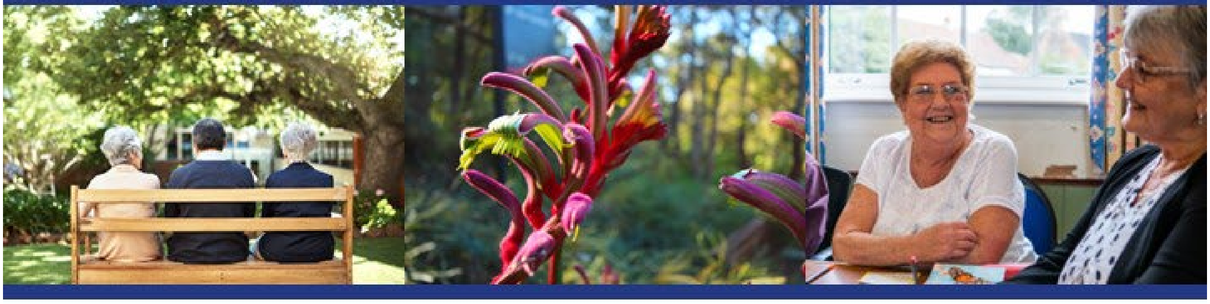
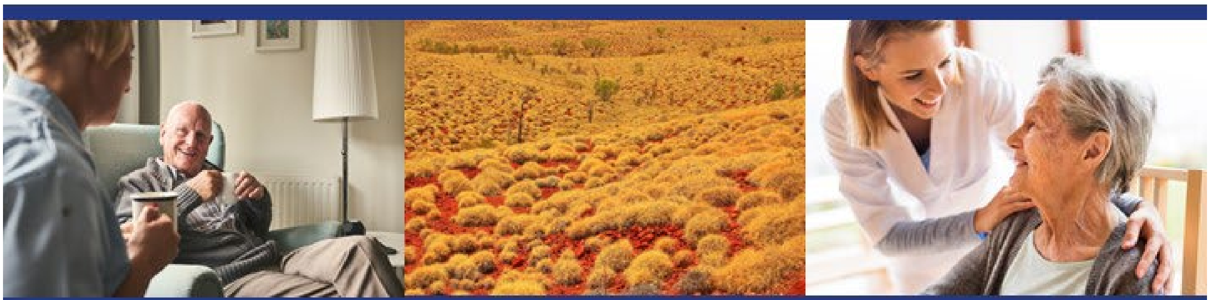


National Partnership Agreement: Comprehensive Palliative Care in Aged Care

WA Deep Dive Impact Evaluation

FULL REPORT

December 2024



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THE UNIVERSITY OF WESTERN AUSTRALIA

The Rural Clinical School of Western Australia

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ACKNOWLEDGEMENTS

This project was funded by the End-of-Life Care Program, Western Australian Department of Health.

The research team would like to thank the contribution of the Reference Group members and the organisations and individuals who actively promoted the surveys.

Special thanks to the bereaved carers and residential aged care homes staff who enriched this project with their experiences and insights for improving palliative care services in WA.

KEY TERMS AND DEFINITIONS

Palliative Care

Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual (WHO, 2024).

Palliative Approach to Care

A palliative approach to care emphasizes the need for a patient and family-centred care that focuses on the person and not only on the illness, the importance of therapeutic interactions between care providers and the patient and family, a clear communication all through the illness trajectory and it stresses in particular the importance of goals of care and advance care planning (Aoun, 2018; Palliaged, 2024).

End-of-Life Care

In the context of this report, 'end-of-life care' is used as an umbrella term to refer to the care provided to a RACH resident, rather than referring specifically to the final 12 months of life. It should be noted that the nuanced clinical distinction between palliative care, end of life care and terminal care have not been delineated for the purposes of this consumer survey.

Visiting Palliative Care Team

In the context of this report, there are no references to the term 'specialist' or 'generalist' palliative care services. In collaboration with the project reference group, the following definition of a 'visiting palliative care team' was provided to consumers:

Consumer Survey Q3.5: Was your relative seen by a 'visiting palliative care team'* in the residential aged care home? [**In WA, there are specialist palliative care teams of doctors, nurses, social workers and other clinicians that visit Residential Aged Care Facilities and Nursing Homes to provide extra support to residents, families and staff. These visiting palliative care teams in WA include MPaCCS from Bethesda Palliative Care Unit, WA Country Heath Palliative Care and Silver Chain].*

Palliative Care Users (PC Users)

In the context of this report, the term Palliative Care User (PC User) is used to describe the group of bereaved carers who indicated their relative engaged with the 'visiting palliative care team' as indicated above and therefore accessed 'specialist palliative care services' at end of life. It should be noted the validity of this self-reported characteristic was reliant upon individual consumers understanding of palliative care services within the aged care home.

Consumers and Bereaved Carers

Throughout this report, the term consumers and bereaved carers are used interchangeably to describe the perspectives of those whose residents lived in a RACH in Western Australia.

Service Providers and RACH Staff

Throughout this report, the term service provider and RACH staff is used interchangeably to describe the perspectives of those who are employed by RACHs in Western Australia.

Rural and Country WA

Throughout this report, the terms Rural and Country WA are used interchangeably as a description of geographical location, in contrast to metropolitan Western Australia.

Death Literacy

Death literacy is knowledge about, and understanding of, the death system –which is all the things that are Death, Dying, Loss and Grief (DDLG) related in a society. Death literacy is our "know how" and includes 4 key things: 1) Knowledge about end-of-life planning, the end-of-life system and how it works, 2) Skills related to care and having conversations about DDLG, 3) Knowing how to take action–accessing community support and informal networks, 4) Experience –normalising DDLG, wisdom learnt through personal experiences (Noonan et al., 2016).

Grief Literacy

Grief literacy is defined as the multidimensional capacity to access, process, and use knowledge regarding the experience of loss: it comprises knowledge to facilitate understanding and reflection, skills to enable action, and values to inspire compassion and care. These dimensions connect and integrate via the interdependence of individuals within sociocultural contexts. Grief literacy extends beyond the individual person; instead, it is a broader concept that reflects the capacity and values of a community and society (Breen et al., 2022).

Residential Aged Care Homes (RACHs)

Throughout the course of this evaluation the aged care sector and government preferences in relation to terminology surrounding Residential Aged Care Facilities (RACFs) was altered to Residential Aged Care Homes (RACHs), and this has been reflected throughout the report. It should be noted that all bereaved carer and service provider quotes were not altered.

EXECUTIVE SUMMARY

In May 2020, Department of Health WA entered into the National Partnership Agreement (NPA) for Comprehensive Palliative Care in Aged Care, with the purpose to improve palliative and end-of-life care for older Australians living in residential aged care homes (RACHs).

The national NPA evaluation is being conducted by consulting firm 'Nous', whilst state-based monitoring and analysis is being undertaken by the Western Australian Department of Health End-of-Life Care Program (EOLCP).

In July 2023, the Perron Institute were commissioned by the EOLCP to conduct an independent 'deep-dive' impact evaluation.

The aim of the independent deep dive impact evaluation was to understand the broader impacts of the NPA projects on residents, families, carers and service providers and to provide recommendations for long-term planning.

The independent evaluation was carried out across three phases:

Phase One
Consumer Survey
(bereaved carers)

Phase Two
Service provider
consultations on findings
of consumer survey

Phase Three
RACH Staff Survey
on NPA initiatives

This independent evaluation was informed by 428 people across WA. This included 317 bereaved carers, each telling us about a relative who was a resident in an RACH in WA and died between 2021-2024. It also included 111 current employees from the aged care sector who worked in RACHs in various capacities, both clinical and non-clinical, plus the input and advice of the Project Reference Group.

The cumulative impact of NPA initiatives across WA has been positive and evident in reports from both bereaved carers and RACH staff:

1) Palliative care services improved the experiences of residents and their family carers in most aspects of care as compared to residents who did not access palliative care services.

2) RACH Staff from sites with NPA initiatives reported practices with higher quality indicators than those working in non-NPA RACH sites.

Major positive outcomes: Compared to non-NPA sites, NPA sites staff reported:

- A decrease in residents transferred to hospital for symptom management.
- An increase in preferred place of death being documented.
- An increase in utilising documented information about preferred place of death.

- An improvement in staff confidence in their skills and understanding of Palliative Care.
- More residents and families were provided with information about end-of-life planning.
- More utilisation of care documents to recognise and respond to clinical deterioration.
- Improved coordination between GPs/hospitals/PC teams.
- More staff are supported to participate in palliative care training and education.
- More staff have access to timely clinical advice if a resident’s condition changes.

RECOMMENDATIONS

Service Improvement

The following recommendations are based on evidence from analyses in Phases One, Two and Three detailed in this report and on key suggestions by consumers and service providers for service improvement. Some recommendations are within the realm of the Western Australian Department of Health while others would be within RACH usual business, and some would be potentially addressed to WA Primary Health Alliance (WAPHA), private community GPs and community pharmacies.

1. Build Workforce Capacity and Capability

Capacity

- Address Workforce Retention Issues: Identify key concerns among RACH employees that are influencing high staff turnover within RACHs across WA. These issues relate more broadly to aged care at the federal level, such as recruitment, retention, salaries and conditions of aged care staff.
- Improve access and expand awareness of specialist palliative care services available to RACHs for communities in country WA.

Capability

- Increase the flexibility of training schedules: High staff turnover within RACHs may require a more flexible schedule for educational offerings including training and workshops. There are limitations associated with set curriculum timelines and alternatives are required.
- Provide training opportunities for non-clinical Staff: Personal Care Attendants (PCAs) provide the majority of face-to-face care in RACHs, and educational programs designed specifically for this group warrant further attention around end of life and palliative care programs.
- Provide Dementia-specific education for all clinical and non-clinical RACH staff to improve their care of residents who are diagnosed with dementia and cognitive decline.

- Provide death literacy and grief literacy education to clinical and non-clinical RACH staff to improve skills and confidence in caring for people at end of life and in supporting their families (such as recognising and responding to clinical deterioration).
- Provide mentorship between more senior or qualified RACH staff within individual sites or across RACH providers that may assist in minimising staff burnout.
- RACHs to appoint specific end of life care champions across individual sites to support an organisation-wide cultural shift towards a palliative approach to care for residents, aligned with their advance care planning documentation.

EOLCP have the following NPA Initiatives in progress in this domain: MPaCCS Expansion, Cancer Council WA RACEPC Communicate, WAPHA GP Case Conferencing Coordinator and RCL Expansion.

2. Improve Coordination of Care

Care Planning

- While advance care planning (ACP) documents are often considered around the time of admission to RACH, the findings of consistent challenges and barriers highlight that ACP discussion and documentation are best completed in the community. Work has been successfully happening in this space by Palliative Care WA and groups of compassionate communities, but it needs to be better funded for a much wider and faster population reach. In addition, there is a need to continue innovation and new models of facilitation and support to improve the reach into key population groups.

- The 'care plan for the dying person' is a resource developed by acute and subacute healthcare services in Australia, often at a state level. There is a need to consider the development of a care plan for the dying person tailored for the aged care setting in WA, along with implementation support and ongoing resources. The care plan supports a model of care that combines frequent assessments, critical thinking, individualised care planning, shared decision-making and continuous review to ensure the focus of care is on the dying person and those close to them.

- Residential Goals of Care (RGoC) is a document and process adapted for RACHs from the Goals of Patient Care document and process currently used in WA hospital settings. The tool supports clinical care, provides common language across settings, and complements consumer-led ACP documents. It promotes conversations about goals of care, limits of escalation of care, whether the resident wants to go to hospital and may trigger ACP. Continued implementation of this new model is warranted across WA RACHs.

EOLCP have the following [NPA Initiatives] in progress in this domain: EMHS Transition Support Officer, SMHS Care Coordinator, NMHS Transition Support Navigator, WACHS Residential Goals of Care, MPaCCS Expansion, WAPHA GP Case Conferencing Coordinator.

Access to GPs

- Develop sustainable models of delivering primary care in RACHs in collaboration with GPs to better understand how additional resourcing may improve quality care for residents, as much of primary care is palliative care in this setting.
- Need a proactive approach to prescribing medications at end of life to minimise wait times for residents and distress for family carers related to poor pain and symptom management e.g. through promoting the National Core Medication List in primary care and community pharmacies.
- Improve out of hours access to GPs for RACH residents including weekends and public holidays. This approach would also minimise the need for unnecessary hospitalisations.

EOLCP have the following [NPA Initiatives] in progress in this domain: WAPHA GP Case Conferencing Coordinator, RACGP GP Information Resources and RCL Expansion. For Example, the GP Case Conferencing Coordinator pilot is designed to support place-based coordinator roles within RACHs that act as a conduit between GPs, RACH staff, specialist palliative care services and residents.

Continuity of Care

- Improve data sharing ability among RACH staff, GPs and hospital staff to ensure equal access to ACP documents, Goals of Patient Care to translate to RGoC documents, and residents' preferred place of death.

EOLCP have the following [NPA Initiatives] in progress in this domain: NMHS Transition Support Navigator, SMHS Care Coordinator, EMHS Transition Support Officer and MPaCCS Expansion. For example, *HSP's Transitions of Care pilots are designed to support quality transfer of information at discharge from hospital to RACH, and MPaCCS' hospital liaison nurse to support transition from hospital to RACH and RACH to hospital for those with palliative care needs.*

3. Improve the quality of end-of-life and palliative care

Multidisciplinary Teams

- Increase the number of Allied Health and Spiritual Care staff in RACHs including social workers, occupational therapists and physiotherapists to optimise the quality of end of life.
- Increase a person-centred focus on residents' physical, psychosocial, functional and spiritual needs.

- Introduce grief and bereavement support for resident and family carers, for example grief counsellors employed by RACHs or in specialist palliative care teams.

EOLCP have the following NPA Initiatives in progress in this domain: MPaCCS Expansion (Social Workers).

4. Enhance Communication with and Support for Family and Carers

- RACH staff need access to training in how to share prognosis, palliative care phase and care plans with family members as residents deteriorate and die.
- Undertake education for families and carers about end-of-life and palliative care literacy, in partnership with organisations such as Palliative Care WA.
- More liaison with not-for-profit organisations that can support family carers is needed, with RACHs taking a signposting role via making available a list of services that family carers can tap into. This could be achieved through a collaborative Compassionate Communities model of care.

EOLCP have the following NPA Initiatives in progress in this domain for RACH staff education and training: Cancer Council WA RACEPC Communicate, RCL Expansion, MPaCCS Expansion and WAPHA GP Case Conferencing Coordinator.

Future work to support service improvement

- **Education in End of Life and Palliative Care**

Although there is a wide range of education and training opportunities available to aged care sector staff in WA (and more specifically through the NPA initiative RACEPC), there were repeated recommendations to improve and increase RACH staff training surrounding end of life and palliative care. Future research should explore why these educational opportunities are not being utilised, or alternatively, why the learnings are not successfully translating into practice. A focus on the need of CALD staff and PCAs is warranted.

- **Monitoring Changes in Quality Indicators Over Time**

This evaluation is particularly useful for providing a baseline for experience of care across the six priorities of the WA End-of-Life and Palliative Care Strategy which can be re-examined in future years as new initiatives are implemented across the sector to track their impact on residents/ family carers and RACH staff.

- **Expanding on Understanding GP and Hospital Staff Perspectives**

The lack of coordination among RACH staff, GPs and hospital staff as individuals and as key service providers to the aged care sector should be explored in more detail in order to gain a clearer understanding of how integration and cooperation could be improved. It would be particularly beneficial to identify RACHs where GP access and integration is well established, to understand key success factors and barriers to provision of palliative care.

To bolster the provision of generalist palliative care, further research with GPs needs to be undertaken to understand their perceived barriers and facilitators to provision of high quality and timely palliative care in RACHs.

- **Supporting Family Carers**

Supporting family carers pre- and post-death requires a more sustainable and collaborative model of care that involves supportive informal networks and building referral pathways between RACHs and community-based not-for-profit organisations. This could be achieved through a collaborative Compassionate Communities model of care. This community development approach would assist RACHs in accessing resources available in their local communities.

Another initiative that is gaining momentum in the US and the UK and that RACHs can facilitate is Help Texts which is a text messaging program that delivers twice-weekly text support, education, tips, and reminders to people who are grieving, as well as to their friends and family who want to support them. The program is designed to engage grievers who may not be inclined to seek bereavement counselling but could benefit from additional support. Some hospices have included this initiative as part of their signposting with positive evaluation outcomes (https://helptexts.com/).

Sector Improvement (Models of Care)

The following recommendations for sector improvement, including models of care, have been curated from a considered range of industry reports, academic research and case studies. It is imperative the aged care sector recognises the need for a cultural shift in end-of-life care.

Although the experiences and perspectives of bereaved carers and RACH staff have provided invaluable insights into how end of life and palliative care service provision may be improved in RACHs, it is imperative the aged care sector recognises the value of community networks.

An urgent whole of community response will be required to respond to the imminent impact of ageing in Australia, as collaboration between health care and social care becomes critical.

In building effective and sustainable models of end-of-life care, aged care providers must not only improve the provision of care but expand beyond healthcare systems into communities.

The cost and capacity of current clinical models of care in aged care are not sustainable and services must strive to provide person-centred meaningful care to residents at end of life.

Aged care systems are increasingly burdened by administrative tasks and less focused upon facilitating connections between residents and with the wider community, thus contributing to loneliness, learned helplessness, lack of self-agency and internalised ageism of residents.

A systemic cultural change requires commitment, resources and a process which places residents stated needs and aspirations at the centre, so residents are not merely 'cared for' but also 'cared about'.

Suggested Models of Care

- **Network Centred Aged Care**

This approach is underpinned by community development with a focus on meaningful relationships and network centred aged care. As an example, the 10K initiative focused on the maintenance and development of social networks and relationships for a group of elders who lived in an aged care home in the Western Suburbs of Sydney (Rahn et al, 2020). The role of the community development worker was to engage with the resources and networks within a 5-kilometre radius of the home. At the same time there was a focus on developing the agency of people (staff and residents) within the home so that they took collective action/s to solve problems such as loneliness and overcome barriers such as an overreliance on clinical approaches to care provision. Although the project was conducted with residents in Sydney NSW, the approach is likely to be adaptable to other similar aged care settings (Rahn et al, 2020).

- **Compassionate Connectors Program**

Building effective and sustainable models for EOL care means improving how care is provided as well as expanding models beyond the healthcare system to include the community. The Compassionate Connectors Program was trialled for terminally ill older people living at home in the South West of WA. Connectors supported patients and their family carers referred by the health service to identify networks of care that can meet their practical and social needs. The program significantly improved social connectedness, reduced social isolation and reduced hospital admissions and lengths of stay (Aoun et al., 2023; Aoun et al., 2022). Such model of care needs considering how it can be adapted in RACHs, where RACH residents can be supported to maintain and enhance their social networks within and prior to their entry to their RACH, and RACHs could engage with, contribute to, and draw upon their local communities.

- **Wellness Hubs**

Bupa is piloting a wellness hubs initiative in six of its aged care homes in regional areas of Queensland, where there is a shift from an illness and reactive approach of care to a restoration and wellbeing-centred care model and a care delivery program with a holistic focus. The Bupa wellness hubs are led by nurse practitioners in partnership with general practitioners and allied health teams who review and manage multidisciplinary care – including telehealth. The Wellness Hubs are already having a positive impact on resident outcomes. These include proactive healthcare management, enhanced admission experiences, smoother care transitions, reduced hospital transfers, and improved clinical indicators (ARIIA, 2023).

These suggested outward looking models of care require different perspectives and skills in addition to those gained through clinical training. Public health perspectives and community development skills need to be added to the aged care team, through revising staff profiles, arranging secondment from community services, or seeking the necessary skills from volunteers. However, it takes time and a concerted effort to recognise that change is needed and desirable. A combination of behavioural, cultural and systems change is required and resistance to such changes will be encountered along the way.

- **INSPIRED Model of Care**

The INSPIRED model has been promoted as an effective evidence-based approach to provision of end-of-life care for residents at RACHs (Chapman et al., 2018; Forbat et al., 2019; Forbat et al., 2024; Rainsford et al., 2020). Research has found that this model's use of monthly needs rounds with RACH staff and specialist palliative care facilitates care planning for residents with high symptom burden or complex needs at end of life. An economic evaluation highlighted that an investment of $75 million for increase nurse practitioners and multidisciplinary services would result in between $135 and $310 million reduction of costs due to hospitalisations and emergency services (Forbat et al., 2020; Palliative Care Australia & KPMG, 2020).

However, it is worth noting the resources required by such initiatives may impose limits on their relevance and sustainability if the resources to enact the program are not provided, as many require the participation and/or supervision of nurse practitioners, not always available to aged care services, while care in practice is provided overwhelmingly by staff at Personal Care Assistant (PCA) level. Programs that equip and support PCAs through training and mentoring (rather than primarily focusing on registered nurses) also warrant further attention.

CONCLUSION

Provision of quality palliative care services for residents of RACHs can facilitate quality of life at end of life and foster a good death for the resident, their family and RACH staff. To do so, additional training and increased capability of staff is required, care should be effectively planned and coordinated, communication between RACH staff, residents, families and other agencies needs to improve, and the quality of care provided should allow the resident to live and die with dignity.

Current systems are geared to doing tasks (with ever-increasing burdensome administration) rather than facilitating connections between residents and with the wider community, thus contributing to loneliness, learned helplessness, lack of self-agency and internalised ageism of residents. This change in culture requires commitment, resources and a process which put residents stated needs and aspirations at the centre, so residents are not merely 'cared for' but also 'cared about'. The scale and imminent impact of ageing we are soon facing requires a whole of community urgent response and collaboration across health and social care is critical.

Ultimately, to achieve an effective, affordable & sustainable end-of-life care system, a public health approach based on a close partnership between clinical services and communities/civic institutions is the optimal practice to be infused in any model of care (Figure 20). "The New Essentials concept proposes a way of integrating the processes and operations of the four basic components— specialist palliative care, generalist palliative care, compassionate communities and civic end-of-life care—that make up palliative and end-of-life care" (p.4, Abel et al., 2018).

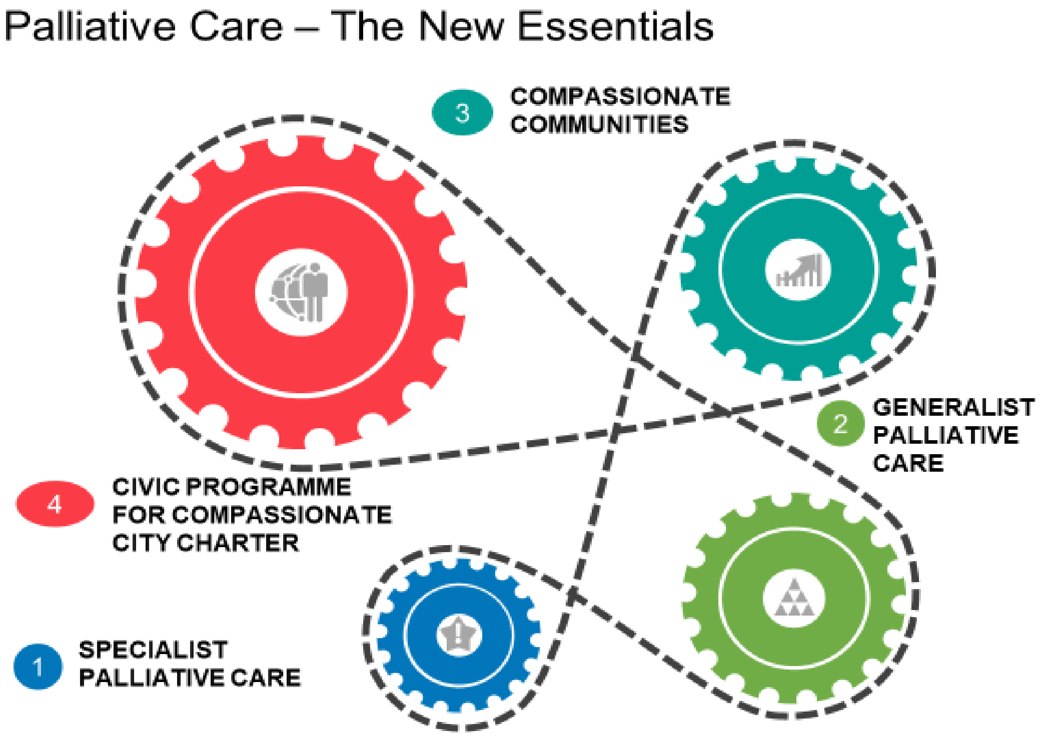

Figure 1: The New Essentials Palliative Care Model (Abel et al., 2018)

INTRODUCTION

In May 2020, the Department of Health WA entered into the National Partnership Agreement for Comprehensive Palliative Care in Aged Care (NPA). The purpose is to improve palliative and end-of-life care coordination for older Australians living in Residential Aged Care Facilities (RACHs).

The national NPA evaluation is being conducted by consulting firm ‘Nous’, whilst state-based monitoring and analysis is being undertaken by the Western Australian Department of Health End-of-Life Care Program. Nous has addressed the impact of COVID-19 on the NPA.

In July 2023, the Perron Institute were commissioned by the Western Australian Department of Health End-of-Life Care Program (EOLCP) to conduct an independent ‘deep-dive’ impact evaluation.

This approach ensured that existing reporting and data collection efforts were not replicated, as the EOLCP reports to Nous on a bi-annual basis responding to Nous evaluation questions.

Detailed monitoring and analyses of the nine individual NPA projects was outside the scope of the independent evaluation.

The agreed upon scope and methods of the WA independent ‘deep dive’ impact evaluation were designed to elicit the specific views of consumers (bereaved carers) and service providers (RACH staff).

Evaluation Objectives

The overarching aim of this evaluation was to understand the broader impact of WA’s NPA initiatives on residents, families, carers and service providers. The objectives were to: (i) to gain a consumer perspective on palliative care in RACHs, (ii) to identify key challenges/gaps in the provision of end-of-life care (EOLC), and (ii) to determine how service delivery can adapt and improve to meet community needs and expectations.

This was achieved by undertaking a consumer survey (Phase 1), service provider consultations around the consumer survey findings (Phase 2) and an RACH staff survey on the NPA initiatives (Phase 3). Based on the combined study findings, service and sector improvements recommendations were provided for long-term planning.

Policy Context & Frameworks

There were three policy frameworks utilised in the design of the independent evaluation:

1. WA End-of-Life & Palliative Care Strategy Priorities (Department of Health WA, 2018, p. 6)

2. WA NPA Project Logic Map (End of Life Care Program, 2021)

3. National Outcomes (Nous, 2021, p. 11)

Current Landscape WA

The broader landscape within which this independent evaluation was carried out must also be considered, as macroenvironmental changes that took place across WA between 2021-2024 may have influenced responses received from both consumers and service providers. These factors consider demographic, economic, natural, political and socio-cultural changes. At the national level, these considerations have been well documented (Nous, 2020 p.6-7; Nous, 2024 p.14-17). It is worth noting the new Aged Care Act is set to take effect from July 2025 and will impact all states and territories (Department of Health and Aged Care, 2024).

A review of the academic literature and mainstream media coverage specific to WA during the period 2021 – 2024 provides an overview of the potentially influential factors relevant to the cohorts who participated in this study.

Aged Care Workforce Capacity

In 2021, ACIL Allen conducted a study into the economic and social contribution of the aged care sector in WA, concluding labour shortages were an increasingly significant issue for the sector that would constitute a crisis. In conjunction with capacity constraints across public hospitals, the delivery of essential services to aged care residents was noted as a potential financial risk to the state government and health risk to individuals and communities more broadly (ACIL Allen, 2021).

