangements evidenced in the literature will be shared in the national evaluation and will contextualise the Measure's arrangement.• Findings from examination of good practice funding and delivery arrangements will help identify areas of improvement for potential future joint activities/agreements.
To what extent has the Measure achieved its intended outcomes?	<ul style="list-style-type: none">• Markers of quality palliative care in RACFs identified and outcomes measured by evaluations of evidence-based good practice models of care will inform the selection of indicators that will guide data collection and analysis for the national evaluation.
Is there a specific model of care that has been implemented that has proven to be more successful than others?	<ul style="list-style-type: none">• The domestic and international models identified in the literature review will answer the questions on successful models of care outside of the Measure for the national evaluation.• The critical success factors for palliative care models of care will be used as a basis for further exploration in the national evaluation.
Does the Measure and the models adopted in each jurisdiction help to address health system interface issues?	<ul style="list-style-type: none">• Evidence based models of care outside of the Measure that address health interface issues will be used to inform the definition of good practice and will be explored further in the national evaluation.• Success factors and enablers will be used to understand the factors that contribute to models that successfully address health interface issues and identify areas where activities under the Measure can improve.

Appendix A Detailed models of care

This appendix contains detailed information on the models of care identified domestically and internationally.

Model of Care	Key element	Description	Why good practice?	Evaluation or review?
AUSTRALIA				
INSPIRED Model ¹⁷⁸ ACT	Case management	INSPIRED model consists of placing a palliative care nurse practitioner in RACFs. Nurse practitioners conduct 'Needs rounds' to assess residents' palliative care needs and deterioration. Palliative care nurse practitioners provide direct support through clinical assessments and indirect support through needs rounds, which serve to uplift staff capability through care plan discussions.	<ul style="list-style-type: none"> • Normalised death and dying in RACFs • Provided timely access to palliative care specialist • Reduced unnecessary hospitalisations • Improved decision making and planned care for residents, meaning staff and relatives were better informed on resident trajectory • Developed capabilities of RACF staff indirectly through needs rounds. 	<p>A quasi-experimental design in four RACFs. Formal evaluation conducted.</p> <p>Results:</p> <ul style="list-style-type: none"> • Substantial reduction in the length of hospital stays • Lower incidence of death in the acute care setting.
Lavender Palliative Care Suite -	Integrated care	<p>HammondCare operates a nine-bed specialist palliative care unit as part of a 124-place mixed low and high-care home.</p> <p>Integrated, multi-disciplinary approach to care. Access to</p>	<ul style="list-style-type: none"> • Enabled personalised and flexible care routines • Provided for residents' individual physical, psychological, social and spiritual needs • Demonstrated efficacy of providing specialised palliative care in an existing residential aged care setting. 	No formal evaluation or review identified.

¹⁷⁸ Chapman, M, Johnston, N, Lovell, C, et al., "Avoiding costly hospitalisation at end of life: findings from a specialist palliative care pilot in residential care for older adults," British Medical Journal. 2015.; Johnston, N, Lovell, C, Liu-, W-M, et al., "Normalising and planning for death in residential care: findings from a qualitative focus group study of a specialist palliative care intervention," British Medical Journal. 2016.

Hammond Care ¹⁷⁹ VIC		HammondCare acute care, clinical training service and in-house pharmacy.		
Geriatric Flying Squad ¹⁸⁰ NSW	Specialist outreach service	Service provides a rapid response and a clear point of contact for RACF staff to access support. Service provides a comprehensive assessment in the older person's home at the RACF within 2-4 hours of referral, including the provision of palliative care. Expedited ward admission where necessary. Assessment occurs at the person's home in the aged care facility if this is their choice.	<ul style="list-style-type: none"> • Provided proactive and timely care, in the home where possible • Improved decision support making through risk stratification • Improved care coordination and continuity of care • Developed capability across individuals, units and organisations • Established quality indicators through comprehensive geriatric assessment • Provided access to network of specialist palliative care professionals through partnerships. 	No formal evaluation or review identified.
Outreach geriatric medication advisory service ¹⁸¹ NSW	Case management	Multidisciplinary case conferences involving GP, geriatrician and pharmacists and residential care staff held for each resident.	<ul style="list-style-type: none"> • Provided holistic, person-centred care through the multidisciplinary team • Improved appropriate medication prescribing to residents. 	<p>A randomised controlled trial in one RACF, for residents with medication problems and/or challenging behaviours. Formal evaluation conducted.</p> <p>Results:</p> <ul style="list-style-type: none"> • Medication appropriateness improved • Inappropriate prescribing decreased, particularly for benzodiazepines.
Indigenous Palliative Care Service Delivery	Capability building	Created a conceptual model that outlined seven key principles for Indigenous palliative care service	<ul style="list-style-type: none"> • Developed capabilities of RACF workforce to identify needs specific to Indigenous peoples in Australia. 	No formal evaluation or review identified.

