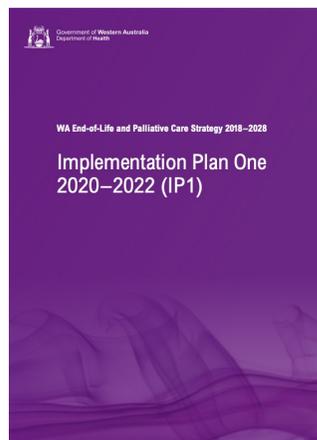




WA End-of-Life and
Palliative Care Strategy
2018–2028



Prepared for
WA DEPARTMENT OF HEALTH:
CLINICAL EXCELLENCE DIVISION,
CLINICAL LEADERSHIP & REFORM –
HEALTH NETWORKS: END-OF-LIFE CARE
August 2021

NATIONAL PARTNERSHIP AGREEMENT:
COMPREHENSIVE PALLIATIVE CARE IN AGED CARE
CONSULTATION FORUM – ENGAGEMENT REPORT

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Summary: Forum Background and Objectives

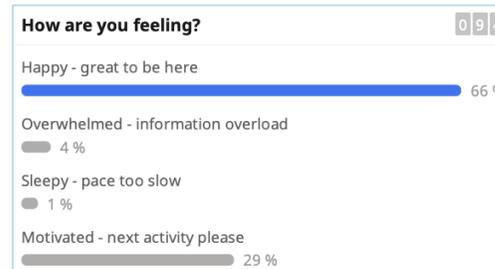
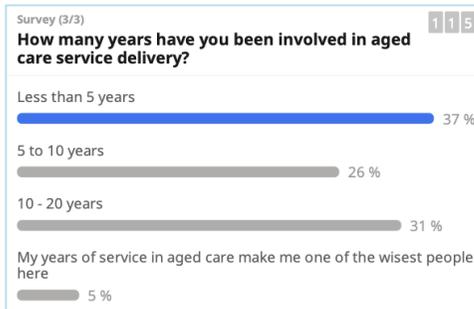
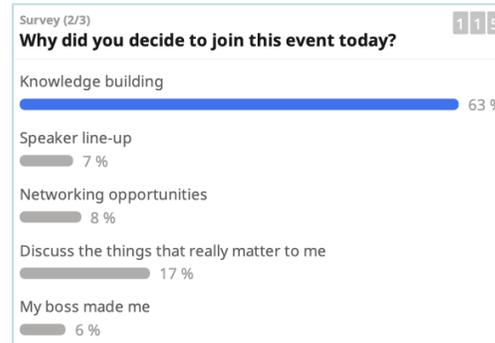
- Aligned with the WA Palliative Care and End-of-life Strategy 2028 outcomes, and building on existing research, stakeholder consultation and initiatives underway within the Commonwealth National Partnership Agreement for Comprehensive Palliative Care in Aged Care Measure, the collaborative forum held at Optus Stadium on 21 July 2021, provided a unique opportunity for a diverse array of interested stakeholders to share insights, discuss and deliberate key considerations material to improving Palliative Care outcomes across Residential Aged Care.
- As background to the forum, participants were provided with several pre-reading materials noting: the Commonwealth specified the following outputs as requirements under the NPA, in alignment with the *National Palliative Care Strategy 2018*:
 - Delivery of projects that expand existing models of care or support new approaches to the way care is delivered or commissioned for older Australians living in Residential Aged Care Facilities (RACFs), such as:
 - a) 'In-reach' models that include assessments to establish residents' current and emerging palliative care needs.
 - b) Models which support end-of-life care decision making and the development of agreed goals of care in order to meet the needs of individual residents.
 - c) Training, education, assistance and mentoring to focus on building the palliative care capacity of the aged care workforce.
- An overarching intra-jurisdictional national evaluation plan is being developed toward realising relevant national and state based outcomes whilst addressing key findings and recommendations from the Australian Royal Commission in Aged Care Quality and Safety. The Department of Health (DoH) End-of-Life Care Project Steering Committee (PSC) is ultimately accountable for the successful delivery of the NPA.
- With the Metropolitan Palliative Care Consultancy Service (MPaCCS), and, Palliative and Supportive Care Education (PaSCE), forming two existing workstreams funded by the NPA in Western Australia, the allocation of remaining funds – along with the identification of additional opportunities and funding pathways, formed the overarching focus of this collaborative forum.
- With 127 attendees, the forum focussed on balancing knowledge sharing and discussion across the following objectives:
 - To bring together Residential Aged Care and End of Life and Palliative Care sector participants to consider **how to best support WA RAC providers to meet the EOL&PC needs of residents and their families.**
 - To **discuss and prioritise** EOL&PC service delivery models, Advance Care Planning, Education and training provision.
 - To assist in **best informing expenditure across pilot programs and initiatives**, based on consideration of implementation barriers, enablers and opportunities.
 - To provide an opportunity for participants across the network **to strengthen relationships.**
- The following summary highlights some key themes against these objectives with detailed table and online feedback in subsequent sections.