Research conducted in WA similarly noted challenges with attracting and retaining aged care assistants (Dhakal et al., 2020) and the intersection between migrant workers and high staff turnover in RACHs, with employees from CALD communities citing limited support networks, communication challenges and racial discrimination (Adebayo et al., 2023).

Changes Influencing End-of-Life and Palliative Care

There were two key legislative changes that took place in WA during this period including the introduction of Voluntary Assisted Dying (VAD) laws from July 2021 and lifting the State of Emergency declared in WA as a result of the COVID-19 pandemic from September 2022.

Social and cultural norms surrounding death, dying and bereavement for residents living in aged care facilities and their families were directly impacted by the changes to public health measures designed to stop the spread of COVID-19. Visitation allowances for residents that include overnight visitors were restricted. Since then, the use of telehealth in WA RACHs has increased (WAPHA, 2023).

The Australian Centre for Disease Control issued guidelines for the management of acute respiratory infections in aged care facilities which suggest limiting visitation where outbreaks occur but recommend residents receiving palliative care be relocated to better support visitation (ACDC, 2024). There are still concerns surrounding the rates of vaccination against COVID-19, with less than 10% of RACH residents in WA currently vaccinated (RACGP, 2024).

Evaluation Design & Methods

A convergent mixed method approach was adopted when designing the evaluation to obtain a more complete understanding of the impact of WA's NPA initiatives on residents, families, carers and service providers (Creswell & Plano Clark, 2018). Figure 1 provides an overview of the convergent mixed method design adapted to this evaluation.

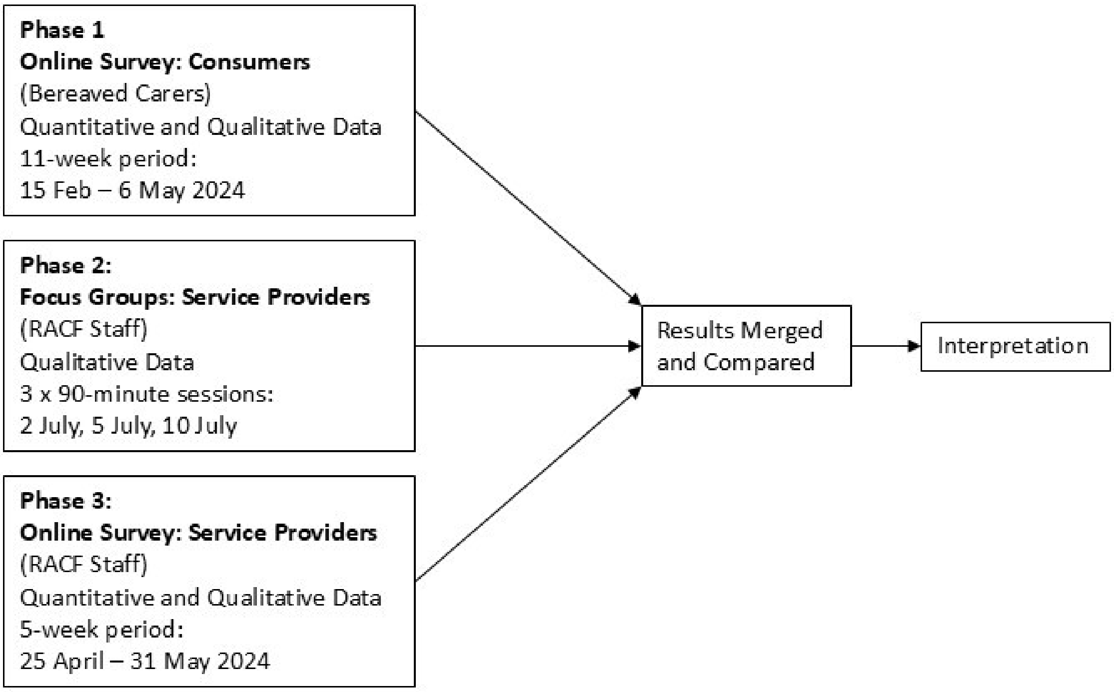

Figure 2: Convergent Mixed Method Design

Ethics Approval

The University of Western Australia's Human Research Ethics Committee granted approval for the 'Evaluation of the National Partnership Agreement (NPA): Comprehensive Palliative Care in Aged Care in Western Australia' (2023/ET000833) on 17 November 2023.

Project Reference Group

In addition to the Perron Institute research team, a reference group was formed to guide the evaluation, with representatives from major stakeholders such as Department of Health WA employees, residential aged care service providers, clinicians, academics, and leaders from consumer advocacy groups and organisations. Appendix 1 lists their names and affiliations.

The reference group convened prior to the project commencing and met regularly at each stage of the evaluation where new information was available, and feedback was required. The availability of individual reference group members varied and where online meeting attendance was not possible, feedback was often provided to the research team via email.

Data Analysis

Quantitative data from the consumer and service provider surveys were analysed using descriptive statistics of response items (i.e., reporting as counts and percentages for each item category), and inferential statistics (e.g., chi-square tests of independence) conducted on nominal and ordinal response items. Qualitative data were subject to thematic analysis and illustrative quotes were included to amplify the voices of bereaved consumers and RACH employees.

PHASE 1:
Consumer Survey
(Bereaved Carers)

PHASE 1: CONSUMER SURVEY

Background

In 2020, a cross sectional mixed-method survey was developed to understand consumers perspectives about palliative care in Western Australia (Aoun et al., 2021), based on the six priorities outlined in WA's End-of-Life and Palliative Care Strategy (2018-2028) (Appendix 2):

1. Care is accessible to everyone, everywhere.
2. Care is person-centred.
3. Care is coordinated.
4. Families and carers are supported.
5. All staff are prepared to care.
6. The community is aware and able to care.

The survey instrument was adapted for use in this evaluation in collaboration with reference group members to suit the intended audience (bereaved carers) and care setting (RACHs). Questions were grouped under subheadings guided by the six priorities: carer and resident demographics; experience with and quality of care in the RACH; formal and informal support before death, at the time of death, and after death.

The online survey comprised a maximum total of 138 questions including all logic flow and 28 of these were open-ended text for the collection of qualitative data. The estimated time to complete the survey was approximately 30 minutes.

Sampling Strategy

There were several considerations in determining the sampling strategy for the consumer survey given the aim to understand peoples' experiences with and perspectives of end-of-life and palliative care across RACHs in WA. In consultation with reference group members, bereaved carers were determined to be the most appropriate participant group compared with carers whose relatives are currently RACH residents, and residents themselves:

- Bereaved carers had previously been more responsive to online surveys than current carers and patients in a similar study conducted within WA (Aoun et al., 2021).
- Bereaved carers would be able to provide a retrospective account of their experiences with end of life and palliative care services in RACHs including their bereavement needs.
- Bereaved carers may be less influenced by "social desirability bias" than current carers whose relatives are still reliant on RACH staff for care. That is, the tendency to answer questions based on what others may think so that they may be viewed more favourably.

As WA's NPA initiatives commenced from 2021 onwards, the potential influence of NPA initiatives on residents, families and carers experiences and perspectives could only be captured if bereaved carers relatives or friends died in a RACH in WA from 2021 – 2024.

Participant Recruitment

The online consumer survey was live for a period of 11 weeks from 15 February – 6 May 2024, hosted via REDCap and accessible via a customised webpage on the Perron Institutes website. Downloadable digital assets were available on the webpage for promotional purposes and included an e-newsletter template, A4 Flyers, QR codes and social media tiles. The integrated marketing campaign comprised of paid Facebook advertising using A/B creative testing, a print ad in The West Australian newspaper, third party promotional activities, e-Newsletters, mass email distribution and engaging a market research firm with access to a paid research panel in WA (Appendix 3).

Results

A total of 317 valid and complete responses were received from bereaved carers who had a relative die in a WA RACH (2021-24).

Characteristics of Sample

Snapshot of Bereaved Carers' Profile

More than half of carers who completed the survey identified as female (63%), median age 51 years. Non-English-Speaking people made up 8% of survey responses and Aboriginal and Torres Strait Islander peoples made up 3%. Almost half of carers were university educated (47%), with just under a third holding a trade qualification (30%). Two thirds of carers were married/partnered (62%). A third of carers identified as their relative's main carer (30%), and over half reported their relationship to the deceased as being a female relative such as daughter/granddaughter (55%). More than one third (36%) of carers provided hands-on care for their relative before they moved into an RACH.

Table 1: Bereaved Carers' Characteristics (N=317)

Gender	**(n)**	**(%)**
Female	200	63
Male	116	37
Non-Binary	1	0
Total	317	100
Age Group	**(n)**	**(%)**
18-24	27	9
25-39	78	25
40-54	67	21
55-74	121	38
75+	16	5
Total	309	97
(Median=51 years, Range=18-91)		
Cultural Background	**(n)**	**(%)**
Australian	259	82

Other English Speaking	32	10
Non-English Speaking	26	8
Aboriginal Torres Strait Islander	9	3
Total	326	103
Education	**(n)**	**(%)**
High School	72	23
Diploma/Certificate/Trade	94	30
University Degree	149	47
Total	315	100
Employment	**(n)**	**(%)**
Working Full Time	143	45
Working Part Time	78	25
Carer Full Time	16	5
Student Full Time	11	4
Unemployed	4	1
Retired	56	18
Other (Disability Support Pension)	8	3
Total	316	100
Marital Status	**(n)**	**(%)**
Never Married	78	25
Married/Partnered	195	62
Separated/Divorced	27	9
Widowed	16	5
Total	316	100
Residential Postcode	**(n)**	**(%)**
Metro	255	84
Rural (Country WA)	48	16
Interstate	1	0
Total	304	100
Main Carer	**(n)**	**(%)**
Yes	93	30
No	221	70
Total	314	100
Relationship to the Deceased	**(n)**	**(%)**
Spouse	13	4
Female Relative	174	55
Male Relative	92	29
Friend	36	11
Other	1	0
Total	316	100
Level of Care Provided Before RACH	**(n)**	**(%)**
Hands-On Care Daily	79	25
Hands-On Care Intermittently	114	36
Hands-On Care Rarely	37	12

No Hands-On Care Provided	75	24
Other	8	3
Total	313	100

Snapshot of Residents' Profile

The gender distribution of deceased residents was 55% female and 45% male, with a median age of 86 years, and 84% were in the metro area. Almost half of residents were reported as having a dementia diagnosis (46%) and co-occurring frailty due to old age (49%). Residents spent a median of 1.8 years in the RACH before their time of death, reported as being between January 2021 and May 2024. Less than half of carers (41%) reported their relative accessed palliative care services whilst a resident in the RACH, less than one third (31%) reported their relative did not receive palliative care services, whilst the remainder of carers reported they were not sure (29%). 46 RACHs were mentioned in the consumer survey.

Table 2: Residents' Characteristics (N=317)

Gender	**(n)**	**(%)**
Female	172	55
Male	142	45
Total	314	100
Resident Age at Death	**(n)**	**(%)**
64 and under	5	2
65-74 years	19	6
75-84 years	105	33
85 and over	188	59
Total	317	100
(Median=86 years, Range=60-102)		
Formal Documentation*	**(n)**	**(%)**
Advance Care Plan	111	35
Advance Health Directive	99	31
Enduring Power of Guardianship	153	48
Goals of Care	31	10
Other (Enduring Power of Attorney)	5	2
**Multiple Responses*		
Postcode of RACH	**(n)**	**(%)**
Metro	264	83
Rural (Country WA)	53	17
Total	317	100
Postcode Before RACH	**(n)**	**(%)**
Metro	255	84
Rural (Country WA)	48	16
Total	303	100
Known Health Conditions*	**(n)**	**(%)**

Frailty due to old age	156	49
Dementia	145	46
Heart condition	44	14
Lung condition	18	6
Cancer diagnosis	45	14
Neurological condition	21	7
Other	28	9
**Multiple Responses*		

Palliative Care Engagement	**(n)**	**(%)**
Yes	129	41
No	97	30
Unsure	91	29
Total	317	100
ED Visits in RACH Total *(Median=1, Range=0-40)*		
ED Visits Last Month of Life (n=214) *(Median=1, Range=0-26)*		
Length of Time in RACH (n=274) *(Median=1.8years, Range=3days-12.5years)*		
Date Admission to RACH *(Range=Feb 2011-May 2024)*		
Date of Residents Death *(Range=Jan 2021-May 2024)*		

Residents Place of Death

Over three quarters of residents died at the RACH (78%), although that was the stated preference of only 21% of residents and 34% of carers. However, half of the residents did not have a preference, or their preference was not discussed.

Table 3: Actual and Preferred Place of Death

	Actual	**Resident Preference**	**Carer Preference**
Residential Aged Care Home	78%	21%	34%
Home	-	27%	22%
Hospital	18%	1%	3%
Hospice / Palliative Care Unit	4%	2%	5%
No Preference	-	27%	25%
Not Discussed	-	22%	9%

Groups for Comparison

Analyses focused on comparing quality indicators across three key variables:

- Whether the deceased relative engaged with palliative care services during their time at the RACH: palliative care user (PC Yes), palliative care nonuser (PC No), or unsure (PC Unsure);
- The geographic location of the RACH in WA: metropolitan or rural (Country WA); and
- Whether the survey respondent identified as their relative's main carer: main carer or secondary carer.

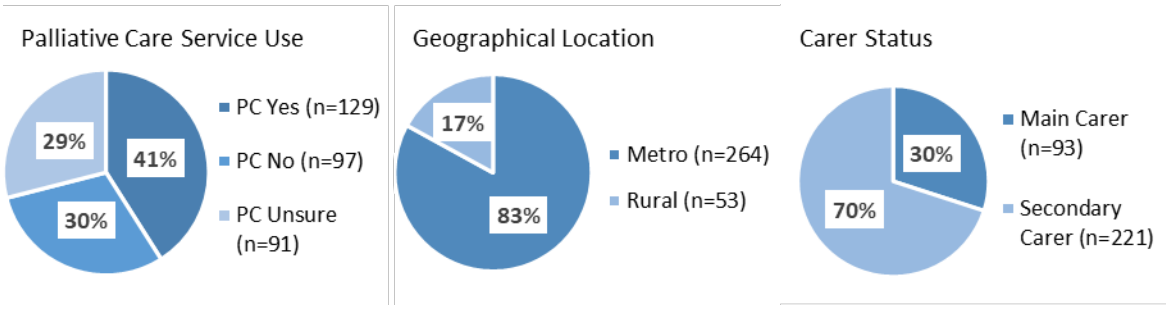

Figure 3: Comparison Groups

The comparisons were undertaken across three variables: use of palliative care (PC) (n=129)/non-use of PC (n=97)/ unsure (n=91); metro (n=264)/rural (n=53); and carer status whether main carer (n=93)/secondary carer (n=221). Each of these analyses has been conducted for each priority area.

There were more secondary carers in the unsure group: 14% main carers were in the unsure group vs 35% of secondary carers in unsure group ($p<0.001$).

There were more rural people in the unsure group: 26% of metro respondents were in the unsure vs 43% of rural respondents in unsure group ($p=0.006$).

Comparison of Quality Indicators Between Groups for Each Priority

The results are presented as overall total quality indicators with scores 65% or higher being positive (what is working well) or quality indicators with room for improvement where the scores are lower than 65% (what is not working so well). This is followed by comparisons between the three palliative care user groups, the two groups of carer status, the two regional groups, and quotes from bereaved carers reflecting these results (both positive and not so positive).

It should be noted that Appendix 4 contains detailed quantitative results pertaining to each of the indicators across all six priority areas. Whilst figures in the tables featured in the appendix are reported to 1 decimal place, they are cited as whole numbers in the body of the report for ease of use for the reader. Whilst the total sample size was N=317, the tables in Appendix 4 indicate the total number of responses for each individual question.

Priority 1: Care is accessible to everyone, everywhere

Table 4: Overall quality indicators for total sample- Priority 1 (Appendix 4-Priority 1)

What is working well…	What is NOT working so well…
• 79% for overall quality of care (excellent/good) • 75% could access care as soon as they needed. • 72% for quality of care at EOL (excellent/good) • 69% for relief of pain (excellent/good) • 65% for practical assistance (excellent/good)	• 42% received as much support as wanted after resident's death • 49% for receiving enough support at the time of death (definitely) • 52% received as much support as wanted overall (definitely) • 63% for relief of symptoms other than pain (excellent/good)

Priority one key differences (Figure 3): For the majority of the indicators in Priority one, PC users reported higher quality than the other two groups (non-users and unsure), except for relief of pain, practical assistance and quality of care at end of life where the three groups were nearly similar in their reporting of these being excellent/good. The significant differences between the three groups were in receiving as much support as wanted overall (p=0.003) and receiving enough support at time of death (p=0.007). In general, the unsure group had higher rates than the non-user group. Overall quality of care was slightly higher for the user and the unsure groups (at over 80%) compared to the non-users (73%).

The indicators with the highest quality for users at about 80% were for "overall quality of care provided" and "quality of care at end of life". The indicator with the lowest quality for users at 47% was for "receiving as much support as wanted after the resident's death" followed by 59% for "receiving enough support at the time of death".

The differences by metro/rural and by carer status were not pronounced.

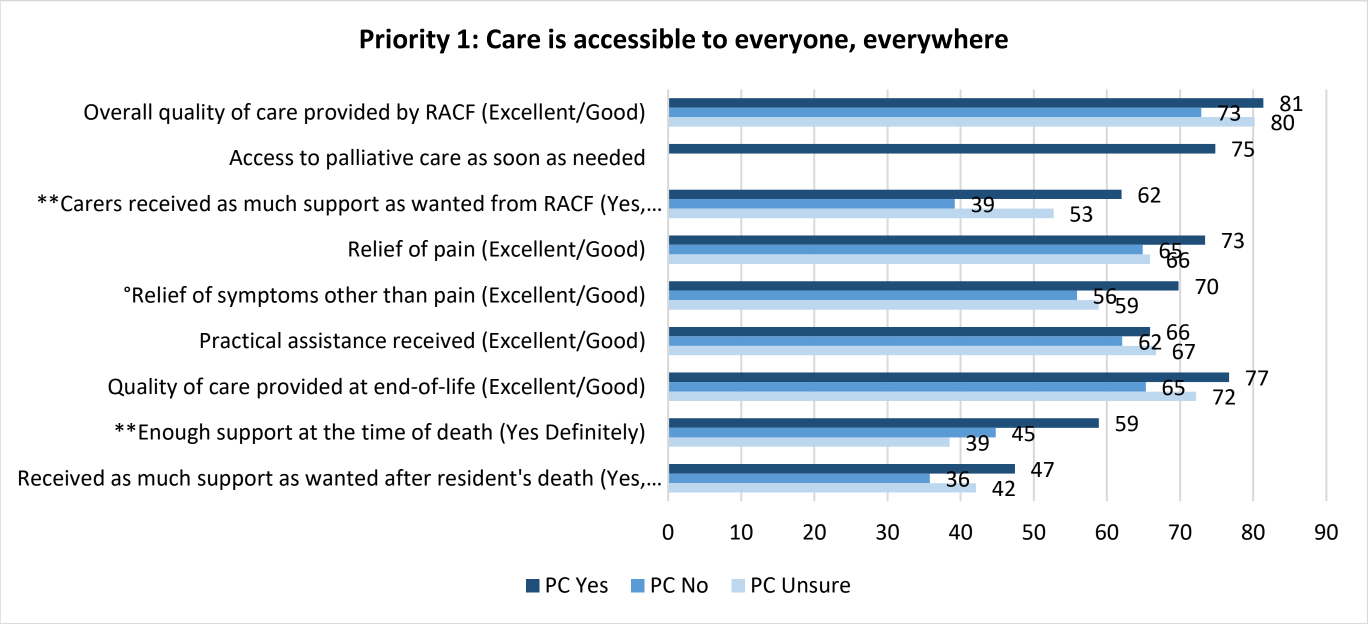

Figure 4: Comparison by palliative care user groups – Priority 1

*Chi-square p-values: *** <0.001, ** <0.01, * <0.05, ° <0.1*

Quotes from Bereaved Carers

"Mum received amazing care for the entire time she was in care. The Residential Care Facility team felt very much like an extended family." (Bereaved Carer 64)

"Mum, Dad and I had discussed their end of life wishes many times over the last few years, so we all knew what to expect and what we wanted. Mum's death and dying was perfect. It was exactly as she wanted it to be." (Bereaved Carer 10)

"My mum's passing was the worst experience of my life, I'm still traumatised by the experience. She was gasping, gaging, and looked like she was in so much pain." (Bereaved Carer 80)

"Mum was definitely not in pain in the hospital, I knew the treatment she'd receive in the nursing home might not be quite up to hospital standard, but I didn't realise just how bad it would be." (Bereaved Carer 68)

Priority 2: Care is person-centred

Table 5: Overall quality indicators for total sample- Priority 2 (Appendix 4-Priority 2)

What is working well…	What is NOT working so well…
• 88% of the residents' documented wishes were considered • 74% had values respected and considered • 65% able to discuss worries/fears with staff	• 63% asked about EOL documentation • 62% indicated the inclusion of residents in care decisions as excellent or good • 61% carers involved in care decisions at EOL as much as wanted • 60% indicated the residents' cultural background was always or most of the time respected and considered

	• 58% indicated the inclusion of carers in care decisions as excellent or good • 58% emotional support provided to resident was excellent or good • 58% indicated the residents' spiritual/religious beliefs were always or most of the time respected and considered • 53% indicated that the residents were involved in care decisions at EOL as the residents wanted • 43% indicated that spiritual support provided to residents is excellent or good

Priority Two key differences (Figure 4): For the majority of the indicators in Priority two, users reported higher quality indicators than the other two groups. The indicator with the highest quality for users at 92% was for "documented residents' wishes being considered" followed by 78% for "values being respected". The indicator with the lowest quality for users at 52% was for "spiritual support provided" followed by 57% for "residents being involved in care decisions". As a whole sample, 17% of decisions were made without the carers or residents wanting it, and this proportion was lower for the users (13-16%) and higher for the non-users (21-22%). The three indicators that showed significant differences, with users outperforming the other two groups, were: Carers being asked about EOL formal documentation; Inclusion of residents in decision making; carers involved in decisions about EOLC; cultural and religious/spiritual beliefs respected; carers able to discuss worries/fears with RACH staff.

Metro respondents reported being asked about pre-existing EOL documentation more than the rural respondents (65% vs 51%, p=0.049). "Care decisions that the residents would not have wanted" indicator was more prevalent in rural areas (25% vs 15%, p=0.09).

Main carers reported being asked about pre-existing EOL documentation a lot more than the secondary carers reported (85% vs 54%, p<0.001).

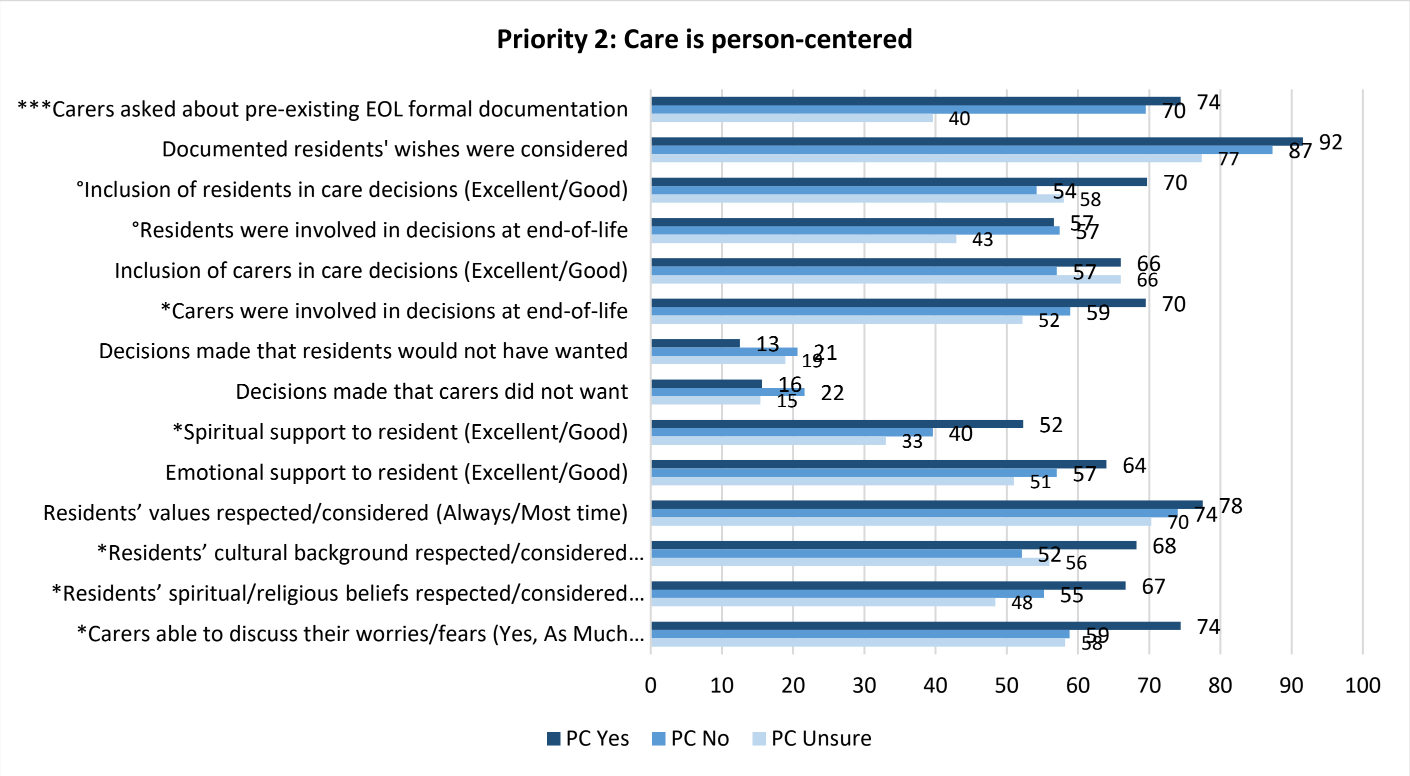

Figure 5: Comparison by palliative care user groups-Priority 2

*Chi-square p-values: *** <0.001, ** <0.01, * <0.05, ° <0.1*

Quotes from Bereaved Carers

"We couldn't fault them in their care for Mum in the last 48 hours or with my sister and I in supporting our emotional needs. Highly rated staff." (Bereaved Carer 46)

"As a Catholic, mum was able to have our local priest visit regularly and take communion. The resident chaplain was also very helpful and supportive of mum." (Bereaved Carer 92)

"As there were so many staff changes, communication was not effective. We needed to be checking and supervising all the time to the point, that we had wondered if we should have kept her at home with 24/7 nursing. It was really hard as we couldn't leave her alone at all although she was in an aged care facility and paying dearly to be there". (Bereaved Carer 9)

Priority 3: Care is coordinated

Table 6: Overall quality indicators for total sample-Priority 3 (Appendix 4-Priority 3)

What is working well…	What is NOT working so well…
• 83% RACH staff worked well with visiting pall care team (definitely/to some extent) (for palliative care service users only) • 80% members of visiting pall care team worked well together team (definitely/to some extent) (for palliative care service users only)	• 59% had planned out of hours care if condition declined • 59% thought visits to ED were helpful

• 76% RACH staff worked well with GP team (definitely/to some extent)	

Priority Three key differences (Figure 5): Users reported high levels of coordination (over 80% for definitely/to some extent) within PC team members, between RACH staff and PC team; 87% worked well with GPs; 67% reported that ED visits were helpful and 72% had planned out of hours care, while the other two groups had much lower proportions for these indicators. All these differences were significant.