¹⁷⁹ Productivity Commission, "Introducing competition and informed user choice into human services: Reforms to human services. Chapter 3: End-of-life care in Australia." 2017.; HammondCare, "Reforms to Human Services submission." 2017.

¹⁸⁰ NSW Agency for Clinical Innovation, "ACI Clinical Innovation Program – Specialised geriatric outreach for residential aged care." 2014.

¹⁸¹ Crotty, M, Halbert, J, Rowett, D, et al., "An outreach geriatric medication advisory service in residential aged care: a randomised controlled trial of case conferencing," British Geriatrics Society, 33(6). 2004.

Conceptual Model ¹⁸² NT		delivery: 1) Equity 2) Autonomy and Empowerment 3) The Importance of Trust 4) Humane, Non-judgmental Care 5) Seamless Care 6) Emphasis on Living 7) Cultural Respect.		
Austin Health's Residential InReach service ¹⁸³ VIC	Specialist in-reach service	A geriatrician-led model that operates seven days a week, from 9 AM to 5 PM. This service offers RACFs telephone advice, geriatrician or nursing reviews, acute interventions and palliative care.	<ul style="list-style-type: none"> • Provided timely access to medical assessment and assistance with clinical decision-making • Improved decision-making around hospital transfers through prioritising and advocating for the resident's best outcomes • Increased documentation of and adherence to advance care plans to assist staff with decision-making and reduce anxiety when a resident deteriorates • Improved staff capacity to engage in advance care planning opportunities in the RACF setting. 	No formal evaluation or review identified.
Aged Care Emergency (ACE) program ¹⁸⁴ NSW	Capability building	ACE supports staff in RACFs to facilitate residents' acute care needs being met within the facility and avoiding an ED presentation. Aim to reduce the need for residents of RACFs to present to an ED for acute care, or where ED presentation is required, to proactively manage the visit. Enhance integration of a range of services for older people.	<ul style="list-style-type: none"> • Increased respect for knowledge and skills of RACF staff • Provided RACF staff access to a network of specialist palliative care providers • Developed collaborative relationships and trust to enable appropriate decision making • Established clear patient goals of care prior to transferring to an ED • Provided proactive case management within the ED. 	<p>Internal review conducted.</p> <p>Results:</p> <ul style="list-style-type: none"> • An estimated 981 residents avoided ED annually • Compared with usual care, ACE saved an estimated \$921,214.

¹⁸² Shahid, S, Taylor, E, Cheetham, S, et al., "Key features of palliative care service delivery to Indigenous peoples in Australia, New Zealand, Canada and the United States: a comprehensive review," BMC Palliative Care, 17(72). 2018.

¹⁸³ Amadoru, S, Rayner, J, Joseph, R, et al., "Factors influencing decision-making processes for unwell residents in residential aged care: Hospital transfer or Residential InReach referral?" Australasian Journal on Ageing, 37 (2). 2016.

¹⁸⁴ NSW Agency for Clinical Innovation, "ACI Clinical Innovation Program – Specialised geriatric outreach for residential aged care." 2014.