Summary: Forum Polling and Evaluation Results

Polling and evaluation results indicated:

- Further opportunity for networking and relationship development, an even spread of time spent in Aged Care service delivery with approximately half of the forum attendees currently working in Residential Aged Care, and a strong desire to learn and hear from the speaker line up.
- Some commentary indicated the pace of the forum was too fast and did not allow sufficient time for panel questions and discussion, with 97% indicating high levels of engagement, participation and satisfaction.

Polling results highlight 85%+ engagement



Expertise represented at the Forum

Sector	% of responses
Acute care	13%
Community care	3%
Education	7%
General Practice	5%
General health care	2%
Government	8%
Member of the community	3%
Peak body	2%
Research	5%
Residential Aged Care	49%
Specialist palliative care	15%
Other	6%

Presentation satisfaction levels

The presentations on service delivery gaps and case studies were of interest and a good opportunity to consider alternative approaches

- 94% strongly agree or agree
- 7% strongly disagree

The presentations and panel discussion gave me a better understanding of how service providers work together to deliver EOL & PC for RAC residents

- 90% strongly agree or agree
- 7% strongly disagree or disagree

Summary: Forum Feedback Reinforces Key Challenges

The challenges identified within the pre-reading were reinforced by participants surfacing the following key themes:

24x7 Palliative Care Services	To reduce pressure on hospital, ambulance, and emergency services, forum feedback acknowledged the need for improved funding toward 24/7 services including MPaCCS, better access to medication and equipment, pathway navigation, backfilling education and training for RACF staff;
Early Engagement and including the patient/ family voice	Palliative care currently very reactive. Need for early patient and family engagement in palliative care and end-of-life decision-making recognising cultural sensitivities and the value of quality advance care planning to reduce hospital admissions;
Critical systems, data, practices and logistics	Investment is required (to help consistently action i.e. forms/ information sharing between GOPC, ACP, hospitals and RACF), to recognise early deterioration of patients, improve both acute and sub-acute service delivery outcomes, provide care/medication when required and provide ongoing monitoring of patients;
Integrated General Practice in Teams	Widespread, well informed and consistent GP involvement is critical to the success of patient, carer and family outcomes – to the extent that GPs should be a central part of the palliative care team. Ensuring service gaps due to eligibility or funding/payments are clear and options in place to address these.
Empowered staff	Time for and access to education and training across health, non-profit and other carer staff is critically needed so they are empowered and provided sufficient responsibilities to service patient and family choices i.e. direct access to specialist palliative care services, deliver medication and provide referrals.
Increased public awareness and support after death	Major focus required on increasing public awareness across all ages, cultures and vulnerabilities - helping remove the 'taboo' and normalising conversations about dying, end-of-life and palliative care. Provision of bereavement and support services for dependants a significant missing piece.
Broader more holistic view of palliative care	Trends such as increasing burden of disease, complexity, dementia, and demographics relating to aging population will continue to strain the palliative care workforce including social work - so a more holistic view connecting community, families, health and provider services is required to meet future demand.