Significant differences were reported between metro and rural respondents in care coordination. Metro group reported high levels of coordination (over 80%) within PC team members and between RACH staff/ PC team compared to the rural group (50%), however the rural sample size was much smaller.

Main carers reported slightly more planned out of hours compared to secondary carers (67% vs 56%), with difference tending to be significant (p=0.056).

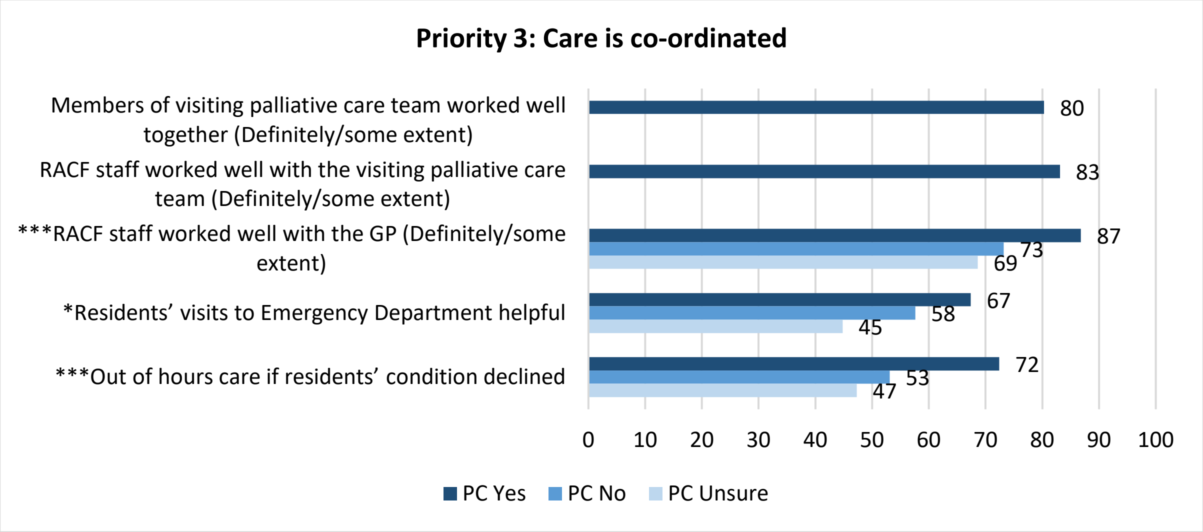

Figure 6: Comparison by palliative care user groups-Priority 3

*Chi-square p-values: *** <0.001, ** <0.01, * <0.05*

Quotes from Bereaved Carers

"Overall, it was my strong impression the onsite nursing staff, GP, NP and other allied health professionals all worked well as a team - one of the few occasions I've seen team-based care work effectively." (Bereaved Carer 24)

"Lack of availability of a doctor led to a lot of delays. There seemed to be no failsafe communication system in place for staff either, so the continuity of care was lacking. Without my assistance, things were often not done, from one shift to the next. Despite this, I still believe the staff often did the best they could." (Bereaved Carer 56)

> *“They were polite to each other. However, because the staff had not increased Mum's pain medication, the visiting team was not able to increase the dosage administered by the morphine pump. I got the distinct impression the nursing staff didn't know how their actions affected the ability of the visiting team to do their work.” (Bereaved Carer 68)*

Priority 4: Families and carers are supported

Table 7: Overall quality indicators for total sample- Priority 4 (Appendix 4-Priority 4)

What is working well…	What is NOT working so well…
• 68% info provided to carers about resident’s condition	• 61% emotional support to carers • 33% offered info about grief and bereavement services • 30% could stay at RACH overnight • 27% contacted in the weeks after resident death • 16% carers spoke to services about their experience of illness/death • 15% carers contacted about 6 months after resident death

Priority Four key differences (Figure 6): Overall, the lowest quality indicators were in how families and carers were supported, and the lowest being “support after residents’ death”, with the users group faring slightly better than the other two groups but still as low as 20-30% in quality. The three indicators showing a significant difference between the three groups were: information provided to carers about resident’s condition; carers could stay overnight; carers offered information about grief and bereavement.

Although the quality indicators were very low by region, metro respondents reported more support in the weeks after death (28% vs 19%), more support in the months after death (17% vs 8%) and were offered more information on grief and bereavement services (35% vs 23%).

Overall, main carers reported being better supported than secondary carers in terms of being able to stay with the resident overnight (41% vs 24%), more supported in the weeks/months after death (38% vs 22%; 21% vs 12%) and were offered more information on grief and bereavement services (41% vs 30%) and all these differences were significant. It may well be that primary carers were the ones being focused on for more support because of their more hands-on care and more frequent visits to RACH.

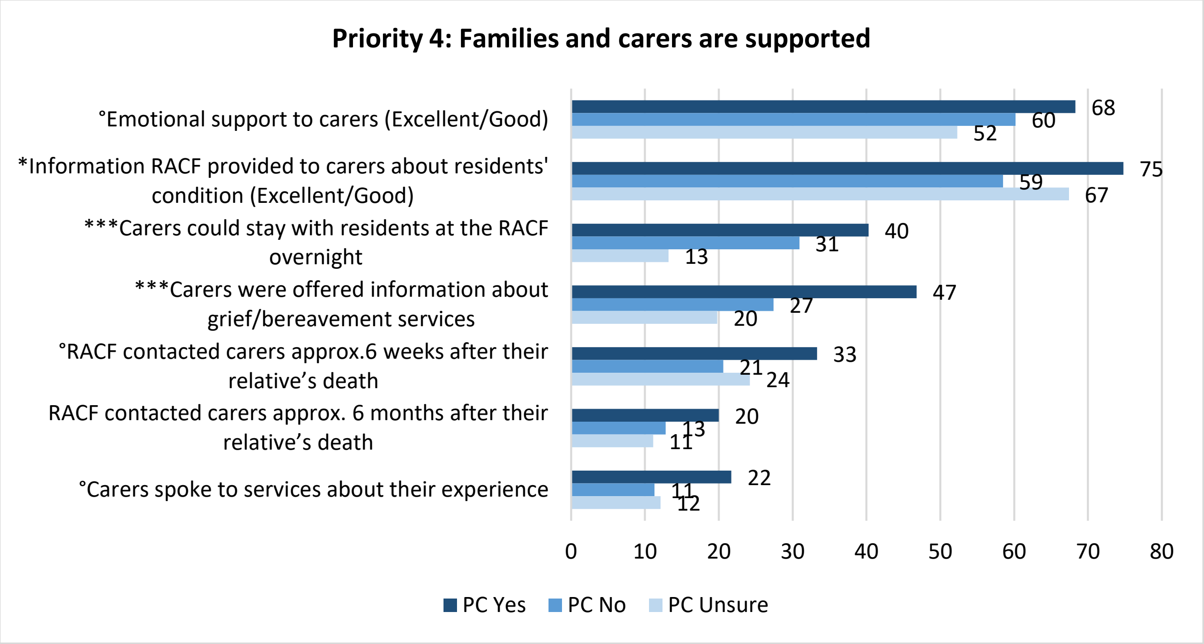

Figure 7: Comparison by palliative care user groups-Priority 4

*Chi-square p-values: *** <0.001, ** <0.01, * <0.05, ° <0.1*

Quotes from Bereaved Carers

"During the dying process my sister and I were able to stay by mum's bedside, a total of 4 nights and 3 days. During that time the staff looked after mum with great love and care. They regularly moved her, changed her, and checked on her pain medication. The family were able to come and go as suited them. We were given all the support possible." (Bereaved Carer 17)

"Everyone seemed preoccupied with making sure all of the official procedures were done that there was no actual 'care' given to residents. When issues were brought up with management, we felt we were not listened to and labelled whingers." (Bereaved Carer 73)

"Staff were not understanding of the urgency of the situation surrounding the loved one's death, was held up on entry to nursing home and missed last moments of their life." (Bereaved Carer 84)

Priority 5: All staff are prepared to care

Table 8: Overall quality indicators for total sample- Priority 5 (Appendix 4-Priority 5)

What is working well…	**What is NOT working so well…**
• 86% perceived staff as very competent/competent • 84% said that residents were treated with compassion/kindness • 83% residents treated with respect/dignity • 80% carers treated in a sensitive manner	• 63% provided with info when requested

Priority Five key differences (Figure 7): This priority on “all staff prepared to care” has one of the highest quality indicators (high 80%) for users and the unsure group in terms of “being treated with respect and dignity, with compassion and kindness and the competence of staff”. However, the non-user group had lower rating for staff competence than the other 2 groups (p=0.025). The user group fared better in terms of being provided with information when requested (p=0.027).

There were no pronounced differences by metro/rural or carer status.

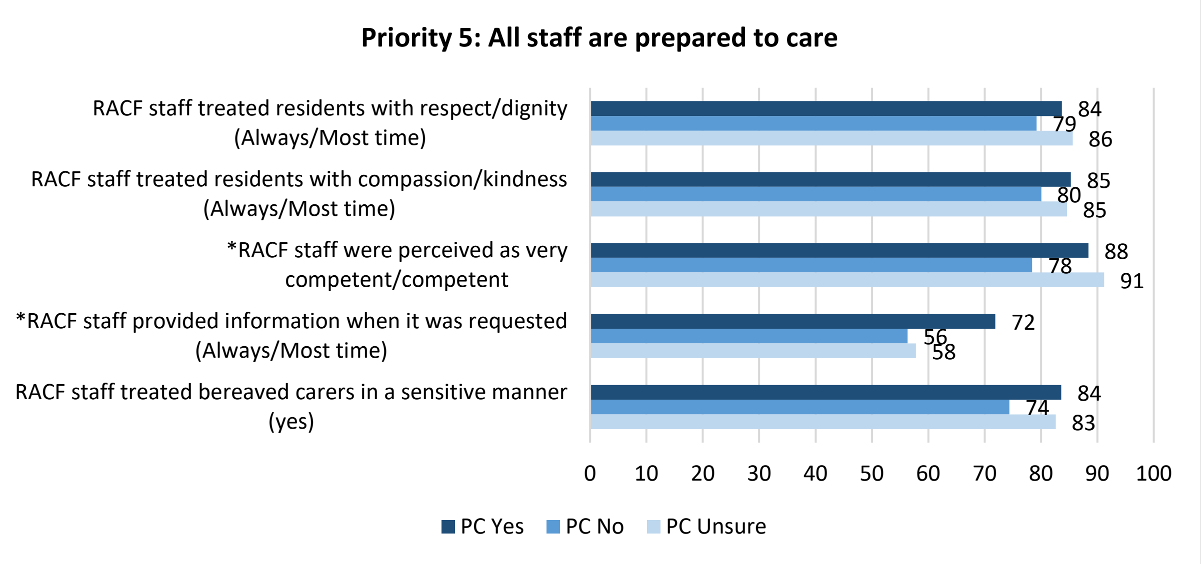

Figure 8: Comparison by palliative care user groups-Priority 5

*Chi-square p-values: *** <0.001, ** <0.01, * <0.05*

Quotes from Bereaved Carers

“Staff came to Mum's room to pay their respects and were visibly upset when Mum died. This was very touching and comforting to know that she was well thought of and cared for by the team.” (Bereaved Carer 64)

“Competent in most day-to-day care but very limited skills in palliative care demonstrated multiple times during end-of-life care.” (Bereaved Carer 12)

“Staff seemed stressed and therefore unable to provide as much kindness and compassion to patients as I would have liked to see considering the cost”.

“It was all quite cold in the sense that the communication was made he has passed, and then they wanted the room cleaned out as soon as possible of personal belongings to make room for the next patient.” (Bereaved Carer 71)

Priority 6: The community is aware and able to care

Table 9: Overall quality indicators for total sample- Priority 6 (Appendix 4-Priority 6)

What is working well…	**What is NOT working so well…**
• 89% received informal support *before* and *after* death • 86% perceived helpfulness of informal support *before* and *after* death (very/quite helpful)	

Priority Six key differences (Figure 8): Informal support includes support from family, friends and also from not-for-profit organisations. There were high quality indicators of informal support or its helpfulness before and after death (high 80s). The user group reported having more informal support before death compared to the other two groups (p=0.029), possibly because palliative care services are more likely to signpost to not for profit organisations (Aoun et al., 2017).

There were no differences in the regional and carer status distribution.

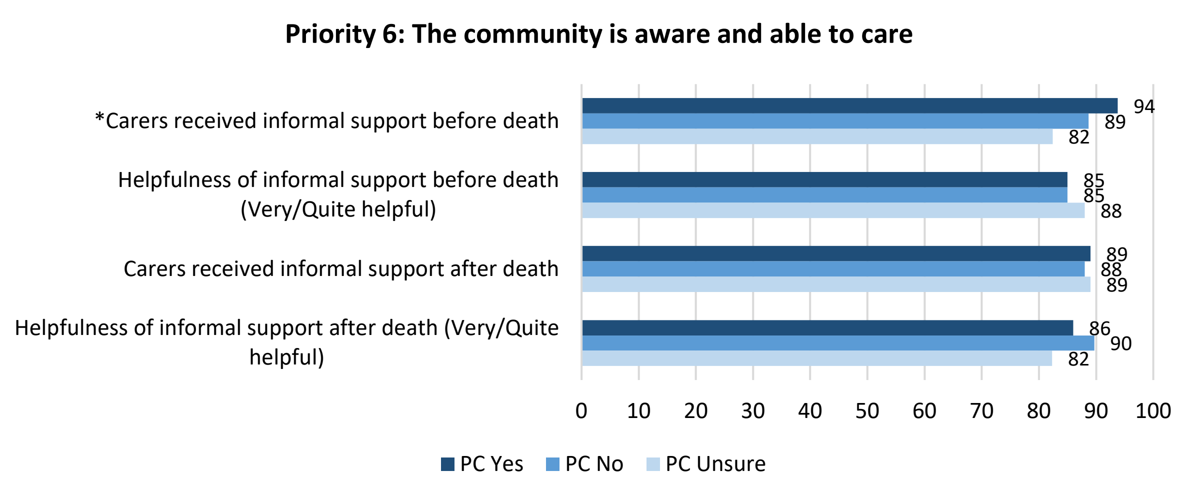

Figure 9: Comparison by palliative care user groups-Priority 6

*Chi-square p-values: *** <0.001, ** <0.01, * <0.05*

Quotes from Bereaved Carers

"Availability of family to sit with him as he died over the course of a week. He was hallucinating at the end and regularly falling off the bed if someone didn't stop him. He needed constant reassurance. We did not think this could be provided by the aged care facility." (Bereaved Carer 67)

"Carers WA was the only practical and caring support I received throughout my 8 years as a carer. It provided me a free course online which I graduated, free counselling and networking with other carers who were enduring the same path." (Bereaved Carer 32)

"Other family or friends who thought it best to "stay away" as they did not want to be upset seeing mum so ill!!!" (Bereaved Carer 31)

"Lack of communication- people held off talking to us so as not to intrude." (Bereaved Carer 94)

"Lack of knowledge of how to support." (Bereaved Carer 203)

Phase 1- Suggestions For Improvements

Bereaved carers suggested the following to improve the experience of residents and their families: improve staff skills and availability, quality of care at end of life, access to and care from GPs, communication of staff with family members, and overall care at the home.

RACH Staff availability and training

A repeated theme raised by bereaved carers was the belief that RACH staff needed additional training and skills in providing care to residents at end of life. They were concerned that the limited knowledge negatively impacted the care provided to their family members. Bereaved carers also commented that limited nursing and personal care attendants also affected how the resident was cared for, with residents needs not being addressed in a timely manner. They suggested that more staff and consistency with staff members would assist in provision of higher quality care to their family members. Bereaved carers also requested additional availability of occupational therapy and physiotherapy services for the resident.

Quotes from Bereaved Carers

There is huge scope for increasing palliative care knowledge and skills for residential care facility workers… this was concerning for the family and meant it took much longer to achieve good symptom management and comfort. (Bereaved Carer 12)

They need more staff, especially on floors where there are a few residents who needed two-person assistance. (Bereaved Carer 72)

Quality of care provided at end of life

Bereaved carers commented that the quality of care at end of life could be improved through multiple avenues, including:

- More consistent development and review of resident care plans.
- Improve transitions between stages of disease progression, increasing functional decline and challenging behaviours. This requires improved death and grief literacy of staff.
- Targeted care provided for specific conditions, e.g., dementia, Parkinson's.
- Proactivity with care planning and resident needs, not reactive, e.g., commence discussions on palliative care in advance.
- Maintain dignity and respect of residents (e.g., cultural sensitivity, privacy, greater focus on non-symptom management needs such as quality of life, psychosocial, spiritual needs)

Quotes from Bereaved Carers

More dementia reviews and the ability to move to higher level care as needed. … More information and involvement of a palliative care team or staff BEFORE entering palliative care stage so that decisions are made collaboratively and with an understanding of what is happening and why. (Bereaved Carer 56)

Every resident coming into aged care facility should have a palliative care plan set up, family also should be given education on signs of dying and how to support someone die well. It's hard to watch people suffer. (Bereaved Carer 11)

Improve access to and care from GPs

Limited access to GPs was a common thread in many comments, with bereaved carers recommending improved access to and communication with GPs, as well as more timely coordination of medical care when a resident's condition deteriorates. More specifically, family commented that RACHs should have:

- Greater availability outside of business hours
- Greater accessibility to speak directly to GP
- Improve coordination of medical care during palliative stages
- GPs awareness regarding appropriate and timely pain management
    - Adequate pain management plan
    - Access to medications in a timely manner
    - Prescribing the correct amount
    - Review and adjust medications as needed

Quotes from Bereaved Carers

Ensure adequate medical support in nursing home. Ensure adequate plans for pain management. Have appropriate management in end-of-life care to avoid the ongoing pain and suffering of our elderly who should have the dignity to die. (Bereaved Carer 44)

Need better medical services, especially when the carer lives a long way away. The Dr needs to be accessible outside of office hours especially weekends. My mums pain management should have been managed within the facility and not requiring transport to hospital. (Bereaved Carer 42)

Improve communication with and support for family carers

Bereaved carers expressed concern when there was limited communication from the RACH. They suggested that there should be a greater focus on collaborative decision making, which can only occur when information and updates are shared with the family and family are listened to. Bereaved carers recommended that education should be provided to family on the palliative care process, such as navigating the stages of dying, explaining to family what is happening, why, and timelines. They also commented that communication between staff needed to improve, describing how some personal care attendants were unaware of the residents' end of life status.

Quotes from Bereaved Carers

Listen to the family members. Take things seriously. Just because they may have seen events hundreds of times. For the family it is the first time. (Bereaved Carer 12)

More information/updates, more transparency, more sharing of information. (Bereaved Carer 85)

Realistic and timely information about possible end of life experience. (Bereaved Carer 42)

I would improve on the induction into aged care. More personal follow up on how I was coping (it is a big adjustment to be your mother's full-time carer to letting her go into the hands of strangers). Having more resources available of the big emotions I had to process. This guilt of making the decision to put your loved one into care. (Bereaved Carer 39)

Quality of service within the home

Although not directly pertaining to palliative care services, bereaved carers recommended improvements to the general quality of service provided within the RACH. This included improving the mealtime experience (e.g., food, timing, atmosphere); more options for outdoor spaces, outings or activities; and modifications to the residents' living spaces to improve the aesthetic and functional design and reduce the risk of falls and increase comfort. Bereaved carers also suggested that families should have the option to stay overnight with the resident and that additional time would be permitted for bereaved carers to vacate the residents' room after death.

Phase 1- Summary of Highlights

More than half of bereaved carers who completed the survey identified as female (63%), median age 51 years. Almost half of carers were university educated (47%). A third of carers identified as their relative's main carer (30%), over half reported their relationship to the deceased as being a female relative such as daughter/granddaughter (55%), and 84% lived in the metropolitan area. Less than half of carers (41%) reported their relative accessed palliative care services whilst a resident in the RACH, less than one third (31%) reported their relative did not receive palliative care services, whilst the remainder of carers reported they were not sure (29%).

Just over a half of deceased residents were female (55%) with a median age of 86 years, and 84% were in the metro area. Almost half of residents were reported as having a dementia diagnosis (46%) and co-occurring frailty due to old age (49%). Residents spent a median of 1.8 years in the RACH before their time of death, and 78% died in the RACH.

The survey provided useful feedback to services as to where they are meeting the six priorities of the Strategy and where there are still unmet needs as experienced by their consumers.

The overall good quality indicators related to the following: 79% of bereaved carers reported the quality of care as being excellent/good, and 72% reported the quality of end-of-life care being excellent/good. What is also working well is that the staff considered residents EOL wishes that were documented (84%), and residents' values were respected and considered (74%). Care was coordinated between the RACH staff, the visiting palliative care team and the GPs (about 80%). Staff were perceived as competent (86%), they treated residents with compassion/ kindness/ respect/ dignity (84%).

Overall, as a total sample (N=317), the lowest indicators were in:

- **Priority Two** (person centred care) particularly in being asked about EOL documentation; carers and residents involved in care decisions at EOL as much as wanted; emotional support provided to resident; cultural background respected and considered; spiritual/religious beliefs respected and considered.
- **Priority Four** (Families and carers are supported) especially in emotional support to carers; offered info about grief and bereavement services; could stay at RACH overnight; contacted in the weeks or months after resident death; carers spoke to services about their experience of illness/death. Priority Four lagged behind the others. Families reported not being well supported before and after bereavement. By contrast, they rated highly the informal support they received from their social networks and not-for profit organisations.

For the majority of the indicators in all priorities, PC users reported higher quality than the other two groups. It was encouraging to know that palliative care services made the experience of residents and families considerably better in most aspects of care.

<u>Priority One</u>

The indicators with the highest quality for users at about 80% were for "overall quality of care provided" and "quality of care at end of life". The indicator with the lowest quality for users at 47% was for "receiving as much support as wanted after the resident's death" followed by 59% for "receiving enough support at the time of death".

<u>Priority Two</u>

The indicator with the highest quality for users at 92% was for "documented residents' wishes being considered" followed by 78% for "values being respected".
The indicator with the lowest quality for users at 52% was for "spiritual support provided" followed by 57% for "residents being involved in EOLC decisions".
Decisions made that carers/residents did not want was lowest for PC users at 13/16% compared to 21/22% for non-users.

<u>Priority Three</u>

PC users reported high levels of coordination (over 80%) within PC team members, between RACH staff and PC team and working well with GPs. While 67% of user group reported that ED visits were helpful and 72% had planned out of hours care, those scores were much lower of the other two groups.

Priority Four

This priority has the lowest quality indicators in how families and carers were supported, and the lowest being "carers being contacted weeks/months after residents' death", with the PC users group faring slightly better than the other two groups but still as low as 20-30% in quality. Those in the PC group were more likely to have information provided about resident's condition (75%) and could stay overnight at RACH (40%) compared to the other two groups.

Priority Five

This priority had one of the highest quality indicators (high 80%) for users and the unsure group in terms of "being treated with respect and dignity, with compassion and kindness and the competence of staff".

Priority Six

Priority six had high quality indicators for informal support by the community and not for profit organisations for all groups and for the perceived helpfulness of these informal networks.

Similarities with Data from Other Reports

While this sample may not be representative of the general RACH population because of the sampling framework where we could only rely on social media and several consumer and service provider networks to reach out to bereaved carers, it is worth considering these comparisons where there were a number of similarities, bearing in mind that the data in this study were self-reported:

- The age profile of our study sample was similar to that of AIHW data June 2023: 6% vs 10% respectively for 65-75 years; 33% vs 31% respectively for 75-85 years; 59% vs 58% respectively for 85+ year (AIHW, 2023b).
- The proportion of residents living with dementia in our study sample was 46% and quite comparable to 54% (AIHW, 2022).
- As of June 2023, there were 19,887 RACH places in WA and out of these 15% were in rural areas (AIHW, 2023c; Department of Health and Aged Care, 2023). In our study sample, 16-17% of carers and residents were from rural areas. Therefore, the regional distribution in our study seems representative of the total RACH population.
- 78% of residents died in RACHs in our study sample. It is reported in that of older people who were living in aged care in the week before death, 79% died in the RACH (AIHW, 2021), pointing to comparable results between our study sample and the total RACH population.

- The median length of stay at RACH in our WA study was 1.8 years, very similar to the median of 1.7 years for RACH population in June 2023 (AIHW, 2023a).

Phase 1- Conclusions

This consumer survey has provided a detailed exploration of experiences during the caregiving journey through to bereavement, identifying what worked well and what could have worked better. It was encouraging to know that palliative care services made the experience of residents and families considerably better in most aspects of care. Of the six priorities, quality indicators for Priority Two (person-centred care) Priority Four (families and carers are supported) lagged behind the others. Families were not well supported before and after bereavement. By contract they rated highly the informal support they received from their social networks and not-for profit organisations (Priority 6).

The suggested improvements by bereaved carers related to the need to improve:

- RACH staff availability and training
- Quality of care provided at end of life
- Access to and care from GPs
- Staff communication with and support for family carers
- Quality of service within the home

Phase one examining consumers' experiences allows for the triangulation of results between consumers and RACH staff (collected in phases two and three) to explore and understand the challenges and difficulties raised regarding care provision in RACHs and support solutions.

PHASE 2:
Service Provider Consultations
(Consumer Survey Findings)

PHASE 2: SERVICE PROVIDER CONSULTATIONS

Introduction

One of the aims of this independent evaluation was to measure the impact of the NPA on residents living in aged care, their families and Aged Care Home (RACH) providers. This section describes Phase Two, where consultations through focus groups were conducted to obtain feedback from the service providers on the bereaved carers survey results and their suggestions for improvement.

Methodology

To capture staff perspectives of the consumer survey results, four 90-minute focus groups were made available on-line over a span of two weeks on different days and times of the week, to provide sufficient opportunity for RACH staff to attend, as advised by Reference Group members.

The research team met with the Reference Group prior to conducting the focus groups to guide this phase of the evaluation and ensure the recruitment and data collection were relevant to the service providers.

To recruit participants for the focus groups, an email was sent to all RACH service providers with information on the sessions. A summary of the consumer survey results was distributed to participants prior to each focus group for their review.

Group facilitators were experienced researchers and palliative care clinicians. Topic guides were informed by the aims of the study: to elicit service providers perspectives on bereaved carers experiences in RACH. The topic questions to guide discussion were as follows:

- Do the survey results align with your experiences?
- What is working well?
- What are the current challenges?
- What needs improving and how?

Data was collected through recording the focus groups with transcription and detailed notetaking during focus groups. Data collection and analysis were iterative and concurrent.

Findings

Three focus groups were conducted over a two-week period to optimise the number of individuals who could participate. Twenty-two participants from 11 agencies in metropolitan areas attended the focus groups (out of the 37 people who had initially registered for these sessions; no participants from rural areas attended). A fourth focus group was cancelled due to very low enrolment. A variety of professional groups were represented at the focus groups, including staff in leadership positions, allied health (coordinator and clinicians), nurses (enrolled and registered), pastoral care, and care workers. One person attended from

MPaCCS; the remainder of participants worked at RACHs, including Aegis, Hall & Prior, Swan Care, Bethanie, Brightwater, Mercy Care, Juniper, Manoah Homes, Baptist Care and Opal Health Care. All participants consented to participate in the focus groups when registering to attend on the UWA-hosted REDCap platform. The sessions started by a PPT presentation of the summary of findings from the consumer survey (bereaved carers survey), followed by the discussions.

Do the survey results align with your experiences?