The Envelope ¹⁸⁵ VIC	Shared care	A simple tool to transfer clinical information during ED transfers. The Envelope maintained privacy of the resident (no clinical information is recorded on the Envelope), was succinct and simple, and kept costs to a minimum.	<ul style="list-style-type: none"> • Improved clinical handover, as perceived by staff • Raised awareness of the importance of clinical handover, as perceived by staff. 	<p>Quasi-experimental study design. Internal review conducted.</p> <p>Results:</p> <ul style="list-style-type: none"> • 163/165 staff (99%) thought the Envelope was useful • 148/165 (90%) staff said it was easy to use • 128/165 staff (78%) and all interviewees believed that using the Envelope improved clinical handover • 152/165 staff (92%) indicated they would continue to use the Envelope.
CARE-PACT ¹⁸⁶ QLD	Specialist in-reach services	Comprehensive Aged Residents Emergency and Partners in Assessment, Care and Treatment (CARE-PACT) program: a hospital substitutive care and demand management project that provides a consultative service for GPs regarding their resident's acute healthcare issues. CARE-PACT is a dedicated, hospital-based, single point of telephone contact for referral of deteriorating RACF residents for GPs, paramedics, RACF staff and community health providers. CARE-PACT partners with existing community and hospital-based services to facilitate linking of	<ul style="list-style-type: none"> • Optimised continuity of care and effectiveness of discharge with informed collaborative care planning • Improved quality of gerontic nursing care in the ED • Reduced hospital length of stay by having ED receive prior warning of a forthcoming ambulance transfer • Facilitated early discharge through recognising and remediating barriers to discharge early in the presentation. 	No formal evaluation or review identified.

¹⁸⁵ Belfrage, M, Chiminello, C, Cooper, D, et al., "Pushing the envelope: clinical handover from the aged-care home to the emergency department." 2009.

¹⁸⁶ Burkett, E, Scott, I, "CARE-PACT: a new paradigm of care for acutely unwell residents in aged care facilities," Australian Family Physician, 44(4). 2015.

residents with acute care needs to the service best able to fulfill these needs.

Aged Rapid Response Team (ARRT) ¹⁸⁷ NSW	Specialist outreach service	ARRT offers an outreach service to RACFs through rapid access medical and nursing community visits and a telephone service for advice regarding resident palliative care.	<ul style="list-style-type: none"> • Provided timely access to specialist care at home • Prevented unnecessary hospital presentations/admissions • Developed capabilities for registered nurses in RACFs • Increased documentation of advance care planning. 	No formal evaluation or review identified.
Virtual Aged Care Services (VACS) ¹⁸⁸ NSW	Specialist in-reach service	VACS aims to reduce unnecessary hospital presentations and admissions for older people, facilitate early discharge from hospital (reducing length of stay) and streamline older patients' entry points to hospital. VACS was piloted in two RACFs to trial telehealth strategies for delivery.	<ul style="list-style-type: none"> • Improved care coordination and collaborative care plan development with involved providers • Provided access to a network of specialist care providers • Developed capabilities of RACF staff through education • Increased resource utilisation through telehealth strategies. 	<p>Internal review conducted.</p> <p>Results:</p> <ul style="list-style-type: none"> • ED presentations reduced by 60% • Unplanned admissions reduced to approximately 10% • Two-day reduction in LOS for older people.
St. Vincent's Health Network's Palliative Care Nurse Practitioners ¹⁸⁹ VIC	Shared care	A network of acute care facilities and specialist palliative care providers that coordinate to deliver palliative care in community and residential aged care facilities.	<ul style="list-style-type: none"> • Provided timely provision of appropriate care and support • Improved assessment, management and evaluation of patients • Prescribed appropriate medications • Delivered personalised care • Provided continuity of care between hospital and home • Provided advice and support to patients and their loved ones (including care for physical, psychological and spiritual needs). 	No formal evaluation or review identified.

¹⁸⁷ NSW Agency for Clinical Innovation, "ACI Clinical Innovation Program – Specialised geriatric outreach for residential aged care." 2014.

¹⁸⁸ Ibid.

¹⁸⁹ Nous Group, "Stocktake and analysis of activities at the interface between the aged care, health and disability systems." 2020; St. Vincent's Health Australia, "Palliative Care Nurse Practitioners." 2019.