Overall, service providers reported that the bereaved carers survey results aligned with their experiences. Service providers agreed with the challenges expressed by bereaved carers, including the RACH General Practitioner (GP) hesitancy at times to address palliative care issues in a timely manner, limited grief support services, and challenges to manage finite resources. Discussion regarding the role of MPaCCS occurred, as some bereaved carers reported not knowing if palliative care services were involved. Service providers discussed the role of MPaCCS as a consultancy service that supports and upskills RACH staff rather than replacing care provided.

Some discrepancy was reported regarding the quality of communication between staff and family carers, with some sites describing good communication regarding end-of-life care and others stating communication could be improved. Service providers described challenges with limited knowledge and skillsets of some care staff regarding disease trajectories and care provision at end of life. Discussions regarding the palliative care services provided to residents and their family carers primarily focused on symptom management and less on psychosocial, spiritual and bereavement support.

What is working well?

Service providers described multiple elements of care provision at their ACH that worked well in supporting residents and their carers at end of life.

- <u>MPaCCS</u>. All service providers in the focus groups reported using MPaCCS. Service providers described that the MPaCCS service worked well with the RACH for residents who were more medically complex at end of life. They described the role of MPaCCS as a service to empower the RACH to manage issues that arose. Service providers reported that GPs supported by MPaCCS had greater awareness of how to prescribe medications appropriately. They commented that the RACH only refers to MPaCCS with medically challenging residents (e.g., unmanaged pain).
- <u>RACH admission meeting</u>. Service providers reported that RACH are increasingly initiating care planning discussions on admission to the home. This assists in identifying family expectations and priorities for the residents' care at end of life. Service providers report that family members find this beneficial. However, admission meetings that discuss future care planning and palliative care are not implemented across all sites.

- Grief support. On site chaplains are helpful for bereavement care with family members. Debriefing with staff following a death has been beneficial but does not always occur.
- Staffing coverage. Some RACHs reported increasing RN staffing to cover evenings and weekends, which has been helpful in addressing end of life issues as they arise. An out of hours social worker phone line has been introduced but there has been limited uptake thus far.
- The Palliative Aged Care Outcomes Program (PACOP). The PACOP was highlighted as a useful standardised tool to assess a resident's status and any functional decline, however only some RACHs use the PACOP in practice.
- Symptom management. Service providers report symptom management is done fairly well overall, despite some challenges.

What are the current challenges?

In response to the bereaved carer survey results, service providers described multiple challenges in line with carer experiences: staff knowledge and confidence in providing palliative care services; limited communication between the hospital, RACH, staff, and carers; and limited GP services impacting care provision. Service providers agreed with carers comments about limited government funding available to support carers following a resident's death.

- Symptom management. Despite service providers commenting that symptom management is primarily addressed, they also reported the main challenge as the poor timeliness of GPs prescribing medication. Service providers described the discrepancies noted between family and staff's perspectives about whether symptoms are managed appropriately.

- Limited death literacy and grief literacy of RACH Staff. Limited knowledge and confidence of staff providing palliative care services was commented on by service providers in all focus groups. The education provided on end-of-life care is not done frequently enough to target all new staff, particularly within the context of high staff turnover at some sites. Service providers report that some direct care staff have poor understanding of palliative care and the dying process, resulting in staff occasionally making comments that families overhear, which in turn leads to staff-family misunderstandings. Information sharing between hospital and RACH staff also needs to improve, as this impacts care provision on discharge from hospital.

- Communication with family. Service providers commented that improvements in communication on admission to the RACH and at pivotal moments of disease progression would be beneficial. This is in line with bereaved carers rating their involvement in end-of-life care decisions being not satisfactory. Although one service provider stated that it was the clinical nurse manager's role to communicate with family about end of life needs and not direct care staff, all other sites reported challenges with the direct care staff being uncomfortable with or lacking the skills to discuss the residents' end of life care with family. This then leads to miscommunication and uncertainty.

- GPs. Service providers described challenges accessing GPs after hours and weekends, GPs prescribing medication, and GP hesitancy proceeding with palliative care. As one service provider stated, "the GP would rather prescribe things like antibiotics still before even going down palliative care."
- End-of-life care planning. Residents were not always consulted for advance health directives, with family making advance care planning decisions on their behalf. Families were at times hesitant to complete an advance care planning document. Service providers report struggling when an advance care planning document is not completed and a health event occurs (e.g., a fall, disease progression). Unexpected deaths create additional stress on families.
- Dementia care. Service providers described specific challenges addressing end-of-life care needs for residents living with dementia. They commented that some staff had limited knowledge, skill and confidence regarding provision of palliative care to residents with Dementia.
- Limited death literacy and grief literacy of family carers. Families have limited understanding of palliative care, including end-of-life stages, symptoms, and impact of interventions such as CPR. One strategy discussed was getting MPaCCS and social workers involved can help with this; redirecting them to ELDAC website and provide pamphlets on palliative care.
- Management of finite resources. Service providers spoke of limited resources for grief support and bereavement care and challenges with limited staff.

What needs improving and how?

Participants described the following recommendations for improving palliative care services in RACH:

1. Ongoing RACH staff training.

Increased staff training was recommended by service providers, as they report being keen to improve the care provided and be upskilled about how to care for someone who is dying. This includes educating staff on what to expect at end of life and being proactive rather than reactive for care needs. One service provider described how some staff do not go into rooms when the family is there as they are not confident at answering questions or discussing end of life care with the resident's family. Staff also described the need for diagnosis specific education, such as end-of-life care for residents living with dementia. They did not specify whether training should be online or in person, however it is important that the staff should be paid for attending training sessions. Training should be ongoing and not only when new staff are oriented to the site. This then would improve the person-centred care provided to residents at end of life.

2. RACH Staff access to GPs and allied health.

Service providers described challenges accessing GPs out of hours at most sites, which then impacted the timeliness of palliative care service provision, including medication management and addressing acute deterioration in residents. Service providers commented that having a more proactive and anticipatory approach to palliative care would facilitate staff to address residents needs in a more-timely manner. Staff also recommended improving access to allied health and pharmacy. Service providers shared that a strong allied health team can make a big difference to families, particularly if they have already built rapport with the resident and their support system. A good relationship with pharmacy is also required to manage timely requests for medication.

3. Improved communication between family carers and RACH staff.

Staff agreed with the bereaved carers comments that greater transparency with family members is required, including sharing relevant information in a timely manner. They concurred with the need to have improved processes to communicate with and receive feedback from family. One service provider suggested that improving communication should occur between all levels, including senior staff, junior staff, and the residents and families. This can then facilitate proactive care provision for residents.

Staff described that a key opportunity to communicate with family members is when the resident is admitted to the RACH. They commented that the admission and initial care planning meeting are ideal timings for discussions on advance care planning and goals of care, as well as understanding the family's expectations and residents wishes. Having these discussions early can facilitate care planning when disease progression occurs, thus reducing miscommunication when function declines. One site reported that it was easier to complete the information once they changed to the residential goals of care forms rather than the longer advance care planning forms.

Service providers recommended providing education to families on the importance of palliative care planning, disease progression, and the stages of dying. This includes educating family about pain management and common misconceptions.

4. Grief and bereavement support.

Staff discussed challenges with limited bereavement support following a resident's death, including grief support to the family while the resident is at the RACH, and appropriate timelines for emptying a resident's room. Providing the family with bereavement resources in the community can assist with grief support following the death of a resident. Supporting staff following a death was also recommended, particularly for an unexpected death. Adding a grief counsellor to MPaCCS team would be helpful to family carers and staff. More liaison with not-for-profit organisations that can support family carers needs to happen, with RACHs taking a signposting role via making available a list of services that family carers can tap into.

Phase 2- Conclusions

The aim of this second phase of the evaluation was to assess RACH service providers' perceptions of the bereaved carers survey, which explored their experiences of care provided to residents and their families at end of life. This analysis of the service provider focus groups identified what they reported was working well and existing challenges to palliative care services at RACHs. All service providers in the focus groups reported using MPaCCS and described that the MPaCCS service worked well with the RACH for residents who were more medically complex at end of life. They described the role of MPaCCS as a service to empower the RACH to manage issues that arose.

In response to the bereaved carer survey results, service providers described multiple challenges in line with carer experiences: staff knowledge and confidence in providing palliative care services; limited communication between the hospital, RACH, staff, and family carers; and limited GP services impacting care provision.

Participants described the following recommendations for improving palliative care services in RACH: Ongoing RACH staff training; RACH staff access to GPs and allied health; improved communication between family carers and RACH staff; grief and bereavement support.

While the small sample of service providers in Phase 2 may not be representative of all RACH services across WA, the results below provide insight into service providers perspectives on what is working well, what the current challenges are, and recommendations for improvement in the RACH services provided to residents and their carers at end of life.

This phase complements the wider study's findings from Phase One (the bereaved carers survey exploring experiences of palliative care at RACHs) and Phase Three (the service providers survey exploring the impact of the NPA initiatives on RACHs).

PHASE 3:
Service Provider Survey
(RACH Staff)

PHASE 3: SERVICE PROVIDER SURVEY

Introduction and Methodology

The aim of this third phase of the evaluation was to assess RACH service providers' perceptions of the impact of the NPA quality improvement initiatives on their practice.

This evaluation was guided by the 'National Outcomes and Indicators' established by Nous (2021) as a means of measuring progress against the goals and aims of the NPA initiatives (Appendix 5).

An online survey was adapted to the aged care sector in consultation with Reference Group members through an extensive and reiterative process. Whilst outcomes and indicators established by Nous (2021) were incorporated into the survey, items were purposely adapted and re-worded to better reflect WA.

The online RACH staff survey was live for a period of five weeks from 25 April – 31 May 2024, accessible via REDCap. Promotional activities were strategically targeted to reach all RACH employees within WA including the use of mass email distribution, e-Newsletter inclusions, referrals within reference group members professional networks and word-of-mouth (Appendix 3).

The survey instrument was developed in collaboration with reference group members and the DOHWA EOLPC Team to ensure state-based differences specific to WA were considered. The online survey comprised a maximum total of 53 questions including all logic flow and 11 of these were open-ended text for the collection of qualitative data. The estimated time to complete the survey was approx. 15 minutes.

The survey elicited practice experiences within the Nous (2021) outcomes framework:

Outcome 1: More End-of-Life Care Discussions, Decisions and Documentation
Outcome 2: Improved Access to Information About Palliative and End of Life Services
Outcome 3: Improved Recognising and Responding to Residents' Palliative Care Needs
Outcome 4: Improved Access to Visiting Palliative Care Teams
Outcome 5: Improved Quality of Palliative Care in RACHs
Outcome 6: Residents Dying in Their Preferred Place of Death
Outcome 7: Coordination Among Primary, Acute and Specialist Care
Outcome 8: Integrated Health and Aged Care Systems
Outcome 9: Participation in Palliative Care Quality Improvement Initiatives.

Response categories to quantitative questions used seven-point Likert scale: Strongly Agree/ Agree/ Somewhat Agree/ Neither Agree nor Disagree/ Somewhat Disagree/ Strongly Disagree/ Don't Know. At the end of each outcome section, there was an opportunity for qualitative feedback.

A total of 89 valid and complete responses were received from RACH employees in WA and 72% had engaged with one or more NPA initiatives in their current role.

Results

Characteristics of Sample: RACH Staff

This sample had a median of five years' experience in their current role, with a third having been employed by their organisation for over 5 years. Over a half were employed in a clinical role followed by 29% in a managerial/leadership role. Seven out of the nine NPA initiatives were represented. Almost three-quarters of respondents (72%) had engaged with one or more NPA initiatives at work.

Table 10: Respondents Characteristics – RACH Staff (N=89)

Years of Experience	**(n)**	**(%)**
< 5 Years	47	53
6-10 Years	11	12
11-15 Years	10	11
16-20 Years	9	10
21-25 Years	6	7
> 26 Years	6	7
Total	89	100
(Median=5 years, Range=0-45)		
Length of Employment	**(n)**	**(%)**
Less than 12 months	13	15
1-2 years	12	14
2-3 years	14	16
3-4 years	8	9
4-5 years	11	12
More than 5 years	31	35
Total	89	100
Current Role	**(n)**	**(%)**
Managerial/Leadership Role	26	29
Clinical Role	49	55
Personal Care Role	14	16
Total	89	100
NPA Initiative/s Engagement	**(n)**	**(%)**
Yes	64	72
No	25	28
Total	89	100

Table 11: NPA Reported Initiatives (N=64)

Name of NPA Initiative	(n)	(%)
MPaCCs	37	58
RCL	34	53
RGoC	30	47
RACEPC	15	23
GP Case-Conf	6	9
EMHS	2	3
No. Per Survey Respondent	**(n)**	**(%)**
1 x NPA Initiative	23	36
2 x NPA Initiatives	20	31
3 x NPA Initiatives	14	22
4 x NPA Initiatives	3	5
5 x NPA Initiatives	3	5
6 x NPA Initiatives	1	2
Total	64	100

Comparing Outcome Indicators Between Groups (NPA-Yes and NPA-No)

The preliminary analyses will focus on comparing outcome indicators for two groups: Those who had engaged with one or more NPA initiatives (NPA Yes) and those who had not (NPA No). Figure 9 depicts the delineation between these groups.

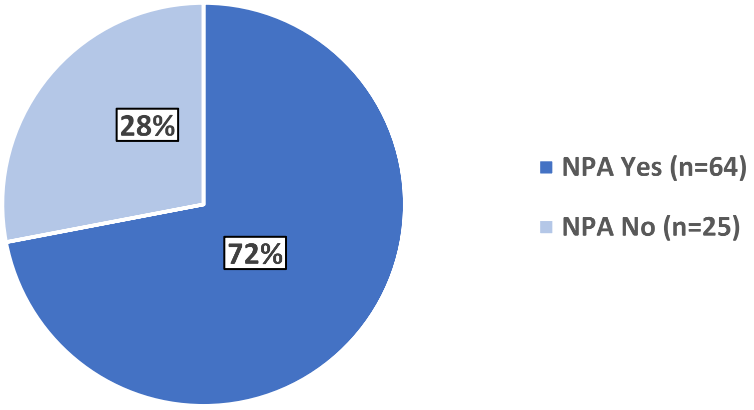

Figure 10: Groups for Comparison – NPA Yes and NPA No (N=89)

Outcome 1: More End-of-Life Care Discussions, Decisions and Documentation

Table 12: Outcome Indicators by Survey Question – Outcome 1

	Total % (N=89)	**NPA Yes % (n=64)**	**NPA No % (n=25)**	
More discussions focused on end-of-life care decision making (Strongly Agree/Agree)	66.3	75	44	**
Increase in numbers of residents who have ACPs or AHDs (Strongly Agree/Agree)	55.1	56.3	52	NS
Increase in number of residents who have a RGoC document (Strongly Agree/Agree)	50.6	56.3	36	NS
Care documents utilised to recognise and respond to clinical deterioration (Strongly Agree/Agree)	71.9	82.8	44	***
Pre-existing end of life care planning documentation requested by RACH (Yes) ^{A}	92.1	98.4	76	**
Residents' end of life care plans are reviewed every 3-6 months	40.4	42.2	36	NS

*Chi-square p-values: *** <0.001, ** <0.01, * <0.05. ^{A} Fisher's Exact test (2x2 tables).*
NS=not significant

Key Differences

Outcome 1: The top scoring indicators were 92% for pre-existing end of life care planning documentation requested by RACH, 72% for care documents utilised to recognise and respond to clinical deterioration, and 66% for more discussions focused on end-of-life care decision making. However, 98% of the NPA group compared to 76% of the non-NPA group have requested to "see the EOLC documentation" (p<0.01); 83% of NPA vs 44% of non-NPA have reported that the "documentation have helped in their response to clinical deterioration" (p<0.001). There were a lot of "more discussions about EOLC decision making" for the NPA group (75%) compared to non-NPA (44%) (p<0.01). The three indicators that were scored the lowest did not show any significant difference between the two groups, namely "residents end of life care plans are reviewed every three to six months (40%); increase in number of residents who have a RGOC document (51%); and increase in numbers of residents who have ACP documents and/or AHDs" (55%).

Quotes from RACH Staff

"End of life is a very complex situation in aged care due to a person having multiple co-morbidities, fluctuating and declining status requiring engaging with family members, to name a few, decision making can be difficult, especially for nurses working in isolation. As a clinical manager I can see there is a lot of work to be done, resources can vary due to the other multiple everyday needs." (Service Provider 65)

> *"There need to be more education about Advance health directives. These need to be complete before coming into aged care. Usually once a person comes to aged care there is dementia and thus too late for them to make an advance health directive." (Service Provider 78)*

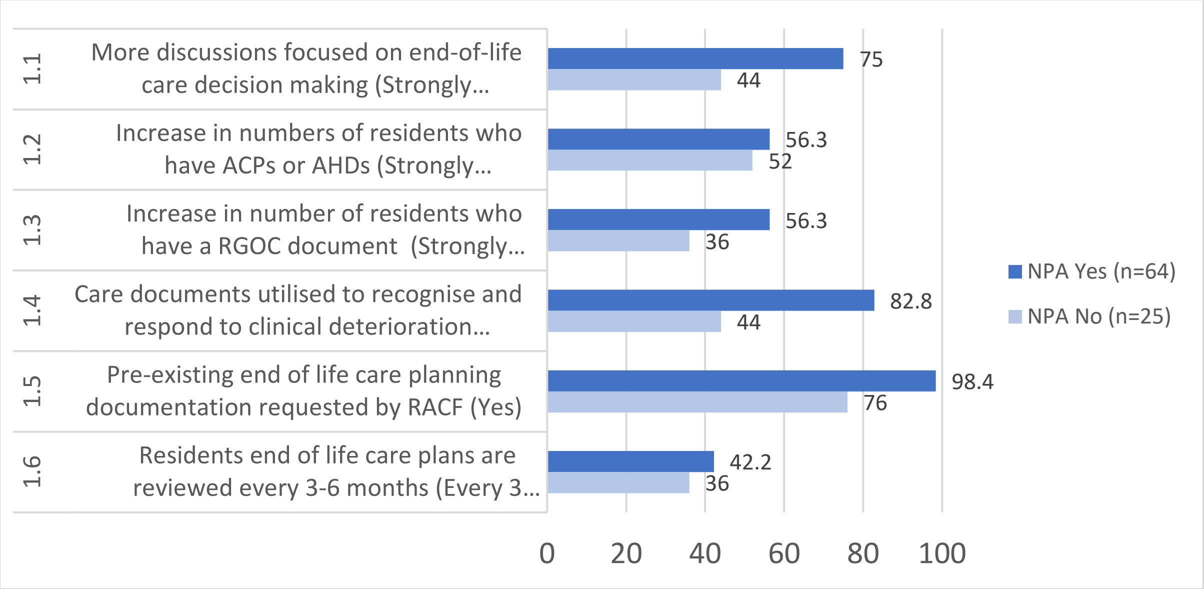

Figure 11: Comparing Outcome Indicators by Group NPA Yes vs. NPA No – Outcome 1

Outcome 2: Improved Access to Information About Palliative and End of Life Services

Table 13: Outcome Indicators by Survey Question – Outcome 2

	Total % (N=89)	**NPA Yes % (n=64)**	**NPA No % (n=25)**	
Residents and families are provided with information about end-of-life planning (Strongly Agree/Agree)	78.7	87.5	56	**
The RACH holds multidisciplinary case conferences about palliative care (Yes)	67.4	76.6	44	**
Residents and families are encouraged to attend (Yes) [palliative care case conf only] (n=60) ^{A}	95.0	95.9	90.9	NS

*Chi-square p-values: *** <0.001, ** <0.01, * <0.05. ^{A} Fisher's Exact test (2x2 tables).*

Key Differences

Outcome 2: 67% of respondents reported that their RACH held multidisciplinary case conferences about palliative care and 95% of those agreed that their RACH encourages residents/families to attend palliative care conferences, with no difference between the two groups. While 88% of NPA group reported that their residents were "provided to access to information about EOL planning, options and services", only 56% of the non-NPA group did (p<0.01); 77% of the NPA group held MDT case conferences about palliative care, only 44% of the non-NPA group did (p<0.01).

Quotes from RACH Staff

“Staff still have confusion regarding the word "palliative". This is strongly associated with the terminal phase. However, recognising deterioration, having the conversations and revisiting RGoC is the precursor that is confused or missed.” (Service Provider 9)

“We provide written information, are open to verbal discussions, regular education and communication when someone moves to terminal care. we also offer our staff psychologist to ring if they are requiring extra external support” (Service Provider 31)

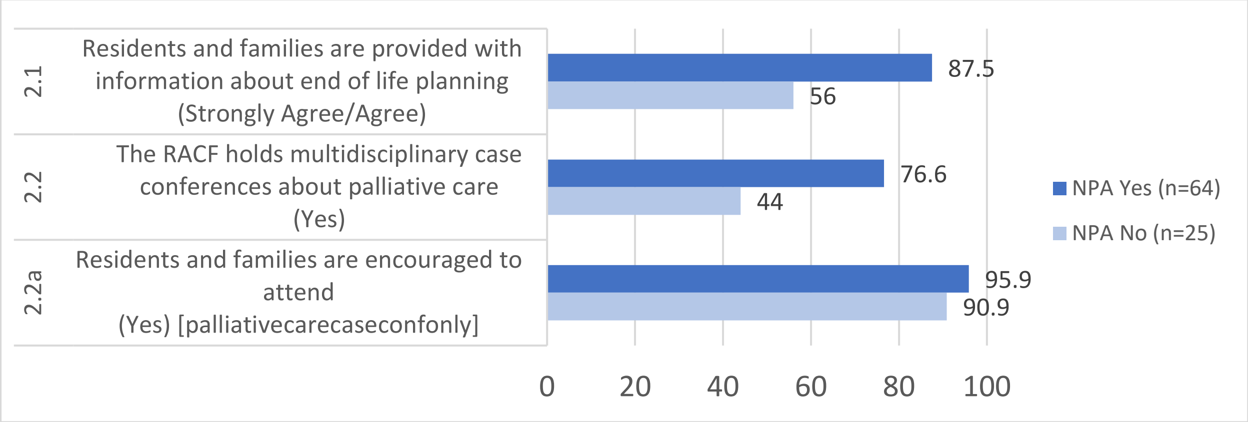

Figure 12: Comparing Outcome Indicators by Group NPA Yes vs. NPA No – Outcome 2

Outcome 3: Improved Recognising and Responding to Residents’ Palliative Care Needs

Table 14: Outcome Indicators by Survey Question – Outcome 3

	Total % (N=89)	**NPA Yes % (n=64)**	**NPA No % (n=25)**	
Residents emotional, spiritual and cultural needs are met at end of life (Strongly Agree/Agree)	79.8	87.5	60	**
Staff are supported to participate in palliative care training and education (Strongly Agree/Agree)	74.2	84.4	48	***
Staff have access to assessment tools to identify clinical deterioration (Strongly Agree/Agree)	76.4	84.4	56	**
Residents can access appropriate medication when changes occur at end of life (Strongly Agree/Agree) ^{A}	85.4	92.2	68	**

*Chi-square p-values: *** <0.001, ** <0.01, * <0.05. ^{A} Fisher’s Exact test (2x2 tables).*

Key Differences

All four indicators in Outcome Three showed very significant differences between the two groups with those for the NPA group being between 80-90%, but those for the non-NPA group lower at about 50-60%. The majority (84.4%) of RACH staff members whose facilities were engaged in an NPA initiative reported being supported to participate in palliative care training and education, compared to less than half (48%) of those who were not (p <0.001).

Quotes from RACH Staff

"I feel we do provide the highest quality palliative care, thanks to our GP, she works one day a week with the Palliative Care team, and we are well supported at a regional level with our Palliative Care team." (Service Provider 50)

"My concern is the lag from the GP prescribing to actually getting the medication in the facility from the pharmacy. If a consumer deteriorates at night they would have to wait till morning when pharmacy is open. I wish these medications were prescribed when a consumer starts to deteriorate and not when they require them." (Service Provider 87)

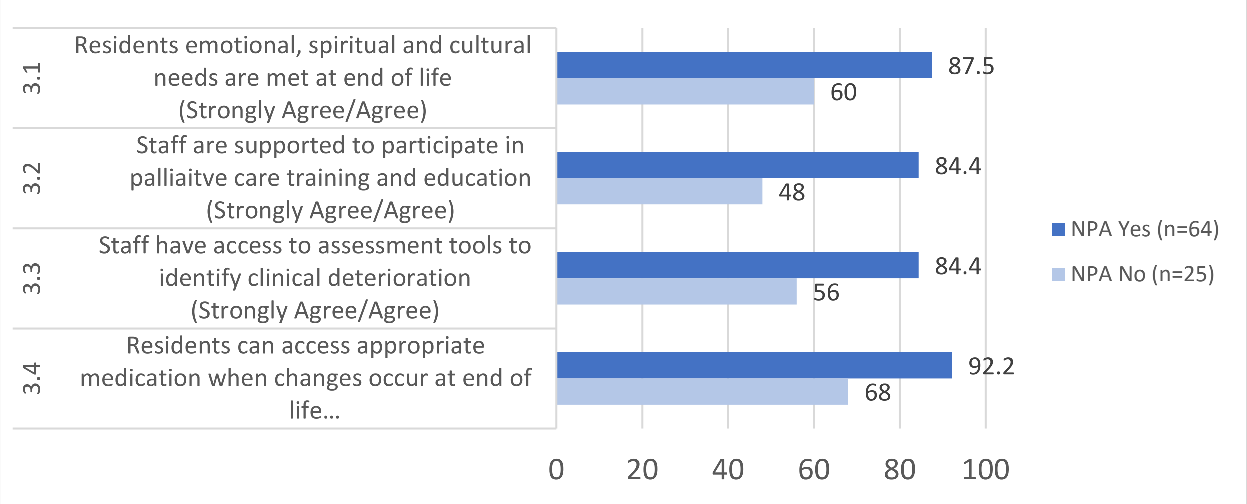

Figure 13: Comparing Outcome Indicators by Group NPA Yes vs. NPA No – Outcome 3

Outcome 4: Improved Access to Visiting Palliative Care Teams

Table 15: Outcome Indicators by Survey Question – Outcome 4

	Total % (N=89)	**NPA Yes % (n=64)**	**NPA No % (n=25)**	
Residents can access palliative care services in a timely manner (Strongly Agree/Agree)	74.2	84.4	48	***

*Chi-square p-values: *** <0.001, ** <0.01, * <0.05. ^{A} Fisher's Exact test (2x2 tables).*

Key Differences

The majority (84.4%) of staff whose RACH facilities are engaged in an NPA initiative reported that residents were able to access palliative care services in a timely manner, compared to less than half (48%) of those who weren't, (p<0.001).

Quotes from RACH Staff

“It's difficult to organise family case conferences and time consuming for RACF staff going backwards and forwards as the palliative care team do not liaise directly with families.” (Service Provider 12)

“We have a very accessible and caring visiting palliative care team.” (Service Provider 65)

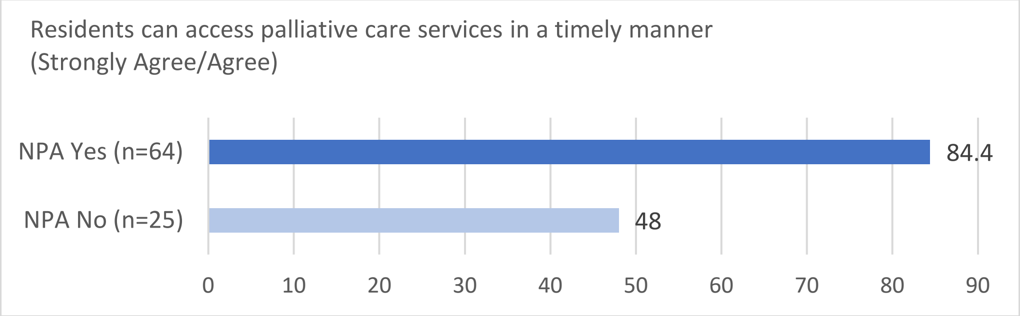

Figure 14: Comparing Outcome Indicators by Group NPA Yes vs. NPA No – Outcome 4

Outcome 5: Improved Quality of Palliative Care in RACHs

Table 16: Outcome Indicators by Survey Question – Outcome 5

	Total % (N=89)	**NPA Yes % (n=64)**	**NPA No % (n=25)**	
Residents are referred to specialist palliative care services if required (Strongly Agree/Agree)	75.3	84.4	52	**
Staff have access to timely clinical advice if a resident’s condition changes (Strongly Agree/Agree)	79.8	89.1	56	***
Staff feel more confident in their understanding of palliative care (Strongly Agree/Agree)	77.5	85.9	56	**

*Chi-square p-values: *** <0.001, ** <0.01, * <0.05. ^{A} Fisher’s Exact test (2x2 tables).*

Key Differences

All three indicators in Outcome Five showed very significant differences between the two groups with those for the NPA group being in the mid to high-80% compared to the mid-50% for the non-NPA group. The majority (89.1%) of staff members whose RACH was engaged in an NPA initiative reported having timely access to clinical advice in the event a resident’s condition changes, compared to only 56% of those who weren’t, (p<0.001).

Quotes from RACH Staff

“Palliative Care/End of Life Coordinator has provided mentoring.” (Service Provider 74)

“Management often state that funding is a barrier to effective rostering of staff, and this is particularly challenging when a resident requires 2-3 assessment and 1 hourly checks during the terminal phase.” (Service Provider 9)

“There is no training or support given to staff about it. there's usually not even a basic handover, let alone told when someone is moved to palliative care.” (Service Provider 49, NPA No)

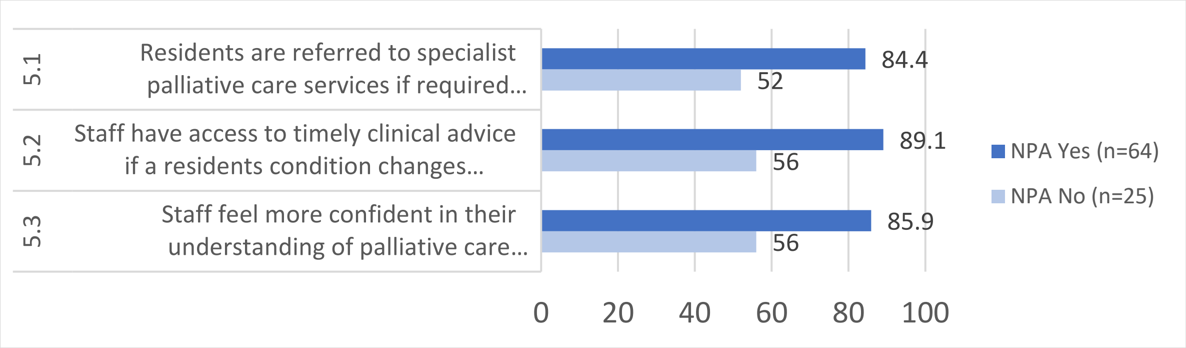

Figure 15: Comparing Outcome Indicators by Group NPA Yes vs. NPA No – Outcome 5

Outcome 6: Residents Dying in Their Preferred Place of Death

Table 17: Outcome Indicators by Survey Question – Outcome 6

	Total % (N=89)	**NPA Yes % (n=64)**	**NPA No % (n=25)**	
Residents preferred place of death is documented by the RACH (Strongly Agree/Agree)	67.4	76.6	44	**
Staff know how to utilise information about residents preferred place of death (Strongly Agree/Agree)	56.2	64.1	36	*
Less residents are transferred to hospital for symptom management at end of life (Strongly Agree/Agree)	64	71.9	44	*

*Chi-square p-values: *** <0.001, ** <0.01, * <0.05. ^{A} Fisher's Exact test (2x2 tables).*

Key Differences

Outcome 6: On “dying on preferred place”, all three indicators were at 65-75% for the NPA group compared to about 40% for the non-NPA group, and the differences between the two groups were significant. Over three quarters (76.6%) of staff whose RACH are engaged in an NPA initiative reported that residents preferred place of death was recorded and documented, compared to less than half (44%) of those who weren't (p<0.01).

Quotes from RACH Staff

“Generally, People seemed appreciating of the fact that palliative care takes place in the facility, so they don't need to go to hospital, only once have I had an enquiry about someone going home, however it did not eventuate.” (Service Provider 65)

“ACP have been completed with more information in the last 12 months. It is easier to know which residents are for transfer to hospital.” (Service Provider 74)

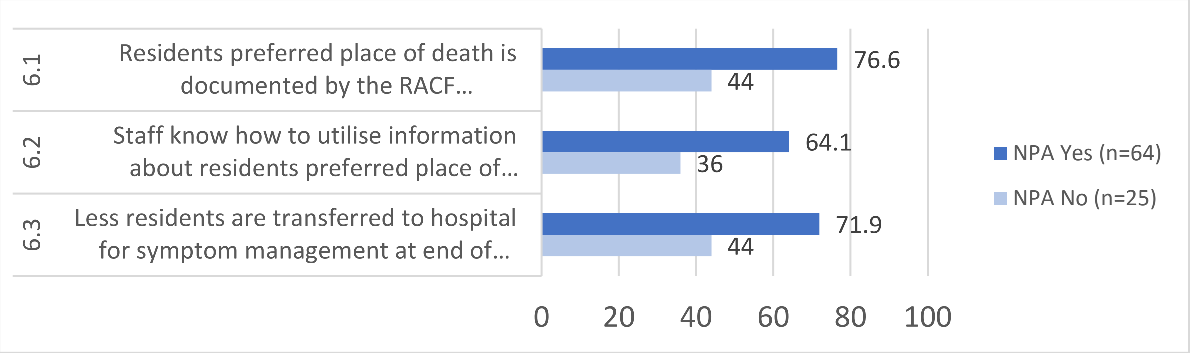

Figure 16: Comparing Outcome Indicators by Group NPA Yes vs. NPA No – Outcome 6

Outcome 7: Coordination Among Primary, Acute and Specialist Care

Table 18: Outcome Indicators by Survey Question – Outcome 7

	Total % (N=89)	**NPA Yes % (n=64)**	**NPA No % (n=25)**	
Improved coordination of palliative care between GPs, hospitals and PC Teams (Strongly Agree/Agree)	51.7	62.5	24	**
RACH staff support GPs to coordinate case conferencing (Strongly Agree/Agree)	60.7	64.1	52	NS
Improved coordination of palliative care provided by GPs and RACH staff (Strongly Agree/Agree)	50.6	59.4	28	**

*Chi-square p-values: *** <0.001, ** <0.01, * <0.05. ^{A} Fisher's Exact test (2x2 tables).*

Key Differences

Outcome 7: The indicators were on the lower side for both groups, with about 60% for NPA group and 25% for the non-NPA group, with significant differences (p<0.01). Almost two thirds (62.5%) of staff whose RACH was engaged in an NPA initiative reported an improved coordination of palliative care services between GP's, hospitals and palliative care teams, compared to one quarter (24%) of those who weren't (p<0.01). There was no significant difference between the two groups in terms of RACH staff supporting GPs to coordinate case conferencing.

Quotes from RACH Staff

"Our GPs are excellent and usually allow us to coordinate with other services (they will always support a referral) and then follow recommendations given by service." (Service Provider 7)

"Coordination of specialists tends to be dealt with by medical and nursing staff. Spiritual Care staff are not generally involved. Sometimes they are not informed of what is happening." (Service Provider 63)

"GP reluctant to accept deterioration and has implemented things that may be unnecessary or not required such as continuing with medications." (Service Provider 73)

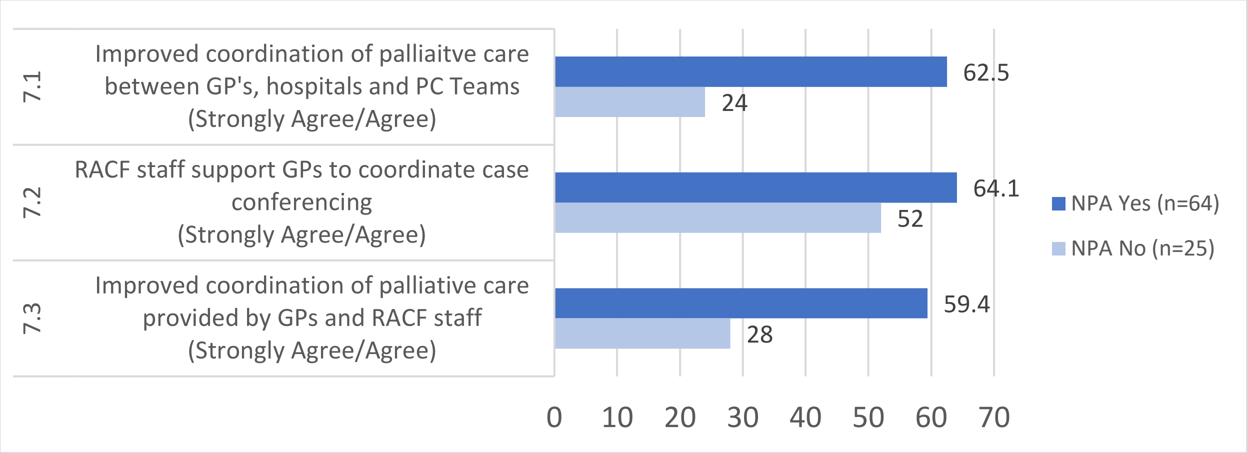

Figure 17: Comparing Outcome Indicators by Group NPA Yes vs. NPA No – Outcome 7

Outcome 8: Integrated Health and Aged Care Systems

Table 19: Outcome Indicators by Survey Question – Outcome 8

	Total % (N=89)	**NPA Yes % (n=64)**	**NPA No % (n=25)**	
Improved coordination of care from hospital discharge to RACH (Strongly Agree/Agree)	37.1	42.2	24	NS

*Chi-square p-values: *** <0.001, ** <0.01, * <0.05. ^{A} Fisher's Exact test (2x2 tables).*

Key Differences

Outcome 8: "Improved coordination of care from hospital discharge to RACH" was the lowest rated indicator for the NPA group (42%) but still higher than the 24% of the non-NPA group, with no significant difference between the two groups.

Quotes from RACH Staff

"I still see clients who are terminally ill on admission they have been in hospital for 5 weeks and there is no ACP." (Service Provider 64)

"As per goal of care and communication with NOK and GP residents are transferred to hospital. Ambulance services sometimes get bit hard as we have to go through virtual consultation." (Service Provider 71)

"Hospitals do not communicate when transfers are occurring, do not provide updates on clients, send clients without medications which are not available at RACF and may take time for emergency pharmacy deliveries to occur if available." (Service Provider 6)

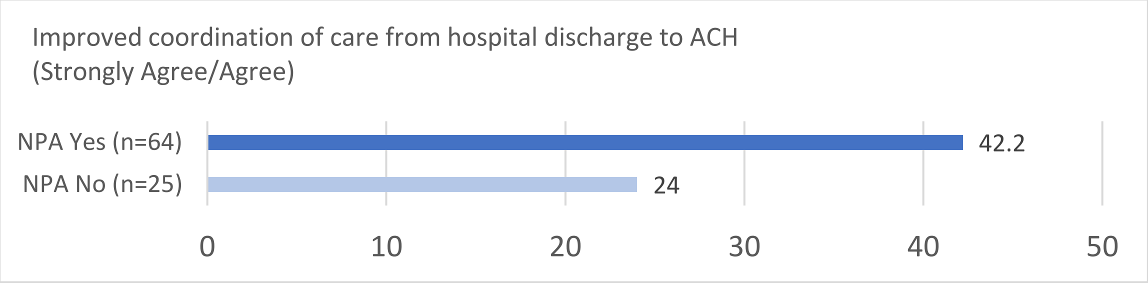

Figure 18: Comparing Outcome Indicators by Group NPA Yes vs. NPA No – Outcome 8

Outcome 9: Participation in Palliative Care Quality Improvement Initiatives

Table 20: Outcome Indicators by Survey Question – Outcome 9

	Total % (N=89)	**NPA Yes % (n=64)**	**NPA No % (n=25)**	
End of life care is reviewed via an audit process, or after death audit (Yes)	39.3	45.3	24	NS
RACH participates in the national palliative care improvement initiative (PACOP) (Yes)	23.6	29.7	8	*

*Chi-square p-values: *** <0.001, ** <0.01, * <0.05. ^{A} Fisher's Exact test (2x2 tables).*

Key Differences

Outcome 9: While "participation in audits or quality improvement initiatives" was better for the NPA group, this indicator was on the lower side for both groups, although 36% reported they did not know if their home participated in such initiatives. Almost one third (29.7%) of staff whose RACH were engaged in an NPA initiative reported their RACH participates in the national palliative care improvement initiative, PACOP, compared to only 8% of those who weren't (p<0.05).

Quotes from RACH Staff

"Would be great if organisation was on board and it could be rolled out into our systems and processes." (Service Provider 69)

"Aged Care is very busy and PACOP is very demanding with what must and how to perform." (Service Provider 16)

"I have been advocating using the PACOP but as yet, had no agreement from upper management, I will try again, I feel it is a great improvement initiative." (Service Provider 5)

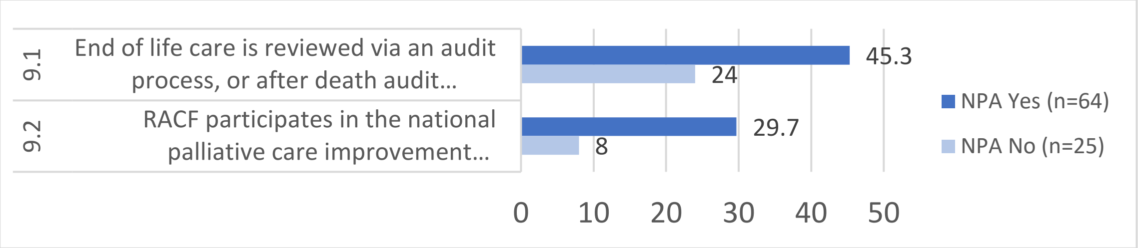

Figure 19: Comparing Outcome Indicators by Group NPA Yes vs. NPA No – Outcome 9

Phase 3- Summary of Highlights

The analyses comparing NPA and Non-NPA responses indicated large significant differences between these groups across outcomes and indicators of quality palliative care, with the NPA group having higher quality indicators overall. Table 21 summarises the results.

Table 21: Statistically Significant Results – NPA Sites vs. Non-NPA Sites

RACH Staff Reported…

Accessing Palliative Care	**NPA**	**Non-NPA**	**p-value**
Residents have timely access to PC services	84%	48%	(p<0.001)
Referrals are made to specialist PC services	84%	52%	(p<0.01)
Symptom Management	**NPA**	**Non-NPA**	**p-value**
Access to clinical advice if a resident's condition changes	89%	56%	(p<0.01)
Access to medication when changes occur at end of life	92%	68%	(p<0.01)
Provision of Palliative Care	**NPA**	**Non-NPA**	**p-value**
Support to participate in PC education and training	84%	48%	(p<0.001)
Access to assessment tools to identify deterioration	84%	56%	(p<0.05)
More confidence in their skills and understanding of PC	86%	56%	(p<0.01)
Coordination of Services	**NPA**	**Non-NPA**	**p-value**
Improved coordination of PC teams, GPs and hospitals	63%	24%	(p<0.01)
Improved coordination of PC delivered by GPs and RACH	59%	28%	(p<0.01)
RACH staff provided GPs support for case conferences	64%	52%	NS
Improved coordination between the RACH and hospitals	42%	24%	NS
Unnecessary Hospitalisations	**NPA**	**Non-NPA**	**p-value**
A decrease in residents transferred to hospital	72%	44%	(p<0.05)
Planning for End-of-Life Care	**NPA**	**Non-NPA**	**p-value**
More discussions about end of life were taking place	75%	44%	(p<0.01)
They asked residents about their existing care plans	98%	76%	(p<0.01)
An increase in residents with ACP documents or AHDs	56%	52%	NS
An increase in residents with RGOCs	56%	36%	NS
Utilising Care Plans	**NPA**	**Non-NPA**	**p-value**
Care plans help recognise and respond to deterioration	83%	44%	(p<0.001)
Care plans are reviewed every 3 – 6 months	42%	36%	NS
Preferred Place of Death	**NPA**	**Non-NPA**	**p-value**
Residents preferred place of death is documented	77%	44%	(p<0.01)
They utilise records regarding preferred place of death	64%	36%	(p<0.05)

Holistic Care for Residents	**NPA**	**Non-NPA**	**p-value**
Residents' emotional, spiritual, cultural needs are met	88%	60%	(p<0.01)
Information About Palliative Care	**NPA**	**Non-NPA**	**p-value**
Information about PC is provided to residents/families	88%	56%	(p<0.01)
Information About Their Relative	**NPA**	**Non-NPA**	**p-value**
Multidisciplinary case conferences about PC are held	77%	44%	(p<0.01)
Residents and families encouraged to attend case confs	96%	91%	NS

Outcome 1: There were significant differences between the two groups with NPA sites having better outcomes in terms of "more discussions about EOLC decision making; EOLC documentation requested by RACH; and documents utilised to recognise and respond to clinical deterioration. Only about 50% of RACHs reported an increase in numbers of residents who have ACPs documents or AHDs or RGoCs, and about 40% reporting EOLC plans being reviewed 3-6 months, and the difference between the two groups was not significant.

Outcome 2: Significant differences existed between the 2 groups in terms "provided to access to information about EOL planning, options and services", held MDT case conferences about palliative care, with NPA sites performing much better.

Outcome 3: On "improved recognition and response to needs", all four indicators showed a significant difference between the 2 groups, with NPA sites performing significantly better.

Outcome 4: On "access palliative care in a timely manner", the NPA sites performed significantly better.

Outcome 5: On "improved quality of palliative care", all three indicators showed a significant difference between the 2 groups, with NPA sites performing better.

Outcome 6: On "dying in preferred place", all three indicators showed a significant difference between the 2 groups, with NPA sites performing better.

Outcome 7: On "coordination among primary, acute and specialist care", although indicators were on the lower side for both groups than indicators in earlier outcomes, there was a statistical difference between the 2 groups in terms improved coordination between GPs, hospitals and PC Teams and between GPs and RACH staff. There was no difference as to RACH staff supporting GPs to coordinate case conferencing.

Outcome 8: "Improved coordination of care from hospital discharge to RACH" was the lowest rated indicator and showed no difference between the 2 groups.

Outcome 9: While "participation in audits or quality improvement initiatives" was better for the NPA group, this indicator was on the lower side for both groups, although 36% reported they did not know if their home participated in such initiatives.

Phase 3- Conclusions

The aim of Phase 3 was to assess RACH service providers' perceptions of the impact of the NPA quality improvement initiatives on their practice. These analyses have focused on comparing outcome indicators for two groups: those who had engaged with an NPA initiative and those who had not. Seven out of the nine NPA initiatives were represented. Almost three-quarters of respondents had engaged with one or more NPA initiatives at work, the most prevalent were MPaCCS, RCL and RGoC. This sample of respondents had a median of five years' experience in their current role, with a third having been employed by their organisation for over five years. Over a half of respondents were employed in a clinical role followed by 29% in a managerial/leadership role.

While this sample of respondents may not be representative of the total population of RACH staff in WA, the impact of the NPA initiatives on practice was quite evident from the consistent trend in the comparisons between the two groups and the significant differences in many of the indicators. The NPA group reported much better practice across most indicators in Outcomes one to six. However, three indicators that surprisingly did not perform well and showed no difference between the two groups was the increase in numbers of residents who have ACP documents, AHDs and those who have RGoCs, and residents' EOLC plans being reviewed three to six months.

More attention regarding better quality practice in outcomes seven to nine is needed where indicators scored a lot lower, namely coordination among primary, acute and specialist care (Outcome Seven); integrated health and aged care systems (Outcome Eight); and participation in palliative care quality improvement initiatives (Outcome Nine). In particular, there was no significant difference between the 2 groups in terms of RACH staff supporting GPs to coordinate case conferencing; improved coordination of care from hospital discharge to RACH; and EOLC reviewed via an audit process or after death audit.

Triangulation of data from the three phases of this study will be described in the next section of the report, which will contribute to a greater understanding of the extent and quality of palliative care services needed in RACHs in Western Australia.

TRIANGULATION OF FEEDBACK:
Consumers & Service Providers

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THE UNIVERSITY OF WESTERN AUSTRALIA

The Rural Clinical School
of Western Australia

TRIANGULATION OF FEEDBACK USING FRAMEWORK OF WA NPA PROJECT LOGIC MAP

Introduction

This step in a convergent research design involves the transformation of results to facilitate a comparison of two different data types (Creswell & Plano Clark, 2018). In the context of this independent evaluation, we focused on the state-based policy frameworks. This section of the report will first merge the consumer and service provider findings, and then compare the results to understand key similarities and differences.

Qualifying Questions

Both the consumer survey and service provider surveys contained qualifying questions to enable the easy identification of participants who had engaged with an NPA initiative and distinguish them from those who had not. The reference group agreed a short description should be displayed underneath the following consumer survey question for additional clarity and context.

Consumer Survey Q3.5: Was your relative seen by a 'visiting palliative care team'* in the Residential Aged Care Home? **In WA, there are specialist palliative care teams of doctors, nurses, social workers and other clinicians that visit Residential Aged Care Facilities and Nursing Homes to provide extra support to residents, families and staff. These visiting palliative care teams in WA include MPaCCS from Bethesda Palliative Care Unit, WA Country Heath Palliative Care and Silver Chain.*

RACH staff members were explicitly asked about whether their current RACH as a place of employment had implemented one or more of the NPA initiatives. A hyperlink was available for respondents to review brief descriptions of the NPA initiatives (Appendix 6).

Staff Survey Q3: To your knowledge, has your RACH been involved in the implementation of any of the following palliative care quality improvement initiatives over the past 12 months? *(Please tick all that apply)*.

Consumers were divided into three groups based on their relative's engagement with a visiting palliative care team – PC Users, Non-Users and Unsure – compared with the service providers who were divided into two groups based on whether the RACH they work for has engaged with one or more NPA initiatives over the last 12 months – termed NPA sites and non-NPA sites. Considered together, these five groups include all 406 survey responses and merged results provide an understanding of the impact of NPA initiatives across WA. The broader impacts of WA's NPA initiatives are summarised based on the outcomes and impacts outlined in the WA NPA Project Logic Map (DOHWA, 2021). Figure 19 presents the evaluation process in a flowchart.

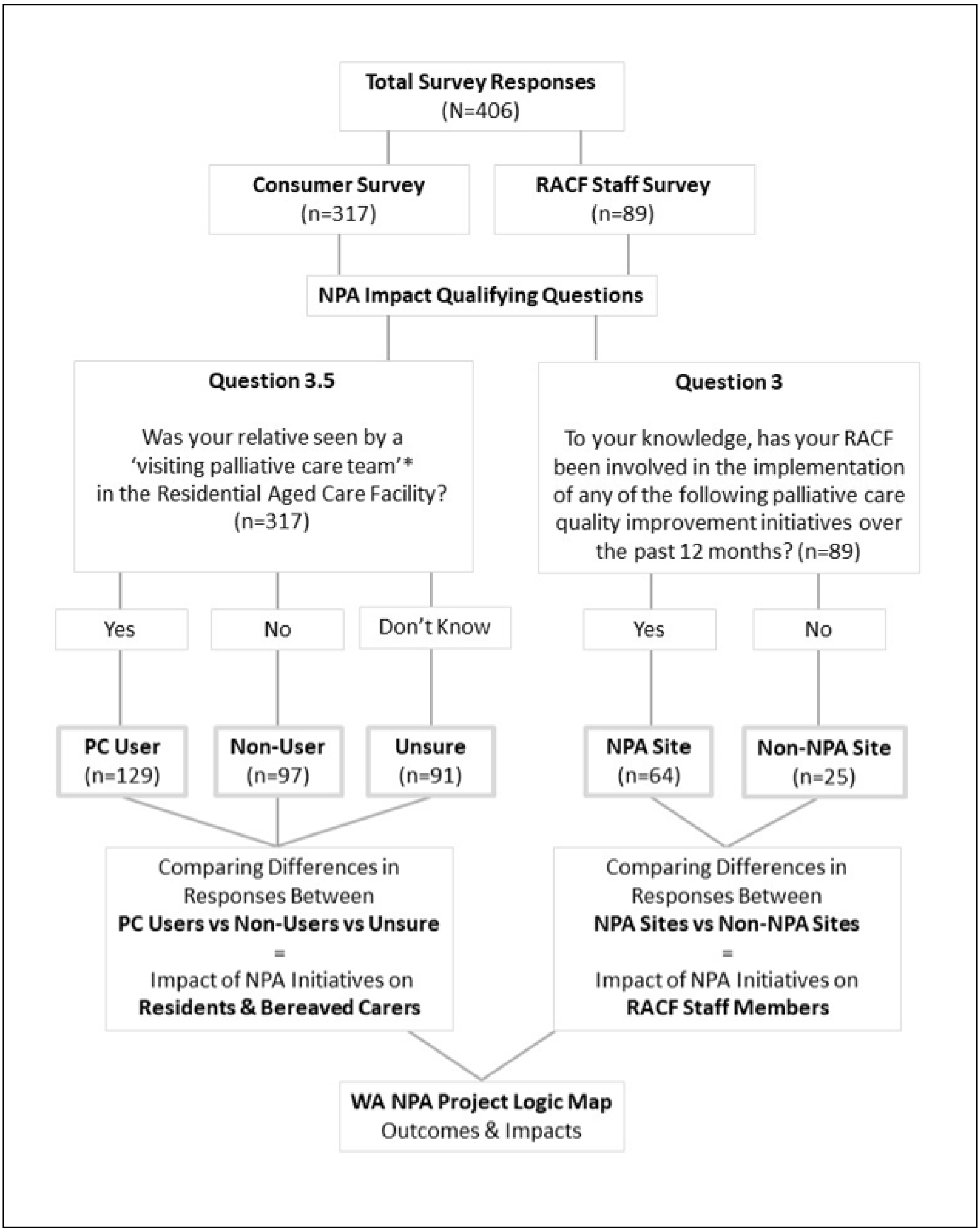

Figure 20: Flowchart of Triangulation Process

Combined Results: Consumers & Service Providers

The comparative results are presented in the following tables using WA Logic Map Outcomes (Appendix 7) as the framework. The quality indicators varied slightly between the two surveys, so they are matched as closely as possible.

Table 22: The quality of life (physical, psychosocial and spiritual) of older Australians with a life-limiting illness living in RACHs, and their families/ carers, is improved.

RACH Staff Reported…	NPA Site	Non-NPA Site
Residents emotional/ spiritual/ cultural needs met at EOL	88%	60%
Bereaved Carers Reported…	**PC User**	**Non-PC User**
Emotional support to resident	64%	57%
Emotional support to carer	68%	60%
Spiritual/religious values respected	67%	55%
Cultural background respected	68%	52%
Personal values respected	78%	74%
Carers could discuss fears/worries with staff	74%	59%

Eighty-eight percent of staff working in NPA sites reported that they believe they are meeting the holistic needs of residents to a greater extent than what bereaved carers have reported. Personal values are well respected by both PC users and non-users, but all other holistic indicators are not well supported and that matches the non-NPA sites (Table 22).