REACH Aged Care in the South (REACH) ¹⁹⁰ SA	Shared care	A program where GPs worked with facilities to assist with residents' urgent needs and ongoing medical services.	<ul style="list-style-type: none"> • Provided urgent assessment for residents' whose usual GP was unavailable • Provided ongoing medical services to RACF patients • Assisted with facilities clinical governance • Provided education and training and participation in Medical Advisory Committee 	<p>Evaluation conducted..</p> <p>Results:</p> <ul style="list-style-type: none"> • 111 GPs as practitioners for 750 patients within 6 pilot RACFs • Reduction of unnecessary emergency department transfers within the first 12 months • Inconclusive economic evaluation <p>The program was closed in 2014 because of changes to government funding and subsequent changes to the REACH business model.</p>
BUPA Model of Care ¹⁹¹ Various jurisdictions	Integrated care	A program where GPs deliver preventative healthcare and immediate medical treatment in residential aged care facilities.	<ul style="list-style-type: none"> • Provided individual services in RACFs, including delivery of palliative care • Trained and educated GPs as required 	<p>Evaluation conducted.</p> <p>Results:</p> <ul style="list-style-type: none"> • Unplanned hospital transfers reduced by half • Initial indications that this approach is saving acute care \$500,000 per care home annually in unplanned transfers
INTERNATIONAL				
Residential Aged Care Integration Program (RACIP) ¹⁹²	Specialist outreach service	RACIP is a quality improvement intervention to support residential aged care staff and includes on-site support, education, clinical coaching and care coordination provided by	<ul style="list-style-type: none"> • Provided education and clinical coaching through education sessions and access to gerontology clinical coaching • Developed a collaborative relationship between GNSs and facility staff 	<p>Randomised control trial. Formal evaluation conducted.</p> <p>Results:</p>

¹⁹⁰ Reed, R, "Models of general practitioner services in residential aged care facilities." Australian Family Physician. 2015.

¹⁹¹ Ibid.

¹⁹² Boyd, M, Armstrong, D, Parker, J, et al., "Do Gerontology Nurse Specialists Make a Difference in Hospitalization of Long-Term Care Residents? Results of a Randomized Comparison Trial." American Geriatrics Society. 2014.

New Zealand		gerontology nurse specialists (GNSs) employed by a large district health board.	<ul style="list-style-type: none"> Established quality initiatives and indicators (e.g. RN Care guides) Improved care coordination for high-risk residents Provided access to a network of gerontology specialists, e.g. with secondary care Older Adult Specialists and primary and secondary care services. 	<ul style="list-style-type: none"> The hospitalization rate after the intervention increased 59% for the comparison group and 16% for the intervention group Significantly lower rate change for those admitted for medical reasons for the intervention group (13% increase) than the comparison group (69% increase).
Aged Residential Care Health Utilisation Study (ARCHUS) ¹⁹³ New Zealand	Case management	A complex multi-disciplinary team intervention in long-term care facilities. A GNS conducted baseline facility needs assessment and quality indicator benchmarking. A multi-disciplinary team (MDT) meetings were held involving a geriatrician, facility GP, pharmacist, GNS and senior nursing staff.	<ul style="list-style-type: none"> Improved integration of RACF with geriatricians and with emergency/acute services Educated RACF staff to increase their use of research and current guidelines Improved RACF palliative care practices Provided alternative residential aged care models to target care for high risk groups, e.g. those with end-stage dementia. 	<p>Formal evaluation conducted.</p> <p>Results:</p> <ul style="list-style-type: none"> The intervention did not impact overall rates of acute hospitalisations or mortality (previously published) Intervention resulted in fewer 'big five' admissions with no significant difference in the rate of other acute admissions The intervention group were 34.7% less likely to have a 'big five' acute admission than controls.
Gold Standard Framework (GSF) ¹⁹⁴ United Kingdom	Case management	A model of end-of-life care, in nursing homes in England. The GSF helps practitioners to identify individuals in need of supportive end-of-life care, to assess their needs, symptoms, preferences and other concerns important to them.	<ul style="list-style-type: none"> Increased discussion with residents and families about care towards the end-of-life Improved communication with GP out-of-hours services Introduced procedures for anticipatory medication and greater staff confidence in caring for people at the end-of-life. 	<p>Formal evaluation conducted.</p> <p>Results:</p> <ul style="list-style-type: none"> The programme resulted in improved processes for delivering end-of-life care At follow-up, there were significant changes in the proportions of homes

¹⁹³ Foster, S, Boyd, M, Broad, J, et al., "Aged Residential Care Health Utilisation Study (ARCHUS): a randomised controlled trial to reduce acute hospitalisations from residential aged care,"

¹⁹⁴ Badger, F, Clifford, C, Hewison, A, & Thomas, K, "An evaluation of the implementation of a programme to improve end-of-life care in nursing homes," Palliative Medicine, 23. 2009.