Table 23: RACH residents and their families/carers receive quality of EOL&PC that meets their changing needs and known wishes.

RACH Staff Reported…	NPA Site	Non-NPA Site
Responding to clinical deterioration	83%	44%
Access to PC in a timely manner	84%	48%
Access to appropriate medication when changes occur	92%	68%
Access to timely clinical advice	89%	56%
EOLC plans reviewed every 3-6 months	42%	36%
Bereaved Carers Reported…	**PC User**	**Non-PC User**
Overall quality of care	81%	73%
Quality of care at EOL	77%	65%
Info provided to carers about resident condition	75%	59%

All indicators on receiving high quality EOLC that meets their changing needs are of high quality and comparable as reported by PC Users and NPA sites. However, non-NPA sites lag behind. The timely response and access to appropriate care by NPA sites have likely contributed to 80% of PC Users rating the quality of care as excellent/good (Table 23).

Table 24: The EOL&PC experience of families and carers of RACH residents is improved.

RACH Staff Reported…	NPA Site	Non-NPA Site
More discussions focused on EOLC decision making	75%	44%
RACH hold multidisciplinary case conferences	77%	44%
Bereaved Carers Reported…	**PC User**	**Non-PC User**

Residents involved in decisions at EOL	57%	57%
Inclusion of residents in care decisions in general	70%	54%
Carers involved in decisions at EOL	70%	59%
Inclusion of carers in care decisions in general	66%	57%
Carers received as much support as wanted	62%	39%
Carer could stay overnight with relative	40%	31%
Care decisions made but not wanted	16%	22%

The increase in discussions on EOL decision making and case conferencing in NPA sites have likely contributed to about 70% of PC user-carers feeling included in decision making and having less of the unwanted care decision being made. Where these discussions and care conferencing were not happening to the same extent in non-NPA sites, non-PC users reported less satisfaction (Table 24).

Table 25: RACH residents experience a "good death" in their place of choice, in accordance with their known wishes.

RACH Staff Reported…	**NPA Site**	**Non-NPA Site**
Preferred place of death documented	77%	44%
Utilising documented info about preferred place of death	64%	36%
Existing EOL plans documentation requested	98%	76%
An increase in residents with ACP documents or AHDs	56%	52%
An increase in residents with RGoCs	56%	36%
Bereaved Carers Reported…	**PC User**	**Non-PC User**
Enough support provided by RACH at time of death	59%	45%
Asked about existing EOL plans documentation	74%	70%
Documented wishes considered	92%	87%

EOLC documentation was reported to be used by NPA sites and PC Users and non-PC users to a great extent. However, the increase in residents with ACP documents, AHDs and RGoCs is low and similar in NPA and non-NPA sites. Carers did not feel they had enough support at the time of the resident's death (Table 25).

Table 26: The capacity, capability and confidence of the clinical and non-clinical RACH, primary care and hospital workforce to provide quality EOL&PC is optimised.

RACH Staff Reported…	**NPA Site**	**Non-NPA Site**
Confidence in understanding PC	86%	56%
Supported to participate in PC education/training	84%	48%
Access to assessment tools to identify deterioration	84%	56%
Bereaved Carers Reported…	**PC User**	**Non-PC User**
Relief of pain	73%	65%
Relief of symptoms other than pain	70%	56%

The higher confidence in understanding PC, support to attend education sessions, and using assessment tools in NPA sites may have contributed to PC users reporting greater satisfaction with relief of pain and other symptoms as compared to non-PC users. All these indicators were lower in the non-NPA sites and reflected in lower satisfaction for non-PC users (Table 26).

Table 27: The community's confidence in the quality of EOL&PC provided to RACH residents and their families/ carers is increased.

RACH Staff Reported…	**NPA Site**	**Non-NPA Site**
Residents and families provided with info about end-of-life planning	88%	56%
Bereaved Carers Reported…	**PC User**	**Non-PC User**
Staff competence	88%	78%
Residents treated with respect and dignity	84%	79%
Residents treated with compassion/kindness	85%	80%
Carers treated in sensitive manner	84%	74%
Staff provided info when requested	72%	56%

Both PC users and non-users have highly rated the competence of staff, and how well they were treated by staff. The extent of provision of information by staff is reflected in the extent of receipt of info by carers (Table 27).

Table 28: Health system resources are used more sustainably, including reduced demand on specialist EOL&PC.

RACH Staff Reported…	**NPA Site**	**Non-NPA Site**
Improved coordination between GPs/hospitals/ PC teams	63%	24%
Improved coordination of PC provided by GPs and RACH staff	59%	28%
Less residents transferred to hospital	72%	44%
Improved care coordination between hospital and RACH	42%	24%
EOLC reviewed via an audit process	45%	24%
Referral to specialist palliative care if required	84%	52%
Bereaved Carers Reported…	**PC User**	**Non-PC User**
Perceived cooperation RACH/ GPs	87%	73%
Residents' visits to ED helpful	67%	58%
Out of hours planned care if condition declined	72%	53%

Coordination between primary care, acute and specialist teams were not highly rated by NPA sites and much less by non-NPA sites, with the worst coordination of care reported by staff as occurring being between RACHs and hospitals. PC users and non-users perceived the cooperation between GPs and RACH more favourably than the RACH staff. However, 72% of NPA sites reported a decrease in number of residents admitted to hospital and 67% of PC users reported that the ED visits were helpful (Table 28).

WA NPA Project Logic Map – Synthesis of Outcomes and Impacts

The WA NPA Project Logic Map is displayed in Appendix 7. The synthesised results from the three phases of this evaluation provide further evidence to support the national literature review findings reported by Nous (2020). Bereaved carers called for a more person-centred care system that encompasses the residents' needs in the physical, psychological, emotional and spiritual domains. Carers requested more timely information and appropriate resources to feel supported and needed to be more involved in care decisions undertaken within the RACH. They pointed to challenges in workforce capacity and capability and accessing health services. Staff reported needing access to ongoing education and training as identifying and communicating about residents' palliative care needs has been highlighted as a consistent service gap. This is compounded by health interface challenges, these being access to primary, secondary and tertiary health care services.

While these gaps and challenges are not particular to WA, this evaluation has been able to shine a light on the cumulative impact of the NPA initiatives, using this deep dive methodology. One primary and common aspect of the palliative care in aged care model adopted in WA is the integration of specialist palliative care into RACHs in metropolitan areas. The impact of this integration has been evident in reports from both bereaved carers and staff:

1) Overall, bereaved carers reported that residents utilising palliative care services resulted in improved experiences for both residents and their family carers in most aspects of care as compared to residents who did not access palliative care services.

2) Staff from sites with NPA initiatives reported practices with higher quality indicators than those working in sites with no NPA initiatives.

The following discussion uses the impacts headings of the WA Project Logic Map (Appendix 7 in full report) to discuss the differences in responses between those who did or did not receive specialist palliative care and those services that did or did not engage with NPA initiatives.

Health and Quality of Life:

- Overall, bereaved carers and staff reported that residents who received specialist palliative care services reported good levels of pain and symptom management and were able to access palliative care as soon as it was needed.
- However, bereaved carers who were not connected with palliative care reported lower satisfaction levels with pain and symptom management.
- Staff at RACHs engaged in NPA initiatives reported using assessments to track clinical deterioration and had more discussions on EOL care decision making than non-NPA sites. There were also statistically significant differences in the number of multidisciplinary case conferences held at NPA sites compared to non-NPA sites.

- A statistically significant difference was noted between residents accessing palliative care versus those who did not in relation to whether their cultural or spiritual background was respected, with those receiving palliative care rating their satisfaction much higher.
- Residents' emotional, spiritual and cultural needs were also reported to be better met in NPA sites according to staff, but bereaved carers did not share this opinion to a great extent.
- In addition, bereaved carers reported not being well supported by staff in general and at the time of and after the resident's death.

It seems grief and bereavement support were not factored in this current model of care investment. A recent systematic review by Vandersman et al. (2024, p1) reported that "families of people entering and living in residential and aged care settings have complex and dynamic bereavement care needs. The quality of care provided to an older person at the end of their life and after death care can influence family caregivers' grief reactions". Future initiatives need to address grief and bereavement support for staff and family carers. However, supporting family carers pre- and post-death needs a more sustainable and collaborative model of care that involves supportive informal networks and referral pathways from RACHs to community-based not-for-profit organisations. This could be achieved through a collaborative Compassionate Communities model of care. A community development approach could facilitate RACHs in accessing and developing resources available in their local communities.

Access and Choice:

- Residents preferred place of death was documented with greater frequency in NPA user sites and these sites did better in utilising documentation on preferred place of death. Seventy eight percent of residents died in RACHs and 18% in hospitals.
- While RACH was the stated preferred place of death for only 21% of residents, there were 27% who stated no preference and 22% whose preference was not discussed, bringing the total to 70% which is close to the actual RACH place of death proportion, reported in phase 1.
- However, areas that show a need for improved performance and for which there is no statistically significant difference between the NPA and non-NPA sites was an increase in numbers of residents who have ACP documents, AHDs and RGoCs, and whether residents' EOL care plans are reviewed every three to six months.

This may warrant developing systems that support revisiting care plans. One example of a successful program addressing the discussion and documentation of resident care needs runs monthly palliative care needs rounds for residents with high symptom burden by Forbat et al. (2019) and Rainsford et al. (2020), as described in the recommendations section. While ACP documents are often considered around the time of admission to RACH, the findings of consistent challenges and barriers highlight that advance care planning discussion and documentation are best completed in the community. Work has been happening in this space, but it needs to be better supported for a much wider population reach.

Understanding:

- More PC users reported being included in decision making about their relative's care.
- Service providers also reported that more residents and carers were provided with information about EOL planning in sites that use NPA initiatives.
- Staff in NPA sites felt more confident in their understanding of palliative care.

It is worth noting that the unsure group (29% of total sample) had significantly more rural respondents than the groups who did know if they received or did not receive palliative care, highlighting the need to expand and raise awareness of specialist palliative care models in country WA.

Capability:

- A significant finding of the study was challenges with limited skills and confidence in caring for people at EOL, pointing to low death literacy and grief literacy levels, as reported by both staff and bereaved carers.
- Non NPA user sites scored significantly worse than NPA user sites when asked whether staff were supported to participate in palliative care training and education.
- PC users rated the competence of staff higher.

Service providers suggested increased use of professionals such as spiritual care, social work, occupational therapy, and physiotherapy to optimise quality of life at end of life. This may assist with a better experience of dying and death for residents and their carers.

Care Coordination and Communication:

- NPA users reported a higher percentage of residents were able to access appropriate medication in a timely manner.
- However, both service providers and bereaved carers reported challenges accessing GPs for dying residents. Bereaved carers of residents receiving palliative care services had a statistically significant higher rating than those who did not receive PC, in terms of how well the RACH staff worked with the GP; whether emergency department visits were perceived as helpful; and whether out of hours care plans were in place if their condition deteriorated.
- There were no statistically significant differences based on NPA initiatives in terms of RACH staff supporting GPs to coordinate case conferencing; coordination of care from hospital discharge to RACH; and EOL care reviews via audit process or after death audit.

There is a need to improve partnerships across the sector within the context of the poorly integrated system that exists. Future research could do a deep dive into RACHs that have good GP services versus those that do not, identifying what makes it work well and how can these factors be systematised to improve overall access to and care from GPs. The issue of variable access to GPs and medications was not significantly impacted by the current NPA initiatives and calls for further work.

System:

- NPA sites reported having a decrease in residents transferred to hospital for symptom management compared to non-NPA sites.
- More PC users perceived resident's visits to ED were helpful compared to non-PC users; and more reported out of hours planned care if condition deteriorated.
- The proportion of decisions that were made but not wanted by carers or residents varied between 13% and 22% with the lower end for those who did receive palliative care, although the differences were not significant. However, this proportion is compatible with a similar UK study being about 20% (Office for National Statistics, 2015).

Research has long supported that a palliative approach should be offered earlier in the disease trajectory rather than reactive end-of-life care. A palliative approach to care can facilitate addressing residents needs in a proactive rather than reactive manner, as factors such as disease progression and symptom management are discussed earlier on in the trajectory. This approach reduces the reactive responses to poorly managed symptoms, such as through conducting proactive medication management reviews and ensuring an out of hours care plan is developed.

Strengths and Limitations of the Study

Consumers

The consumer survey sample may not be representative of the general RACH population because of the sampling framework where we could only rely on social media and several consumer and service provider networks to recruit bereaved carers. However, there were important similarities in several variables between this study sample and the general RACH population as cited in several official reports and detailed in Phase One of this report: the age distribution of residents, proportions of residents living with dementia, proportion of rural residents, proportion of residents dying in RACHs, and median length of stay at RACHs. These similarities in the demographic and clinical profile of residents gives more weight to the consumer feedback and by consequence the conclusions and recommendations from this study. Furthermore, the experiences of bereaved carers echo those in other literature calling for a more person-centred care system that encompasses the residents and carers support needs in the psychological, emotional, and spiritual domains.

It is worth noting that even with the lay-friendly definition of specialist palliative care 'Visiting Palliative Care Team' (as recommended by the reference group), there was confusion amongst consumers about whether their relative resident at RACH had engaged with palliative care services.

The current model of RACHs engaging with and referring their residents to 'specialist palliative care services' namely MPaCCS, who visit their premises but mostly meet with RACH staff and not the families, was not always obvious for consumers. Where 'generalist' palliative care was provided to residents by existing RACH staff including the GP and nursing team, consumers may have perceived this as a 'visiting palliative care team'.

Service Providers
Similarly, the sample of the RACH staff survey may not be representative of the general RACH staff population, however their feedback reflects already-known challenges, as do their suggestions for improvement.

It should be noted that disruptions due to COVID-19 restrictions across WA meant that RACHs could not implement NPA pilot projects according to schedule. In addition, not all RACHs engaged in NPA initiatives completed the survey which may have influenced results.

Competing surveys in the same timeframe as this study

Recruiting for the two surveys was challenging in a time where both consumers and service providers have been targeted to participate in surveys and other forms of consultation. At the time of conducting this study, bereaved carers (Next of Kin) and RACH staff were both over surveyed populations due to the number of submissions prepared for the Royal Commission into Aged Care Quality & Safety, improvement initiatives, independent evaluations being conducted by public and private organisations, and an increase in RACH regulation and compliance.

In addition, Commonwealth and WA Departments of Health both simultaneously conducted online surveys and/or facilitated online education and training sessions for RACH staff. Going forward, collaboration with the various teams involved in EOL&PC in aged care initiatives would avoid duplication and unintended reduction of opportunities to engage with potential participants. For example, some NPA project teams conducted their own evaluations based on each initiative. The RACH survey and focus groups that formed the independent evaluation brief may have had more uptake if duplicate requests from various teams did not occur.

RECOMMENDATIONS:
Service & Sector

RECOMMENDATIONS FOR SERVICE IMPROVEMENT

The following recommendations are based on evidence from analyses in Phases One, Two and Three detailed in this report and on key suggestions by consumers and service providers for service improvement. This evaluation explored bereaved carers' and service providers' experiences of palliative care for residents in RACH. They described what worked well and what could have worked better. Overall, specialist palliative care services improved the experiences of residents and families in most aspects of care as compared to residents who did not access palliative care services. Bereaved carers and service providers described four primary recommendations for improving palliative care services in RACH:

1. Building workforce capacity and capability (including staffing levels and improving staff knowledge and skillset in addressing end of life care needs)
2. Improving coordination of care (including care planning, access to GPs, and continuity of care)
3. Improving the quality of end-of-life and palliative care
4. Enhanced communication with and support for family and carers.

A summary of bereaved carers and service providers recommendations on how to improve end of life care at RACHs is listed in Appendix 8, including further participant quotes to give voice to the recommendations. Some recommendations are within the realm of the Western Australian Department of Health while others would be within RACH usual business, and some would be potentially addressed to WA Primary Health Alliance (WAPHA), private community GPs and community pharmacies.

1. Build Workforce Capacity and Capability

Capacity

- Address Workforce Retention Issues: Identify key concerns among RACH employees that are influencing high staff turnover within RACHs across WA. These issues relate more broadly to aged care at the federal level, such as recruitment, retention, salaries and conditions of aged care staff.
- Improve access and expand awareness of specialist palliative care services available to RACHs for communities in country WA.

Capability

- Increase the flexibility of training schedules: High staff turnover within RACHs may require a more flexible schedule for educational offerings including training and workshops. There are limitations associated with set curriculum timelines and alternatives are required.

- Provide training opportunities for non-clinical Staff: Personal Care Attendants (PCAs) provide the majority of face-to-face care in RACHs, and educational programs designed specifically for this group warrant further attention around end of life and palliative care programs.
- Provide Dementia-specific education for all clinical and non-clinical RACH staff to improve their care of residents who are diagnosed with dementia and cognitive decline.
- Provide death literacy and grief literacy education to clinical and non-clinical RACH staff to improve skills and confidence in caring for people at end of life and in supporting their families (such as recognising and responding to clinical deterioration).
- Provide mentorship between more senior or qualified RACH staff within individual sites or across RACH providers that may assist in minimising staff burnout.
- RACHs to appoint specific end of life care champions across individual sites to support an organisation-wide cultural shift towards a palliative approach to care for residents, aligned with their advance care planning documentation.

EOLCP have the following NPA Initiatives in progress in this domain: MPaCCS Expansion, Cancer Council WA RACEPC Communicate, WAPHA GP Case Conferencing Coordinator and RCL Expansion.

Supporting Quotes – Survey Respondents

There is huge scope for increasing palliative care knowledge and skills for residential care facility workers. (Bereaved Carer 12)

Lack of training, communication, or support from nursing staff or management. Care staff are mostly left to figure things out for themselves. (Service Provider 49)

Emotional demands providing palliative care can be emotionally taxing on staff. (Service Provider 33)

Staff are not given training opportunities to learn how to help residents who are deteriorating (no longer eating or drinking regularly) aside from reporting the issue. (Service Provider 51)

2. Improve Coordination of Care

Care Planning

- While advance care planning (ACP) documents are often considered around the time of admission to RACH, the findings of consistent challenges and barriers highlight that ACP discussion and documentation are best completed in the community. Work has been successfully happening in this space by Palliative Care WA and groups of compassionate communities, but it needs to be better funded for a much wider and faster population reach. In addition, there is a need to continue innovation and new models of facilitation and support to improve the reach into key population groups.

- The 'care plan for the dying person' is a resource developed by acute and subacute healthcare services in Australia, often at a state level. There is a need to consider the development of a care plan for the dying person tailored for the aged care setting in WA, along with implementation support and ongoing resources. The care plan supports a model of care that combines frequent assessments, critical thinking, individualised care planning, shared decision-making and continuous review to ensure the focus of care is on the dying person and those close to them.

- Residential Goals of Care (RGoC) is a document and process adapted for RACHs from the Goals of Patient Care document and process currently used in WA hospital settings. The tool supports clinical care, provides common language across settings, and complements consumer-led ACP documents. It promotes conversations about goals of care, limits of escalation of care, whether the resident wants to go to hospital and may trigger ACP. Continued implementation of this new model is warranted across WA RACHs.

EOLCP have the following NPA Initiatives in progress in this domain: EMHS Transition Support Officer, SMHS Care Coordinator, NMHS Transition Support Navigator, WACHS Residential Goals of Care, MPaCCS Expansion, WAPHA GP Case Conferencing Coordinator.

Access to GPs

- Develop sustainable models of delivering primary care in RACHs in collaboration with GPs to better understand how additional resourcing may improve quality care for residents, as much of primary care is palliative care in this setting.
- Need a proactive approach to prescribing medications at end of life to minimise wait times for residents and distress for family carers related to poor pain and symptom management e.g. through promoting the National Core Medication List in primary care and community pharmacies.
- Improve out of hours access to GPs for RACH residents including weekends and public holidays. This approach would also minimise the need for unnecessary hospitalisations.

EOLCP have the following NPA Initiatives in progress in this domain: WAPHA GP Case Conferencing Coordinator, RACGP GP Information Resources and RCL Expansion. For Example, the GP Case Conferencing Coordinator pilot is designed to support place-based coordinator roles within RACHs that act as a conduit between GPs, RACH staff, specialist palliative care services and residents.

Continuity of Care

- Improve data sharing ability among RACH staff, GPs and hospital staff to ensure equal access to ACP documents, Goals of Patient Care to translate to RGoC documents, and residents' preferred place of death.

EOLCP have the following NPA Initiatives in progress in this domain: NMHS Transition Support Navigator, SMHS Care Coordinator, EMHS Transition Support Officer and MPaCCS Expansion. For example, *HSP's Transitions of Care pilots are designed to support quality transfer of information at discharge from hospital to RACH, and MPaCCS' hospital liaison nurse to support transition from hospital to RACH and RACH to hospital for those with palliative care needs.*

Supporting Quotes – Survey Respondents

More dementia reviews and the ability to move to higher level care as needed. … More information and involvement of a palliative care team or staff BEFORE entering palliative care stage so that decisions are made collaboratively and with an understanding of what is happening and why. (Bereaved Carer 56)

Every resident coming into aged care facility should have a palliative care plan set up, family also should be given education on signs of dying and how to support someone die well. It's hard to watch people suffer. (Bereaved Carer 11)

Families need more support and encouragement to complete the [ACP] docs in a timely manner. (Service Provider 82)

3. Improve the quality of end-of-life and palliative care

Multidisciplinary Teams

- Increase the number of Allied Health and Spiritual Care staff in RACHs including social workers, occupational therapists and physiotherapists to optimise the quality of end of life.
- Increase a person-centred focus on residents' physical, psychosocial, functional and spiritual needs.
- Introduce grief and bereavement support for resident and family carers, for example grief counsellors employed by RACHs or in specialist palliative care teams.

EOLCP have the following NPA Initiatives in progress in this domain: MPaCCS Expansion (Social Workers).

Supporting Quotes – Survey Respondents

[Staff were] competent in most day-to-day care but very limited skills in palliative care, demonstrated multiple times during end-of-life care. (Bereaved Carer 12)

Providing culturally sensitive care and overcoming language barriers can be challenge. (Service Provider 34)

4. Enhance Communication with and Support for Family and Carers

- RACH staff need access to training in how to share prognosis, palliative care phase and care plans with family members as residents deteriorate and die.
- Undertake education for families and carers about end-of-life and palliative care literacy, in partnership with organisations such as Palliative Care WA.
- More liaison with not-for-profit organisations that can support family carers is needed, with RACHs taking a signposting role via making available a list of services that family carers can tap into. This could be achieved through a collaborative Compassionate Communities model of care.

EOLCP have the following NPA Initiatives in progress in this domain for RACH staff education and training: Cancer Council WA RACEPC Communicate, RCL Expansion, MPaCCS Expansion and WAPHA GP Case Conferencing Coordinator.

Supporting Quotes – Survey Respondents

Listen to the family members. Take things seriously. Just because they may have seen events hundreds of times. For the family it is the first time. (Bereaved Carer 12)

More information/updates, more transparency, more sharing of information. (Bereaved Carer 85)

Realistic and timely information about possible end of life experience. (Bereaved Carer 42)

Would like a folder with information available for families unfamiliar with the dying process and what to expect happen of the dying patient ie: nikki pump, cheyne stoking, death. (Service Provider 85)

Future work to support service improvement

- **Education in End of Life and Palliative Care**

Although there is a wide range of education and training opportunities available to aged care sector staff in WA (and more specifically through the NPA initiative RACEPC), there were repeated recommendations to improve and increase RACH staff training surrounding end of life and palliative care. Future research should explore why these educational opportunities are not being utilised, or alternatively, why the learnings are not successfully translating into practice. A focus on the need of CALD staff and PCAs is warranted.

- **Monitoring Changes in Quality Indicators Over Time**

This evaluation is particularly useful for providing a baseline for experience of care across the six priorities of the WA End-of-Life and Palliative Care Strategy which can be re-examined in future years as new initiatives are implemented across the sector to track their impact on residents/ family carers and RACH staff.

- **Expanding on Understanding GP and Hospital Staff Perspectives**

The lack of coordination among RACH staff, GPs and hospital staff as individuals and as key service providers to the aged care sector should be explored in more detail in order to gain a clearer understanding of how integration and cooperation could be improved. It would be particularly beneficial to identify RACHs where GP access and integration is well established, to understand key success factors and barriers to provision of palliative care.

To bolster the provision of generalist palliative care, further research with GPs needs to be undertaken to understand their perceived barriers and facilitators to provision of high quality and timely palliative care in RACHs.

- **Supporting Family Carers**

Supporting family carers pre- and post-death requires a more sustainable and collaborative model of care that involves supportive informal networks and building referral pathways between RACHs and community-based not-for-profit organisations. This could be achieved through a collaborative Compassionate Communities model of care. This community development approach would assist RACHs in accessing resources available in their local communities.

Another initiative that is gaining momentum in the US and the UK and that RACHs can facilitate is Help Texts which is a text messaging program that delivers twice-weekly text support, education, tips, and reminders to people who are grieving, as well as to their friends and family who want to support them. The program is designed to engage grievers who may not be inclined to seek bereavement counselling but could benefit from additional support. Some hospices have included this initiative as part of their signposting with positive evaluation outcomes (https://helptexts.com/).

RECOMMENDATIONS FOR SECTOR IMPROVEMENT

The final report of the aged care taskforce (Australian Government, 2024) highlights that the aggregate demand for residential aged care will continue to grow and has called for an aged care system that is sustainable and facilitates greater innovation in the sector. However, approaches to support innovation around EOL care will need to include both those focused on the delivery of care, and those that harness partnerships with the community, beyond just ensuring the sector meets community expectations.

According to the demographer Bernard Salt, the number of Australians aged 85 and over will be growing at 60,000 per year by the end of the decade, up from about 20,000 in 2024 (Salt, 2024). A Palliative Care Australia & KPMG (2020) report found that by 2050, national demand for palliative care services will increase by 200%. It is unclear whether the forecast in huge investment, cited in the aged care taskforce report, will cater for this increase in older people: “Investment of $37 billion (in today’s dollars) would be required to build the additional aged care rooms needed by older people in 2050. Over the next decade to 2030, additional investment of approximately $5.5 billion would be required to refurbish and upgrade existing aged care rooms, increasing to $19 billion by 2050” (Australian Government, 2024, p. 7).

Rumbold and Aoun (2021) reviewed the evidence related to consumer preferences and suggested that best practice is defined more by the qualities and values embedded in the care provided, not a particular program structure or setting. The most appropriate model of care is one that can respond flexibly to the variety of needs across the illness trajectory, including at end of life. Milte et al. (2018) surveyed 17 nursing homes across four Australian states to ascertain the characteristics most valued by residents and family members. While residents receiving palliative care were excluded, these values have important implications for understanding the context with which palliative care ideally might articulate. Belonging (feeling at home) is of primary importance to residents, as is flexibility in the care routines provided by staff. Tilden et al. (2012) noted the problem of high staff turnover and the high personal and economic cost that works against quality of care. Thus, an effective model must exist within the challenges of workforce sustainability yet still ensure that residents needs are met within the complexities of their life-limiting disease trajectory.

Models of Care

The INSPIRED model has been promoted as an effective evidence-based approach to provision of end-of-life care for residents at RACHs (Chapman et al., 2018; Forbat et al., 2019; Forbat et al., 2024; Rainsford et al., 2020). Research has found that this model’s use of monthly needs rounds with RACH staff and specialist palliative care facilitates care planning for residents with high symptom burden or complex needs at end of life. An economic evaluation highlighted that an investment of $75 million for increase nurse practitioners and multidisciplinary services would result in between $135 and $310 million reduction of costs due to hospitalisations and emergency services (Forbat et al., 2020; Palliative Care Australia & KPMG, 2020). However, it is worth noting the resources required by such initiatives may impose limits on their relevance and sustainability if the resources to enact the program are not provided, as many require the participation and/or supervision of nurse practitioners, not always available to aged care services, while care in practice is provided overwhelmingly by staff at Personal Care Assistant (PCA) level. Programs that equip and support PCAs through training and mentoring (rather than primarily focusing on registered nurses) also warrant further attention.

Collaborative Models

While services can be improved in their provision of EOL physical care, they are limited in their capacity for more individualised support of older adults and their families. This is not a criticism of services as such, but recognition that individualised social and emotional support is provided through social participation. Interventions of health professionals whose relationships are instrumental, can be humane and compassionate, but cannot replace the web of relationships, arising from various forms of community participation, that has held aged persons throughout their lives. This limitation is often recognised in describing models of integrated care, but such recognition seldom translates to specific strategic recommendations as to how community engagement can be preserved, facilitated and sustained by RACHs and their residents (Rumbold & Aoun, 2021).

Network centred aged care

This approach is underpinned by community development with a focus on meaningful relationships and network centred aged care. As an example, the 10K initiative focused on the maintenance and development of social networks and relationships for a group of elders who lived in an aged care home in the Western Suburbs of Sydney (Rahn et al, 2020). The role of the community development worker was to engage with the resources and networks within a 5-kilometre radius of the home. At the same time there was a focus on developing the agency of people (staff and residents) within the home so that they took collective action/s to solve problems such as loneliness and overcome barriers such as an overreliance on clinical approaches to care provision. Although the project was conducted with residents in Sydney NSW, the approach is likely to be adaptable to other similar aged care settings (Rahn et al, 2020).

Compassionate Connectors Program

Building effective and sustainable models for EOL care means improving how care is provided as well as expanding models beyond the healthcare system to include the community. The Compassionate Connectors Program was trialled for terminally ill older people living at home in the South West of WA. Connectors supported patients and their family carers referred by the health service to identify networks of care that can meet their practical and social needs. The program significantly improved social connectedness, reduced social isolation and reduced hospital admissions and lengths of stay (Aoun et al., 2023; Aoun et al., 2022). Such model of care needs considering how it can be adapted in RACHs, where RACH residents can be supported to maintain and enhance their social networks within and prior to their entry to their RACH, and RACHs could engage with, contribute to, and draw upon their local communities.

Wellness Hubs

Bupa is piloting a wellness hubs initiative in six of its aged care homes in regional areas of Queensland, where there is a shift from an illness and reactive approach of care to a restoration and wellbeing-centred care model and a care delivery program with a holistic focus. The Bupa wellness hubs are led by nurse practitioners in partnership with general practitioners and allied health teams who review and manage multidisciplinary care – including telehealth. The Wellness Hubs are already having a positive impact on resident outcomes. These include proactive healthcare management, enhanced admission experiences, smoother care transitions, reduced hospital transfers, and improved clinical indicators (ARIIA, 2023).

CONCLUSIONS

Provision of quality palliative care services for residents of RACHs can facilitate quality of life at end of life and foster a good death for the resident, their family and RACH staff. To do so, additional training and capacity of staff is required, care should be effectively planned and coordinated, communication between RACH staff, residents, families and other agencies needs to improve, and the quality of care provided should allow the resident to live and die with dignity.

However, the mostly clinically focused current models of care in aged care are not sustainable neither in cost nor capacity, without incorporating social models of care to provide person-centred meaningful care to residents at end of life. This could be achieved through a collaborative Compassionate Communities model of care. Current systems are geared to doing tasks (with ever-increasing burdensome administration) rather than facilitating connections between residents and with the wider community, thus contributing to loneliness, learned helplessness, lack of self-agency and internalised ageism of residents.

The suggested outward looking models of care require different perspectives and skills in addition to those gained through clinical training. Public health perspectives and community development skills need to be added to the aged care team, through revising staff profiles, arranging secondment from community services, or seeking the necessary skills from volunteers. However, it takes time and a concerted effort to recognise that change is needed and desirable. A combination of behavioural, cultural and systems change is required and resistance to such changes will be encountered along the way.

This change in culture requires commitment, resources and a process which put residents stated needs and aspirations at the centre, so residents are not merely ‘cared for’ but also ‘cared about’. The scale and imminent impact of ageing we are facing soon requires a whole of community urgent response and collaboration across health and social care is critical.

Ultimately, to achieve an effective, affordable & sustainable end-of-life care system, a public health approach based on a close partnership between clinical services and communities/civic institutions is the optimal practice to be infused in any model of care (Figure 20). “The New Essentials concept proposes a way of integrating the processes and operations of the four basic components— specialist palliative care, generalist palliative care, compassionate communities and civic end-of-life care—that make up palliative and end-of-life care” (p.4, Abel et al, 2018).

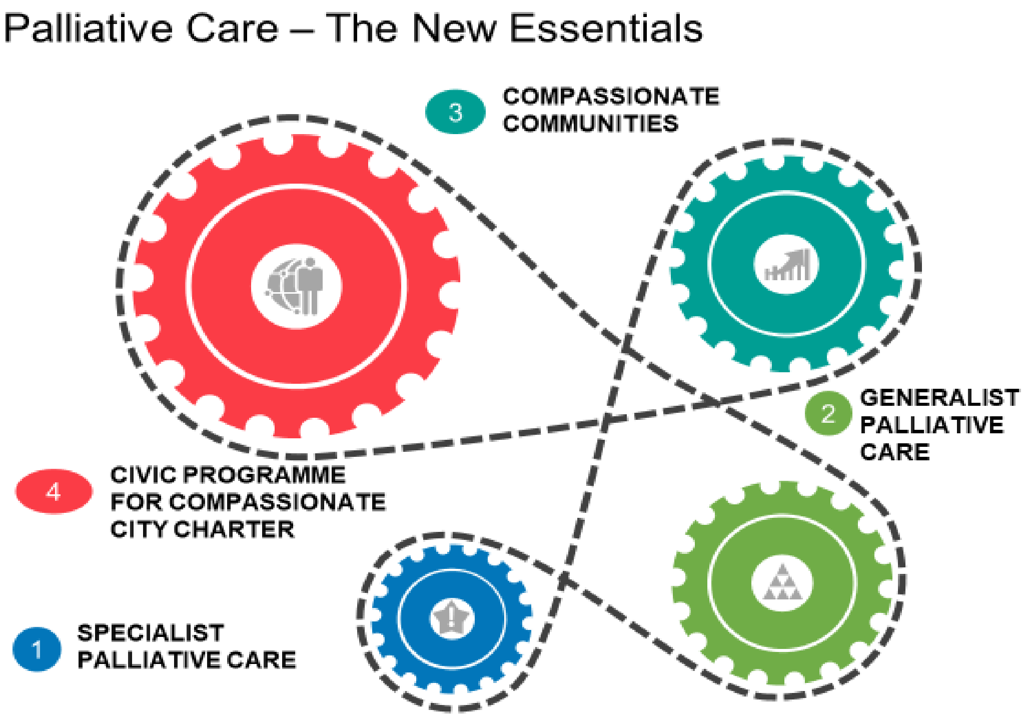

Figure 21: The New Essentials Palliative Care Model (Abel et al., 2018)

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APPENDICES

Appendix 1: Project Contributors

Reference Group Members

- Deirdre Whitty – North Metropolitan Health Service, Residential Care Line
- Frances Arthur – Western Australian Department of Health, End-of-Life Care Program
- Bernadette Nowak – Bethesda Healthcare
- Janet Wagland – Brightwater Group
- Marta Mendiolaza – Bethanie
- Liz Behjat – Aged & Community Care Providers Association
- Clare Mullen – WA Health Consumers' Council

Research Team

- Professor Samar Aoun – Perron Institute/UWA and Chief Investigator
- Professor Kirsten Auret – Rural Clinical School of Western Australia and Co-Investigator
- Professor Bruce Rumbold – La Trobe University/Perron Institute and Co-Investigator
- Jennifer Lowe – Perron Institute Research Fellow
- Dr Julie Brose – Perron Institute Postdoctoral Research Fellow
- Denise Howting – Perron Institute Graduate Biostatistician

Appendix 2: WA End of Life and Palliative Care Strategy (2018-2028) Priorities

1. **Care is accessible to everyone, everywhere.**

   I have access to good quality end-of-life and palliative care, regardless of who and where I am, or how I live my life.

2. **Care is person-centred.**

   I am seen as an individual, and I have the opportunity to be involved in honest discussions with those important to me about my care. My values, culture and spirituality are respected and taken into account when care is given.

3. **Care is coordinated.**

   I receive the right care at the right time, in the right place, from the right people. My care occurs within a coordinated/collaborative approach, enabling care to be delivered seamlessly.

4. **Families and carers are supported.**

   Those close to me and/or caring for me are supported and involved in my care. The contributions made by my family/carer are recognised and valued by those providing my care, including their need to be supported during and after my death.

5. **All staff are prepared to care.**

   Wherever and whenever I am cared for, all staff involved in my care have expertise, empathy and compassion. All staff provide confident, sensitive and skilful care, before, during and after my death.

6. **The community is aware and able to care.**

   I feel supported and empowered to make decisions. My individual preferences are expressed through Advance Care Planning (ACP) and reflected in my end-of-life and palliative care. My community is aware and able to support me and those close to me.

Appendix 3: Promotional Materials & Third-Party Promotion

Have your say to help us improve end-of-life care

Did your family member or friend die in an aged care facility in Western Australia between 2021 - 2024?

SCAN ME

Tell us about your experiences in our online survey...

perroninstitute.org/agedcare

perron institute EST. 1982 for neurological and translational science
Government of Western Australia Department of Health
THE UNIVERSITY OF WESTERN AUSTRALIA

Consumer Survey Flyer

Do you work in a Residential Aged Care Facility in Western Australia?

We want to hear from you about your experiences with palliative and end-of-life care.

https://redcap.link/RACF

SCAN ME

perron institute EST. 1982 for neurological and translational science
Government of Western Australia Department of Health
THE UNIVERSITY OF WESTERN AUSTRALIA

Service Provider Survey Flyer

RACF Staff Consultations

JOIN US ONLINE

We asked Western Australians to tell us about their experiences of end-of-life and palliative care in Residential Aged Care Facilities between 2021 - 2024.

Our consumer survey results offer one perspective, and we are now consulting with RACF staff to understand the views and perspectives of service providers.

You are invited to join us online for a 1.5-hour focus group, where you will hear about the consumer survey results, and have an opportunity to provide us with feedback from your perspective.

Your feedback will be used to inform future funding priorities for end-of-life and palliative care in aged care.

·**Tuesday 2 July** (12pm - 1:30pm AWST)
·**Friday 5 July** (9am - 10:30am AWST)
·**Wednesday 10 July** (1pm - 2:30pm AWST)
·**Thursday 11 July** (1pm - 2:30pm AWST)

There are 4 online sessions to choose from.
Scan the QR code to register, or visit the link below:
https://redcap.link/RACFfocusgroups

Register Now

perron institute EST. 1982 for neurological and translational science
Government of Western Australia Department of Health
THE UNIVERSITY OF WESTERN AUSTRALIA

Focus Groups Flyer

Use your voice to improve end-of-life in aged care

Did your family member or friend die in an aged care facility in Western Australia between 2021 – 2024?

The Perron Institute, The University of Western Australia and the Department of Health are working together to improve end-of-life services in residential aged care facilities across Western Australia.

Your opinion can truly make a difference and improve services for our community in the future. Share your experiences by completing our online survey before 3 May 2024.

perroninstitute.org/agedcare

SCAN ME

THE UNIVERSITY OF WESTERN AUSTRALIA
Government of Western Australia Department of Health
perron institute EST. 1982 for neurological and translational science

Consumer Survey – Newspaper Advertisement 'The West Australian'

Calling All Western Australians to Help Us Improve End-of-Life Services in Aged Care...

http://redcap.link/agedcare

perron institute EST. 1982 for neurological and translational science
Government of Western Australia Department of Health
THE UNIVERSITY OF WESTERN AUSTRALIA

Calling All Western Australians to Help Us Improve End-of-Life Services in Aged Care...

http://redcap.link/agedcare

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Government of Western Australia Department of Health
THE UNIVERSITY OF WESTERN AUSTRALIA

Consumer Survey – Facebook Advertisements

State Government

- WA Electorate Offices
- WA Country Health Service
- WA Department of Health - Healthy WA

Private & NFP Organisations

- Perron Institute
- University of Western Australia Research
- Grief Centre of Western Australia
- Bethesda MPaCCS
- Silver Chain WA
- Carers WA
- MNDAWA
- Health Consumers Council WA
- Parkinsons WA
- South West Compassionate Communities Network
- Salvation Army WA
- Aged & Community Care Providers Association
- Council on the Ageing (COTA) WA
- Cancer Council WA
- Palliative Care WA
- Advocare WA - 'Newsbites'
- Older Persons Advocacy Network
- Neurological Council of WA
- Multiple Sclerosis WA
- Alzheimers WA
- Rotary WA
- Perth Rotary
- Salvation Army WA
- Compassionate Communities Albany, Esperance
- Elder Rights Advocacy
- National Seniors Australia
- Compassionate Friends Mandurah
- Samaritans WA
- Centrecare
- Anglicare WA
- Solace WA
- Country Women Association
- Zonta Clubs

CALD/Faith Communities

- Chung Wah Community Care (Chinese)
- St. Nektarios Church (Greek)
- Saints Constantine & Helen (Greek)
- Melkite Catholic Eparchy of Australia (Arabic)
- Ethnic Communities Council of WA

Funeral Industry Providers

- Mareena Purslowe Funerals
- Purslowe Chipper Funerals
- William Barrett and Sons
- Tender Funerals
- Bowra & O'Dea
- Gift of Grace Funerals
- Archer & Sons
- Amity Rose Funerals
- Perth Cremations

Online Media Outlets

- The West Australian
- Kimberly Echo
- North West Telegraph
- Broome Advertiser
- Pilbara News
- Great Southern Herald
- Narrogin Observer
- Geraldton Guardian
- Bunbury Mail
- South Western Times
- Harvey Waroona Reporter
- MB Times
- AMR Times
- BD Times
- Kalgoorlie Times
- Country Man

RACH Service Providers

- Residential Care Line
- Acacia Living
- Amana Living
- BaptistCare WA
- Bethanie
- Bethesda
- Brightwater
- Catholic Homes
- Hall & Prior Aged Care WA
- Juniper WA
- MercyCare
- Opal Healthcare
- Regents Garden
- Regis
- Roshana Care Group
- Southern Cross Care WA

Online Community Forums

- Caring For Elderly Parents in Australia
- Aged Care Support Group in Australia
- Reddit r/westernaustralia
- Aged Care Online

Appendix 4: Consumer Survey Results - Priorities 1-6

PRIORITY 1	**All**	**PC Team Visit**				**Metro/Rural**			**Main Carer**		
Care is accessible to everyone, everywhere	Total	Yes	No	Unsure		Metro	Rural		Yes	No	
	n (%)	n (%)	n (%)	n (%)	p-value	n (%)	n (%)	p-value	n (%)	n (%)	p-value
Overall quality of care provided by RACH (Excellent/Good)	248 (78.5)	105 (81.4)	70 (72.9)	73 (80.2)	0.276	205 (77.9)	43 (81.1)	0.607	70 (75.3)	176 (80)	0.351
Received access to palliative care as soon as needed [PC Users Only] (Yes)	95 (74.8)	95 (74.8)	--	--	NA	87 (75)	8 (72.7)	1.000	28 (68.3)	66 (78.6)	0.212
Overall, received as much support as wanted from RACH (Yes)	166 (52.4)	80 (62)	38 (39.2)	48 (52.7)	*0.003**	137 (51.9)	29 (54.7)	0.707	47 (50.5)	117 (52.9)	0.697
Relief of pain (Excellent/Good)	215 (68.7)	94 (73.4)	61 (64.9)	60 (65.9)	0.318	175 (67.3)	40 (75.5)	0.243	62 (68.9)	152 (69.1)	0.972
Relief of symptoms other than pain (Excellent/Good)	195 (62.5)	90 (69.8)	52 (55.9)	53 (58.9)	0.077	161 (62.2)	34 (64.2)	0.785	57 (62.6)	137 (62.8)	0.973
Practical assistance received (Excellent/Good)	202 (65)	83 (65.9)	59 (62.1)	60 (66.7)	0.778	168 (64.6)	34 (66.7)	0.779	56 (61.5)	145 (66.8)	0.374
Quality of care provided at end-of-life (Excellent/Good)	226 (72)	99 (76.7)	62 (65.3)	65 (72.2)	0.167	188 (72)	38 (71.7)	0.961	66 (71.7)	159 (72.6)	0.876
RACH provided enough support at the time of death (Yes Definitely)	154 (48.7)	76 (58.9)	43 (44.8)	35 (38.5)	*0.007**	130 (49.4)	24 (45.3)	0.582	47 (51.1)	106 (48)	0.615
Received as much support as wanted after resident's death (Yes)	115 (42.4)	54 (47.4)	29 (35.8)	32 (42.1)	0.273	101 (44.9)	14 (30.4)	0.071	32 (37.2)	82 (44.8)	0.239

**Statistically Significant Difference*

PRIORITY 2	**All**	**PC Team Visit**				**Metro/Rural**			**Main Carer**		
Care is person-centred	Total	Yes	No	Unsure		Metro	Rural		Yes	No	
	n (%)	n (%)	n (%)	n (%)	p-value	n (%)	n (%)	p-value	n (%)	n (%)	p-value
Carers asked about pre-existing EOL formal documentation (ACPs, AHDs…) (Yes)	198 (62.9)	96 (74.4)	66 (69.5)	36 (39.6)	_<0.00*1_	171 (65.3)	27 (50.9)	_0.049*_	77 (84.6)	119 (53.8)	_<0.001*_
RACH considered residents wishes that were documented (Yes)	166 (87.8)	87 (91.6)	55 (87.3)	24 (77.4)	0.109	143 (87.7)	23 (88.5)	1.000	65 (87.8)	100 (87.7)	1.000
Inclusion of residents in care decisions (Excellent/Good)	175 (61.8)	83 (69.7)	45 (54.2)	47 (58)	_0.058_	145 (61.7)	30 (62.5)	0.917	52 (62.7)	122 (61.9)	0.909
Residents were involved in decisions about care at end-of-life (Involved as wanted)	166 (52.9)	73 (56.6)	54 (57.4)	39 (42.9)	0.075	138 (52.9)	28 (52.8)	0.995	50 (53.8)	116 (53.2)	0.929
Inclusion of carers in care decisions (Excellent/Good)	185 (58.4)	84 (66.1)	52 (56.5)	49 (66.2)	0.283	155 (62.8)	30 (65.2)	0.750	59 (64.1)	126 (63.3)	0.893
Carers were involved in decisions about care at end-of-life (Involved as much as wanted)	192 (61.3)	89 (69.5)	56 (58.9)	47 (52.2)	_0.030_	161 (61.7)	31 (59.6)	0.779	58 (63)	132 (60.6)	0.681
Care decisions were made that the resident would not have wanted (Yes)	53 (16.8)	16 (12.5)	20 (20.6)	17 (18.9)	0.225	40 (15.2)	13 (25)	0.085	16 (17.4)	37 (16.7)	0.889
Care decisions were made that carers did not want (Yes)	55 (17.4)	20 (15.6)	21 (21.6)	14 (15.4)	0.416	47 (17.9)	8 (15.1)	0.627	19 (20.4)	35 (15.8)	0.325
Spiritual support RACH provided to resident (Excellent/Good)	135 (42.9)	67 (52.3)	38 (39.6)	30 (33.0)	_0.013*_	117 (44.7)	18 (34.0)	0.151	41 (44.6)	94 (42.7)	0.765

Emotional support RACH provided to resident (Excellent/Good)	184 (58.2)	83 (64.3)	55 (56.7)	46 (51.1)	0.139	150 (57.0)	34 (64.2)	0.338	59 (63.4)	124 (56.4)	0.246
Residents' values were respected and considered (Always/Most time)	235 (74.4)	100 (77.5)	71 (74)	64 (70.3)	0.482	197 (74.9)	38 (71.7)	0.626	71 (77.2)	162 (73.3)	0.474
Residents' cultural background was respected and considered (Always/Most time)	189 (59.8)	88 (68.2)	50 (52.1)	51 (56.0)	*0.035**	160 (60.8)	29 (54.7)	0.407	57 (62.0)	131 (59.3)	0.659
Residents' spiritual/religious beliefs were respected and considered (Always/Most time)	183 (57.9)	86 (66.7)	53 (55.2)	44 (48.4)	*0.021**	156 (59.3)	27 (50.9)	0.26	54 (58.7)	128 (57.9)	0.899
Carers were able to discuss their worries/fears with RACH staff (Yes, as much as wanted)	206 (65)	96 (74.4)	57 (58.8)	53 (58.2)	*0.014**	167 (63.3)	39 (73.6)	0.15	61 (65.6)	142 (64.3)	0.821

**Statistically Significant Difference*

PRIORITY 3	**All**	**PC Team Visit**				**Metro/Rural**			**Main Carer**		
Care is coordinated	Total	Yes	No	Unsure		Metro	Rural		Yes	No	
	n (%)	n (%)	n (%)	n (%)	p-value	n (%)	n (%)	p-value	n (%)	n (%)	p-value
Members of visiting palliative care team worked well together [PC Users Only] (Yes Definitely/to some extent)	99 (80.3)	99 (80.3)	--	--	--	96 (83.5)	6 (50.0)	*0.013**	36 (83.7)	64 (80.0)	0.451
RACH staff worked well with the visiting palliative care team [PC Users Only] (Yes Definitely/ to some extent)	103 (81.1)	103 (81.1)	--	--	--	97 (85.8)	6 (54.5)	*0.020**	36 (87.8)	66 (81.53)	0.373
RACH staff worked well with the GP (Yes Definitely/ to some extent)	241 (76.3)	112 (86.8)	71 (73.2)	58 (68.6)	*<0.001**	202 (76.8)	39 (73.6)	0.615	70 (75.3)	168 (76.47)	0.836
Residents' visits to the Emergency Department were helpful [Attended ED Only] (Yes)	124 (58.5)	64 (67.4)	34 (57.6)	26 (44.8)	*0.023**	104 (58.1)	20 (60.6)	0.788	39 (60.9)	85 (58.2)	0.712
RACH planned out of hours care if residents' condition declined (Yes)	186 (59.2)	92 (72.4)	51 (53.1)	43 (47.3)	*<0.001**	157 (59.9)	29 (55.8)	0.578	62 (67.4)	122 (55.7)	*0.056**

**Statistically Significant Difference*

PRIORITY 4	**All**	**PC Team Visit**				**Metro/Rural**			**Main Carer**		
Families and carers are supported	Total	Yes	No	Unsure		Metro	Rural		Yes	No	
	n (%)	n (%)	n (%)	n (%)	p-value	n (%)	n (%)	p-value	n (%)	n (%)	p-value
Emotional support RACH provided to carers (Excellent/Good)	187 (61.3)	86 (68.3)	56 (60.2)	45 (52.3)	*0.063**	158 (62)	29 (58)	0.599	53 (58.9)	134 (62.9)	0.510
Information RACH provided to carers about residents' condition (Excellent/Good)	208 (67.8)	95 (74.8)	55 (58.5)	58 (67.4)	*0.037**	175 (68.6)	33 (63.5)	0.468	62 (68.9)	144 (67.3)	0.785
Carers could stay with residents at the RACH overnight (Yes)	94 (29.7)	52 (40.3)	30 (30.9)	12 (13.2)	*<0.001**	83 (31.4)	11 (20.8)	0.120	38 (40.9)	54 (24.4)	*0.004**
Carers were offered information about grief and bereavement services (Yes)	103 (33)	59 (46.8)	26 (27.4)	18 (19.8)	*<0.001**	91 (35.1)	12 (22.6)	0.078	38 (41.3)	65 (30)	*0.053**
RACH contacted carers in the weeks after their relative’s death (Yes)	85 (26.8)	43 (33.3)	20 (20.6)	22 (24.2)	0.082	75 (28.4)	10 (18.9)	0.152	35 (37.6)	49 (22.2)	*0.005**
RACH contacted carers approx. 6 months after their relative’s death (Yes)	47 (15.2)	25 (20)	12 (12.8)	10 (11.1)	0.147	43 (16.7)	4 (7.7)	0.098	19 (21.1)	27 (12.4)	*0.053**
Carers spoke to health/social services about their experience of illness/death (Yes)	50 (15.8)	28 (21.7)	11 (11.3)	11 (12.1)	*0.056**	46 (17.4)	4 (7.5)	0.072	19 (20.4)	31 (14.0)	0.157