				that had systems for identifying residents in need of end-of-life care, had care coordinators and were routinely undertaking advance care planning
				<ul style="list-style-type: none"> Minimal change in the proportion of homes undertaking discussions about preferred place of care, however these were high at baseline.
<p>The Supportive and Palliative Care Indicators Tool (SPICT)¹⁹⁵</p> <p>United Kingdom</p>	Capability building	<p>SPICT is designed to provide practical, evidence-informed guidance to help clinicians working in primary and secondary care recognise when their patients might be at risk of dying and likely to benefit from supportive and palliative care in parallel with appropriate ongoing management of their advanced conditions.</p>	<ul style="list-style-type: none"> Identified patients with multiple unmet needs who would benefit from needs assessment and advance care planning Provided clear indicators which clinicians can use to initiate conversations with patients and families Promoted effective communication and coordination between primary and secondary care teams. 	<p>Formal evaluation conducted.</p> <p>Results:</p> <ul style="list-style-type: none"> Patients who died had significantly more unplanned admissions, persistent symptoms and increased care needs By 12 months, 62 (48%) of the identified patients had died. 69% of them died in hospital, having spent 22% of their last 6 months there.
<p>Palliative Care Mobile Unit¹⁹⁶</p> <p>Canada</p>	Specialist in-reach services	<p>A palliative care mobile unit to provide care to residents at end of life. Unit contained palliative care specialists (GP and/or Nurse) to identify palliative care needs at the residential facility.</p>	<ul style="list-style-type: none"> Families and medical teams supported to manage end-of-life symptoms and psychological suffering Avoided unnecessary hospitalizations. 	No formal evaluation or review identified.

¹⁹⁵ Highe, G, Crawford, D, Murray, S, Boyd, K, "Development and evaluation of the Supportive and Palliative Care Indicators Tool (SPICT): a mixed-methods study," British Medical Journal. 2018.

¹⁹⁶ Basson, B, Vassal, P, Richard, A, *et al*, "Role of a Palliative Care Mobile Unit in a nursing home," Review Internationale De Soins Palliatifs, 17(2). 2002.

Palliative Care Leadership Teams (PCLT) ¹⁹⁷ United States	Capability building	PCLT included recruitment and training of Palliative Care Leadership Teams in each facility, followed by six technical assistance meetings for team members. Hospice providers delivered six educational sessions for all nursing home staff using a structured curriculum.	<ul style="list-style-type: none"> • Increased hospice enrolment • Improved pain assessment and nonpharmacologic pain treatment • Increased advance care planning discussions. 	No formal evaluation or review identified.
Social workers to enhance advance care planning ¹⁹⁸ United States	Specialist in-reach services	Nursing home social workers were given a baseline education in advance care planning that incorporated small-group workshops and role play/practice sessions for intervention social workers. Social workers then continued care planning with residents of nursing homes, discussing goals of care at team meetings and “flagged” advance directives on nursing home charts.	<ul style="list-style-type: none"> • Improved documentation of and adherence to residents’ preferred resuscitation orders and other medical interventions • Provided indirect capability uplift of nursing home staff to end-of-life needs (e.g. advance care planning) during team meetings. 	Randomised controlled trial design. Internal review conducted. Results: <ul style="list-style-type: none"> • Intervention residents more likely than the control group to have their preferences regarding cardiopulmonary resuscitation (40% vs 20%, P5.005), artificial nutrition and hydration (47% vs 9%, Po.01), intravenous antibiotics (44% vs 9%, Po.01) and hospitalization (49% vs 16%, Po.01) documented in the nursing home chart • Control residents were significantly more likely than intervention residents to receive treatments discordant with their prior stated wishes.

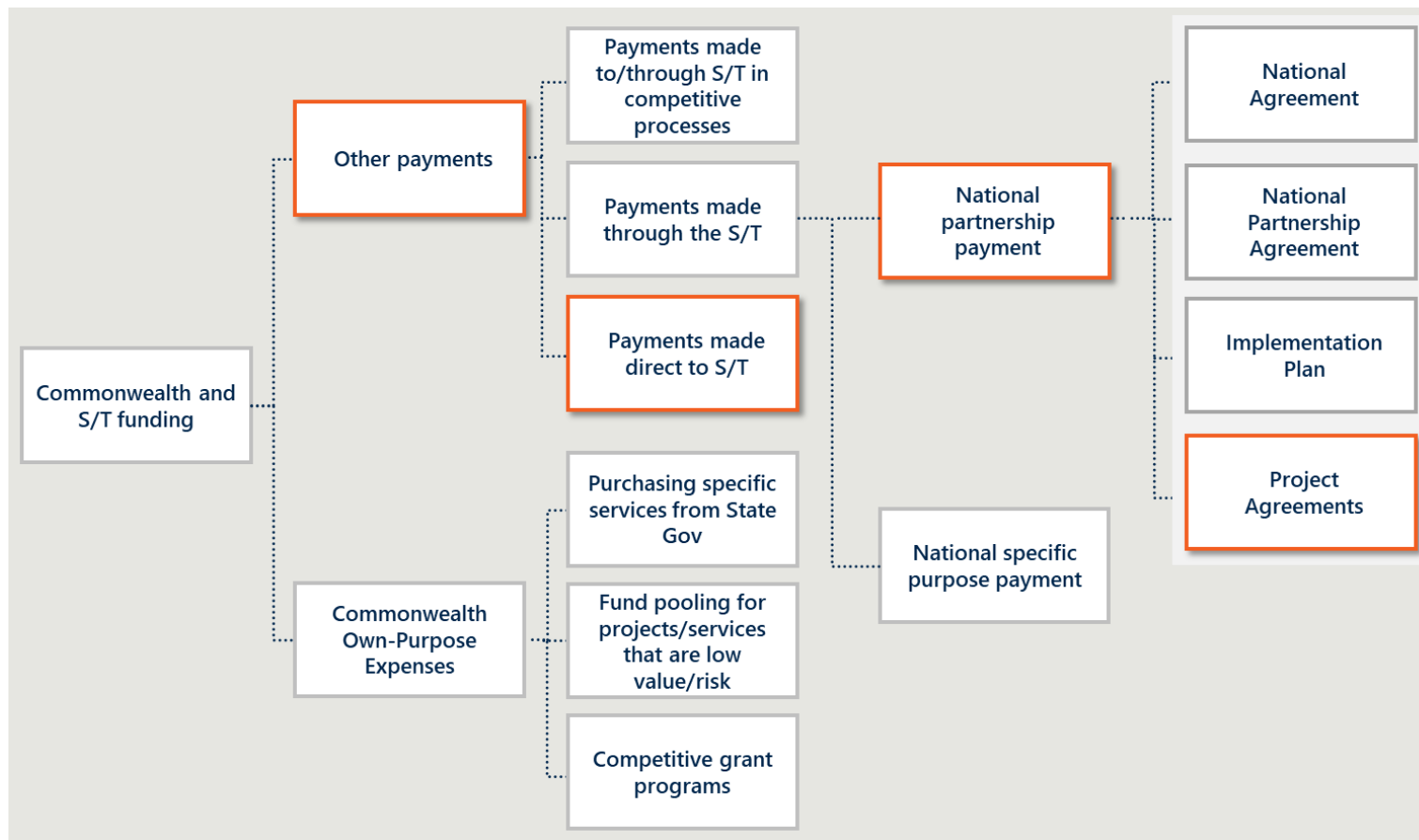
¹⁹⁷ Hanson, L, Reynolds, K, Henderson, M, *et al.*, “A quality improvement intervention to increase palliative care in nursing homes,” *Journal of Palliative Medicine*, 8(3). 2005.

¹⁹⁸ Morrison, R, Chichin, E, Carter, J, *et al.*, ‘The effect of a social work intervention to enhance advance care planning documentation in the nursing home,’ *American Geriatrics Society*, 52: 290-294. 2005.

Appendix B Funding and delivery arrangements

This appendix contains a detailed pathway of Commonwealth and State/Territory funding and delivery arrangements (see Figure 11).

Figure 11 | Pathways for joint funding and delivery arrangements



Appendix C National Partnership Agreements and Project Agreements

This appendix contains an indexing of the Council on Federal Financial Relations active National Partnerships (NPA) and Project Agreements (PA) (see Table 7).¹⁹⁹

Table 7 | Overview of current NPAs and PAs

Sector	Number of active NPAs	Number of active PAs	Total number of active NPAs and PAs
Health	14	50	64
Education	4	2	6
Skills and Workforce Development	1	5	6
Community Services	3	4	7
Affordable Housing	3	1	4
Infrastructure	1	9	10
Environment	8	28	36
Contingent Payments	0	0	0
Other	3	12	15

¹⁹⁹ Council on Federal Financial Relations, 'Agreements.' Accessed 18 September 2020.