**Statistically Significant Difference*

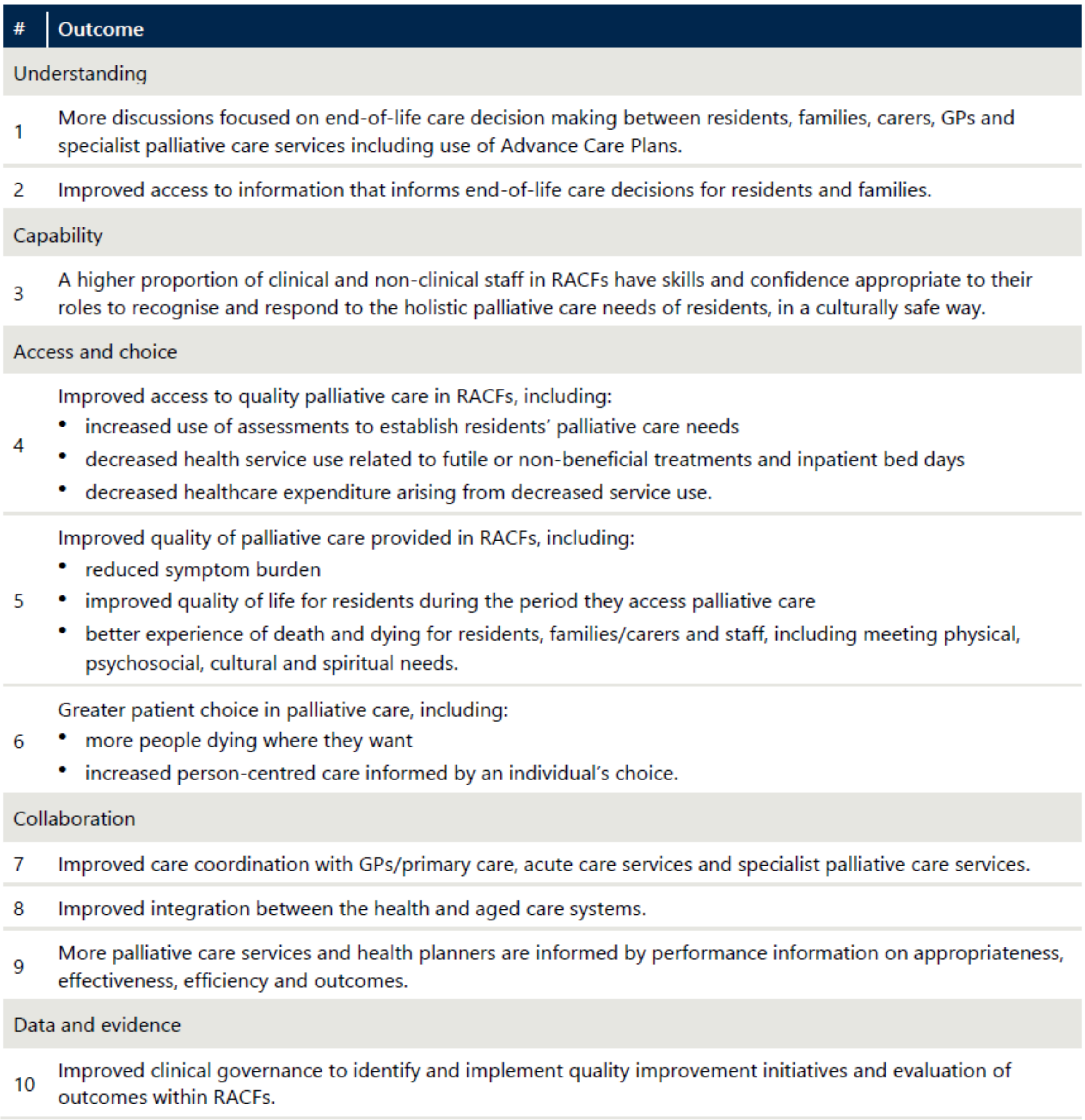
PRIORITY 5	**All**	**PC Team Visit**				**ACH Metro/Rural**			**Main Carer**		
All staff are prepared to care	Total	Yes	No	Unsure		Metro	Rural		Yes	No	
	n (%)	n (%)	n (%)	n (%)	p-value	n (%)	n (%)	p-value	n (%)	n (%)	p-value
RACH staff treated residents with respect and dignity (Always/Most time)	261 (82.9)	108 (83.7)	76 (79.2)	77 (85.6)	0.484	218 (83.2)	43 (81.1)	0.715	75 (81.5)	183 (83.2)	0.724
RACH staff treated residents with compassion and kindness (Always/Most time)	263 (83.5)	110 (85.3)	76 (80)	77 (84.6)	0.543	219 (83.3)	44 (84.6)	0.811	76 (82.6)	186 (84.5)	0.671
RACH staff were perceived as very competent or competent (Very/Competent)	273 (86.1)	114 (88.4)	76 (78.4)	83 (91.2)	*0.025**	224 (84.8)	49 (92.5)	0.144	79 (84.9)	191 (86.4)	0.730
RACH staff provided information when it was requested (Always/Most time)	198 (63.1)	92 (71.9)	54 (56.3)	52 (57.8)	*0.027**	164 (62.6)	34 (65.4)	0.703	65 (69.9)	131 (60.1)	0.101
RACH staff treated bereaved carers in a sensitive manner (Always/Most time)	226 (80.4)	102 (83.6)	67 (74.4)	57 (82.6)	0.219	189 (80.4)	37 (80.4)	0.999	71 (78)	154 (82.4)	0.388

**Statistically Significant Difference*

Priority 6	**All**	**PC Team Visit**				**Metro/Rural**			**Main Carer**		
The community is aware and able to care	Total	Yes	No	Unsure		Metro	Rural		Yes	No	
	n (%)	n (%)	n (%)	n (%)	p-value	n (%)	n (%)	p-value	n (%)	n (%)	p-value
Carers received informal support before death (Yes)	282 (89)	121 (93.8)	86 (88.7)	75 (82.4)	*0.029**	236 (89.4)	46 (86.8)	0.581	83 (89.2)	196 (88.7)	0.886
Carers perceived helpfulness of informal support before death (Very/Quite helpful)	244 (85.6)	104 (84.6)	74 (85.1)	66 (88)	0.786	204 (85)	40 (88.9)	0.495	68 (80)	173 (87.8)	0.087
Carers received informal support after death (Yes)	281 (88.6)	115 (89.1)	85 (87.6)	81 (89)	0.931	235 (89)	46 (86.8)	0.642	82 (88.2)	196 (88.7)	0.896
Carers perceived helpfulness of informal support after death (Very/Quite helpful)	247 (86.1)	104 (86)	78 (89.7)	65 (82.3)	0.391	205 (85.8)	42 (87.5)	0.753	72 (84.7)	173 (86.5)	0.690

**Statistically Significant Difference*

Appendix 5: National Outcomes and Indicators – Nous (2021, p.11)



#	Outcome
Understanding	
1	More discussions focused on end-of-life care decision making between residents, families, carers, GPs and specialist palliative care services including use of Advance Care Plans.
2	Improved access to information that informs end-of-life care decisions for residents and families.
Capability	
3	A higher proportion of clinical and non-clinical staff in RACFs have skills and confidence appropriate to their roles to recognise and respond to the holistic palliative care needs of residents, in a culturally safe way.
Access and choice	
4	Improved access to quality palliative care in RACFs, including: • increased use of assessments to establish residents' palliative care needs • decreased health service use related to futile or non-beneficial treatments and inpatient bed days • decreased healthcare expenditure arising from decreased service use.
5	Improved quality of palliative care provided in RACFs, including: • reduced symptom burden • improved quality of life for residents during the period they access palliative care • better experience of death and dying for residents, families/carers and staff, including meeting physical, psychosocial, cultural and spiritual needs.
6	Greater patient choice in palliative care, including: • more people dying where they want • increased person-centred care informed by an individual's choice.
Collaboration	
7	Improved care coordination with GPs/primary care, acute care services and specialist palliative care services.
8	Improved integration between the health and aged care systems.
9	More palliative care services and health planners are informed by performance information on appropriateness, effectiveness, efficiency and outcomes.
Data and evidence	
10	Improved clinical governance to identify and implement quality improvement initiatives and evaluation of outcomes within RACFs.

Appendix 6: NPA Initiative Descriptions

Palliative Care Quality Improvement Initiatives	Project Providers	Project Aim
Metropolitan Palliative Care Consultancy Service Expansion (MPaCCS)	Bethesda HealthCare	Expansion of specialist palliative care in reach services including patient-based care and staff scenario training.
Residential Aged Care Excellence in Palliative Care Communicate (RACEPC)	Cancer Council WA	Focused online education to RACF staff focused on communication with the palliative patient and responding to clinical deterioration.
NMHS Transition Support Navigator	North Metro Health Service	Integrated support for the RACF Palliative resident between hospital and residential care facilities.
SMHS Care Coordinator	South Metro Health Service	Integrated support for the RACF Palliative resident between hospital and residential care facilities.
EMHS Transition Support Officer	East Metro Health Service	Collaboration with RACFS to support ACP planning and to support the RACF resident moving between hospital and RACF facility.
GP Case-Conferencing Coordinator	WA Primary Health Alliance	Dedicated case conferencing coordinators located in RACFS whose role is support GP's and RACFs in primary care coordination.
Residential Care Line Expansion (RCL)	Residential Care Line	Support delivery of the Clinical Deterioration education package to upskill RACF clinical staff and provide clinical palliative care support.
GP Information Resources	RACGP	Develop a toolkit for GPs to support service delivery in RACF.
Residential Goals of Care (RGoC)	WA Country Health Service	Implementation of the Goals of Care document used in hospital settings to all WACHS MPS sites to support ACP.

Appendix 7: WA NPA Project Logic Map

PROJECT LOGIC MAP

NATIONAL PARTNERSHIP AGREEMENT: COMPREHENSIVE PALLIATIVE CARE IN AGED CARE MEASURE (THE MEASURE)

Building on WA's significant investment in end of life and palliative care (EOL&PC), in alignment with Recommendation 9 of the Sustainable Health Review, the Commonwealth's *Measure* seeks to strengthen national and jurisdictional efforts to improve the EOL&PC provided to residential aged care facility (RACF) residents and their families/carers. Via the Measure's Commonwealth and State co-funding model, the WA Department of Health (DoH) will commission projects that expand evidence-based models of care and/or support new approaches to embed ***quality**** EOL&PC that meets the changing holistic needs and known wishes of residents and their families/carers.

CONTEXT AND NEED

Context
- The Royal Commission into Aged Care, Quality and Safety highlighted access to safe quality EOL&PC as an area for immediate action, aligned to improved standards and a revised Aged Care Act.
- Aligning with the *National Palliative Care Strategy 2018*, the WA Sustainable Health Review's recommendation 9 and the Joint Select Committee on EOL Choices' 2018 recommendations, the *WA EOL&PC Strategy 2018 – 2028* (and associated Implementation Plan One 2020-2022) represent WA's commitment to providing quality EOL&PC to RACF residents, their families and carers.

Need (Priority Areas)
- Sub-optimal system capacity and integration across RACFs, primary care and hospital services.
- Increasing clinical complexity (including dementia), ageing population and demand for EOL&PC.
- Limited access to inclusive and equitable EOL&PC.
- Limited access to after-hours specialist care.
- Ageing, under-staffed RACF workforce with high turnover.
- Inadequate multi-disciplinary staff (including GPs) capacity, capability and confidence in care delivery, including: Assessment and planning; Communication and collaboration (engaging residents and families/carers); Care co-ordination and navigation; Grief and bereavement; Symptom management and direct care (including medication); and clinical deterioration.
- Inadequate consumer/carer EOL&PC knowledge/understanding.
- Low community confidence in the EOL&PC provided by RACFs.
- Increased acute care demand due to unnecessary RACF referrals, transfers and admissions.

INPUTS

Funding and Partnerships
- $11.4M total co-matched Commonwealth and State funding from 2020-2024.

Commissioned Providers
- DoH-commissioned service providers co-develop and implement projects.
- Participating RACFs, primary care and hospital services engage and collaborate as required (facilitated by provider with DoH support).

Governance
- DoH resources support project development, procurement and management.
- DoH End of Life and Palliative Care Advisory Committee (EOLPCAC) provides project advice as requested by the End of Life Care Program.
- DoH Project Steering Committee monitors and endorses all project stages.

ACTIVITIES ("How")

Overall Project
- DoH prioritises projects to meet WA strategic priorities under the NPA Measure, based on this Project Logic Map, evidence and consultation.
- DoH establishes project governance.
- DoH commissions service providers to co-develop and deliver projects as contracted.
- DoH supports commissioned service providers in stakeholder engagement and collaboration.
- Service providers collaborate across projects as appropriate.
- DoH reports on national indicator set to the Commonwealth-contracted consultant.
- DoH commissions WA supplementary WA project evaluation.
- DoH undertakes project-specific evaluation.

Specific Projects (activities will vary)
- Contracted services facilitate RACFs and health services to embed systems and processes that meet project outcomes and outputs, including:
  - Effectively communicating relevant EOL&PC information to RACF residents and their families/carers.
  - Identifying RACF, primary care and hospital service capacity and capability gaps and opportunities for improvement.
  - Providing tailored general and specialist in-reach EOL&PC education and training to clinical and non-clinical RACF, primary care and hospital staff and family/carers about output-specified priority areas.
- All services involved in providing EOL&PC to residents and their families/carers collaborating effectively to coordinate seamless and integrated care.

OUTPUTS ("What")

Overall Project
- Project governance established.
- Current state analysis of WA RACF demographics completed.
- Service providers commissioned by DoH to co-design and implement projects.
- DoH collaborated with Commonwealth-contracted consultant to co-develop national indicator set applicable to WA.
- A DoH-commissioned in-depth supplementary WA evaluation completed.
- DoH project-specific evaluations completed.

Specific Projects (outputs will vary)
- Service capacity and capability gaps and quality improvement opportunities assessed for targeted action/s.
- Effective capacity building embedded in system/process improvements and workforce planning and development.
- Residents and families/carers provided with access to inclusive information that raises their awareness and understanding of EOL&PC and supports engagement, planning and decision making.
- General and specialist in-reach EOL&PC education and training provided to RACF, primary care and hospital staff, including the following priority areas:
  - Communication, engagement and collaboration
  - Assessment and decision making
  - Advance Care Planning (ACP) and
  - Goals of Patient Care (GoPC)
  - Symptom management and direct care (including medications)
  - Clinical deterioration, escalation and referral
  - Grief and bereavement
  - Care coordination (e.g. Accurate transfer of all relevant patient information between hospitals and RACFs).
- ACP completed for RACF residents.
- Services and staff involved in providing EOL&PC to residents and their families/carers collaborated effectively to coordinate quality care.
- Primary care staff (particularly GPs) respond effectively to residents' EOL&PC needs, including medication management and care coordination.

OUTCOMES AND IMPACTS

Outcomes/Benefits (sustainable)
- The quality of life (physical, psychosocial and spiritual) of older Australians with a life-limiting illness living in RACFs, and their families/carers, is improved.
- RACF residents and their families/carers receive quality EOL&PC that meets their changing needs and known wishes.
- The EOL&PC experience of families and carers of RACF residents is improved.
- RACF residents experience a "good death" in their place of choice, in accordance with their known wishes.
- The capacity, capability and confidence of the clinical and non-clinical RACF, primary care and hospital workforce to provide quality EOL&PC is optimised.
- The community's confidence in the quality of EOL&PC provided to RACF residents and their families/carers is increased.
- Health system resources are used more sustainably, including reduced demand on specialist EOL&PC.

Impacts (sustainable)

Health and Quality of Life
- Reduced resident symptom burden and inappropriate/ unnecessary procedures, hospital referrals, admissions and length of stay (LoS).
- A better experience of death and dying for residents and families/carers.
- Increased resident, family/carer and staff satisfaction.

Access and Choice
- Increased access to quality care options informed by regular assessments, Advance Care Planning and Goals of Patient Care planning.
- A higher proportion of RACF residents die in their place of choice.

Understanding
- Improved resident and family/carer understanding of EOL&PC, informing planning and decision making.

Capability and Capacity
- A higher proportion of RACF, primary care and hospital staff have the necessary knowledge, skills and confidence to provide quality EOL&PC, within their scope of practice.

Care Coordination and Communication
- Improved coordination and communication among and between RACF, primary care and hospital staff, and improved integration of the health and aged care systems.

System
- Reduced inappropriate/unnecessary procedures/ treatments, hospital referrals, transfers and admissions.
- Reduced demand for specialist EOL&PC services.
- Improved RACF workforce staffing levels and retention.
- Enhanced community confidence in the EOL&PC provided to RACF residents and their families.

OVERALL AIMS

1. Embed quality* end of life and palliative care into residential aged care, and associated health services, that meets the changing holistic needs and wishes of residents and their families/carers, and contributes to achievement of the *National Palliative Care Strategy 2018*.
2. Enable people to die where they choose, supported by the sustainable provision of the right end of life and palliative care, at the right time, by the right team, and in the right place - for them.

* ***Quality EOL&PC*** *is accessible, person-centred, coordinated, inclusive, equitable, evidence-based care delivered safely and competently to meet the changing holistic needs and known wishes of residents and their families/carers.*

Mar 2021 v1.2

Appendix 8: Recommendations for Improvement – Participant Quotes

	Bereaved carers		Service providers	
General comments		• *“I would: Make sure GP services were available at all hours of the day and night. Allow family members to speak directly to the GP…or at the very least make sure that messages from the GP were relayed to the family. Make sure staff were fully trained in the techniques they need to identify pain (they told me Mum was trying to smile and talk to them when in fact she was trying to point to the painful area and tell them). Make sure staff are comfortable increasing pain relief as necessary. Make sure nursing staff know their duties and how they impact visiting staff from other services. Let people stay overnight if the end is near. Ensure every family/friend etc has the same, adequate amount of time to clear the room if they need it, paid at the normal rate - a minimum of 7 days. Advise them of this when the resident goes into the nursing home and again when they need palliative care.” (Bereaved Carer 68)* • *“I know the staff were friendly and helpful, but I visited Mum every day and had to frequently ask for her urine bag to be emptied and refitted. The non nursing staff were sweet but often didn't appear to know what Mum's care plan was and always deferred to the nursing staff - they were helpful. I know there were staff shortages, and this meant there was not time to spend with Mum other than to perform a function and then leave… Also, Mum had 2 urinary tract infections that were investigated only after I raised concerns about her sudden increase in level of pain and her behaviour change (confusion) that indicated a urinary tract infection. It worried me that this had not been*	•	• *“End of life is a very complex situation in aged care due to a person having multiple co-morbidities, fluctuating and declining status requiring engaging with family members, to name a few, decision making can be difficult, especially for nurses working in isolation. As a clinical manager I can see there is a lot of work to be done.” (Service Provider 65)* • *“Here's a concise version [of what to improve for] end-of-life care in RACHs: - Encourage Advance Care Directives (ACDs) - Incorporate preferences into care plans - Foster open communication - Be culturally sensitive - Provide support and resources - Regularly review and update plans - Educate staff on end-of-life care. Prioritizing these aspects ensures compassionate and person-centred care.” (Service Provider 33)*

		picked up by the staff and made me concerned she had suffered longer than she needed.” (Bereaved Carer 70)		
Workforce capacity	• Increase number of nursing and personal care attendant staff • Increase availability of occupational therapy and physiotherapy staff • Ensure consistency of staff to assist with continuity of care for resident • Increase staff knowledge and confidence on addressing palliative care needs	• *“They need more staff, especially on floors where there are a few residents needed two-person assistance.” (Bereaved Carer 72)* • *“There is huge scope for increasing palliative care knowledge and skills for residential care home workers… this was concerning for the family and meant it took much longer to achieve good symptom management and comfort.” (Bereaved Carer 12)* • *“Better leadership training and skills for the management. The home needed good management but the enrolled nurse in charge while good did not have the adequate training or skills to manage the place well.” (Bereaved Carer 149)* • *“Competent in most day to day care but very limited skills in palliative care demonstrated multiple times during end of life care e.g. trying to administer oral medications when unconscious, long delays (over 1h at times) in administering symptom relief medications after family request, unfamiliarity with medications (e.g. morphine being used for dyspnoea relief and not just pain relief), unfamiliarity with syringe driver (requiring assistance to set up, not wanting to change syringe driver before completion of existing syringe when there was a new order for a higher dose of medications and more than 4h until due change time)” (Bereaved Carer 12)*	• Build workforce capacity in palliative care through regular staff training on palliative and end of life care • Educate staff at all levels, including personal care attendants • Increase confidence and skillset of staff in palliative care • Increase access to allied health, pharmacy, and spiritual care • Ensure all RACH staff have a palliative approach to care	• *“Staff are not given training opportunities to learn how to help residents who are deteriorating (no longer eating or drinking regularly) aside from reporting the issue,” (Service Provider 51)* • *“[We are] unable to access to GP or end of like medications when a resident deteriorates out of hours. [There is a] lack of knowledge and training for staff at all levels.” (Service Provider 12)* • *“We have commenced the ELDACC programme and improved our palliative care greatly.” (Service Provider 32)* • *“We live in remote area, and face-to-face training such as having to travel to Perth is not easily accessible especially for those with kids” (Service Provider 62)* • *“We need more education for carers and junior RNs about what a ‘good death’ looks like and how to facilitate this.” (Service Provider 9)* • *“[We need] relevant and current training and teaching sessions for all staff from specialist teams. Not just online learning or someone reading from a PowerPoint presentation. Talking to an expert allows staff to ask questions.” (Service Provider 12)*
Care coordination and service provision	• More consistent development and review of care plans	• *There should be “More dementia reviews and the ability to move to higher level care as needed. … More information and involvement of a palliative care team or staff BEFORE entering palliative care*	• Ensure residents can access palliative care services as required	• *“Families need more support and encouragement to complete the [ACP] docs in a timely manner.” (Service Provider 82*

	• Improve transitions between stages of disease progression, increasing functional decline and challenging behaviours. This requires improved death literacy of staff. • Refer to palliative care team in a timely manner • Greater access to GP • Greater access to the palliative care team • Improve care provided for specific conditions, e.g., dementia, Parkinson’s. • Timely symptom management and review • Proactive care planning and addressing resident needs, not reactive, e.g., commence discussions on palliative care in advance.	*stage so that decisions are made collaboratively and with an understanding of what is happening and why.” (Bereaved Carer 56)* • *“Every resident coming into aged care home should have a palliative care plan set up, family also should be given education on signs of dying and how to support someone die well. It's hard to watch people suffer.” (Bereaved Carer 11)* • *“Hospitals remain inconsistent in their coordination of care when transferring residents back to their RACH.” (Bereaved Carer 1)* • *“[RACHs should] ensure adequate medical support in nursing home. Ensure adequate plans for pain management. Have appropriate management in end-of-life care to avoid the ongoing pain and suffering of our elderly who should have the dignity to die.” (Bereaved Carer 44)* • *“Need better medical services, especially when the carer lives a long way away. The Dr needs to be accessible outside of office hours especially weekends. My mums pain management should have been managed within the home and not requiring transport to hospital.” (Bereaved Carer 42)* • *“She wasn't offered palliative care because they deemed, she wasn't dying. it's crazy if you have cancer the nursing home will identify a palliative care team if you have Parkinson’s complications and are deteriorating rapidly ‘it's just Parkinson’s’.” (Bereaved Carer 28)* • *“The constant reply to our requests of ‘the doctor comes in on Sundays and will see your Mum then’ was frustrating because Mum had to wait days to be seen. Several times my sister or I took Mum to our*	• Increase after-hours access to GPs • Improve continuity of care and communication processes from hospital to RACH on resident discharge. • Ensure residents have an ACP and that staff know the preferred place of death. • Continue to ensure access to the MPaCCS team to capacity build the RACH staff. • Improve timely pain and symptom assessment, management, and review • Improve access to medications on evenings and weekends •	• *“If client deteriorates and requires end of life care and GP has not prescribed or is not contactable locum service will not prescribe… If unable to manage pain, end up transferring to hospital when could have been cared for at RACH.” (Service Provider 6)* • *“Some doctors take time to realize the changes and deterioration to palliative care and are hesitant to prescribe required medications.” (Service Provider 81)* • *“My nursing home a couple brochures in the entrance but nursing staff and management do very little training or communication to care staff. they usually don't even give a handover, let alone further care training.” (Service Provider 49)* • *“Need further education of staff to improved recognition and deterioration, to improve preparedness. Support for staff to have ACP discussions - currently using MPACCS but site staff need to be involved so can support families.” (Service Provider 6)* • *“It's difficult to organise family case conferences and time consuming for RACH staff going backwards and forwards, as the palliative care team do not liaise directly with families.” (Service Provider 12)* • *“There is no training or support given to staff about it. there's usually not even a basic handover, let alone told when someone is moved to palliative care.” (Service Provider 49)* • *“GP reluctant to accept deterioration and has implemented things that may be unnecessary*

		own GP for a check-up as nursing staff brushed off her symptoms." (Bereaved Carer 46) • *"Every resident coming into aged care home should have a palliative care plan set up, family also should be given education on signs of dying and how to support someone die well. It's hard to watch people suffer. When a resident is injured, e.g. hoisting and disc hurt, then a care plan needs to be put in place. Family had to push very hard to get anything done, - first home was not good at addressing pain." (Bereaved Carer 11)*		*or not required such as continuing with medications." (Service Provider 73)* • *"Have to call and email multiple times for hospital discharge summary on most occasions. Most hospital stays, residents of RACH are discharged quickly with limited investigation." (Service Provider 14)*
Quality of care	• Maintain dignity and respect of residents • Greater focus on non-symptom management needs (e.g., quality of life, psychosocial, spiritual needs)	• *"[Staff were] competent in most day-to-day care but very limited skills in palliative care, demonstrated multiple times during end-of-life care." (Bereaved Carer 12)* • *"My relative supposedly had a stroke but no one called the doctor, and she died 10 hours later. I was not notified until after her death. It was presumed she was just sleeping, and her condition was ignored as anything serious because staff just thought she was being vague as her condition often appeared". (Bereaved Carer 28)* • *"My mother-in-law had a fall - a brain tumour was discovered in hospital - she was able to return to her home in the nursing home and receive palliative care for just under two weeks. This was so good for us as a family. It meant she wasn't in a room in RPH she was in her room in her nursing home - she was peaceful - our surroundings were peaceful. IT was the best outcome we could have hoped for at that point in time." (Bereaved Carer 17)* • *"Some staff were always caring and respectful, while others, because of lack of staff, didn't have the time*	• Address needs of the resident, family, and staff	• *To improve the quality of palliative care in the RACH, we need:* • *"More resources on training and education for staff who would like to be more informed." (Service Provider 7)* • *"More training needed in care certificate surround palliative care so that AINs have the knowledge and skills necessary." (Service Provider 14)* • *"Staff would benefit from access to training on site combined with online learning." (Service Provider 6)* • *"Earlier notification of palliative trajectory. Honest discussion with families. Do they need to go to hospital. Progression of dementia: understanding EOL." (Service Provider 78)* • *"Providing culturally sensitive care and overcoming language barriers can be challenge." (Service Provider 34)*

		to put into the needs of the residents." (Bereaved Carer 107) • *"Most of the support workers were either poorly trained or just didn't care about Mum. 99% of the time they didn't position her hearing aids or glasses." (Bereaved Carer 130)* • *"While it is understood that staffing is a pressure point in this environment, I couldn't understand why her needs weren't addressed in a more timely way. Routine was important for her, and when things were not on schedule, she became distressed. Sometimes near the end of her life her basic needs like toileting were not met soon enough, causing her extreme distress. … As she had (mostly) all her faculties, her dignity was compromised when help didn't come for sometimes lengthy delays." (Bereaved Carer 8)*		• *"I believe that these discussions should be more common- especially after the resident has an incident." (Service Provider 51)* • *"Management often state that funding is a barrier to effective rostering of staff, and this is particularly challenging when a resident requires 2-3 assessment and 1 hourly checks during the terminal phase." (Service Provider 9)*
Family: Communication and support	• Provision of timely and relevant information on palliative care • Improve bereavement care • Communication between staff • Collaborative decision making between staff and family, including information sharing, ensure family are listened to. • Educate family on palliative care process (e.g., explain to families what is happening, why, and timelines; how to navigate stages of dying; symptom management and common signs at end of life)	• *The RACH should:* • *"Listen to the family members. Take things seriously. Just because they may have seen events hundreds of times. For the family, it is the first time." (Bereaved Carer 12)* • *"More information/updates, more transparency, more sharing of information." (Bereaved Carer 85)* • *"Realistic and timely information about possible end of life experience." (Bereaved Carer 42)* • *"I raised any concerns, but these were not always responded to, I had to constantly follow up on everything and in her last year the need for more assessment and higher-level care was ignored, despite my requests." (Bereaved Carer 56)* • *"[RACH should have better] contact with family members, End of life care and training for when signs and symptoms decline so family can prepare and*	• Educate family on advance care planning, disease progression, stages of dying • Improve bereavement care and provide funding • Care planning on admission to home • Complete ACP/GOC with family in a timely fashion	• *"[I] Would like a folder with information available for families unfamiliar with the dying process and what to expect happen of the dying patient ie: nikki pump, cheyne stoking, death." (Service Provider 85)* • *"Case conference only happens when deterioration to residents' condition" (Service Provider 73)* • *"[It would be helpful to] include in the admission pack and some information to the residents and family to read before coming into the home." (Service Provider 47)* • *"GP reviews and makes recommendations re: goals of care. Nurses will then relay to family and discuss ACP and prognosis." (Service Provider 68)*

	• More transparency, updates on disease progression • Education on stages of dying and EOLC	*make arrangements to be there." (Bereaved Carer 83)* • *"I would improve the information provided to me as the spouse. Even though I knew that my husband's health was declining, I wasn't given realistic or any time frames as to how close to death he was at the end of life." (Bereaved Carer 58)* • *"Staff seemed stress[ed] and therefore unable to provide as much kindness and compassion to patients as I would have liked to see considering the cost." (Bereaved Carer 71)*		• *"Families need more support and encouragement to complete the [ACP] docs in a timely manner." (Service Provider 82)*