Summary: Models of Care Initiatives that matter (1 of 3)

#	Opportunities	Strong and consistent supporting commentary provided
1	Community Resource Database	<ul style="list-style-type: none"> Grass roots resource availability, accessibility and awareness of palliative care service, levels of acute care, and relevant service and support pathways . Greater focus on awareness and enabling community, homecare, out-reach services so patients and their families to remain comfortable at home - access to medical / specialist advice / care is available to them outside of hospital. Public awareness resources and materials database accessible to local communities and via primary health network with compassionate communities or similar bereavement/emotional support. Meaningful ageing Australia has Spirituality videos – free – for everyone from patient carer to cleaners to executive. Reflects on good patient care. Good mental health is just as important as making sure you are washed, fed and receive suitable medication.
2	Patient, Family and Carer Voice as part of multidisciplinary team	<ul style="list-style-type: none"> Respect for the dying person and their families. Families, social workers and carers (including volunteers) must be integrated into the multi-disciplinary care team to help provide non-clinical support and progress themselves through the palliative care and end-of-life journey with their loved one. Critical to understand what can and can't be done for patients in their last weeks/ days of life. Need to simplify language and explain the health care process/ pathway i.e. APAT - consulting etc, empower patient with information about their expected care pathway. NODAC Amada example - no ones dies alone at Amada, trialled at 1-2 sites, feedback indicated it was beneficial, constant support person by their side i.e. palliative care assistant.
3	Palliative Care Prioritised in Care Continuum	<ul style="list-style-type: none"> Palliative care not considered separately but a key component of the care continuum. Move heavy reliance on capacity and comfort of people to engage in Palliative care to a system that promotes and ensures palliative care is deeply embedded in service culture and performance arrangements.
4	Improve Investment and Funding Access	<ul style="list-style-type: none"> Improved investment and access to funding i.e. enabling payments for GPs to become part of the multi-disciplinary palliative care team for facilities. Develop and promote clinical/medical champions. Need to improve both in-reach and out-reach service options (ACAT). Hall and Prior example i.e. they have a good rapport with GP looking after the RACFs – who provides medications in advance for 2-3 months after seeing deteriorating resident and recognising needs.

Summary: Models of Care Initiatives that matter (2 of 3)

#	Opportunities	Strong and consistent supporting commentary provided
5	Real-Time Clinical Choices	<ul style="list-style-type: none"> Understanding complexity and circumstance, and enabling real time clinical choices including virtual (telehealth) assessments/consults to be made via appropriate policies, standards, systems, reporting, education and 24 x 7 access to specialist palliative care. Relates to strong leadership and governance mechanisms linking all areas involved in model of care.
6	Clear Pathways and Proactive, Early Engagement	<ul style="list-style-type: none"> Clear disease burden and palliative care pathways for patients, families, carers and health professionals to navigate. No one size fits all approach, so a diverse range of models of care, needs and time management, funding, skills and shared understanding of roles and responsibilities is required to provide individual patient choice. Consistent proactive and early engagement, referrals and information sharing between GP and health services, residents and their families i.e. GOPC/AHD/ACP, significantly improves decision making, quality of life, individual choices, and end-of-life outcomes for both residents and their families. Potential for mandatory ACP when entering RACF.
7	Dedicated Nursing Staff	<ul style="list-style-type: none"> Dedicated Nursing staff at all facilities to facilitate quality information sharing and ACP/AHD for patients and families. Focussed and facilitated oversight ('Palliative Care Direct' - priority care coordination) integrating patient, place/transfers, GP/ED/Ambulance (referral triggers), data, system, care plan, assessment/monitoring and multi-disciplinary specialist palliative care, chronic disease management and support.
8	Accredited, Nationally-Recognised Education and Training	<ul style="list-style-type: none"> Accreditation and nationally recognised education and training programs are required to attract and retain. University/Research projects funded to help build evidence base behind services and models of care. PaSCE and PEPA building awareness programs. Enabling opportunities – such as this forum, for palliative care network development across health professionals, and assist elevate palliative care priority across care continuum. Debriefing sessions and counselling sessions for staff also required to help have future difficult conversations – key is to get people talking together and ongoing not just once.

Summary: Models of Care Initiatives that matter (3 of 3)

#	Opportunities	Strong and consistent supporting commentary provided
9	Extension of Existing Real, Live Examples	<ul style="list-style-type: none"> ▪ Silver Chain Service with 24hr coverage providing comprehensive palliative care services including training. MPaCCS - multi-disciplinary, specialist in-reach service supporting quality ACP along with awareness development across residents and clinical staff at facility - traffic light system used to check/manage patient deterioration. ▪ Southern Cross (Margaret Hubey facility) – assessment of all patients every two weeks to identify early the deteriorating patients i.e. determine trends such as huge weight loss, fluctuations of consciousness and make suitable referrals to dietician, MPaCCS, GP, etc.. Monthly reporting updates. ▪ Akira model – an app, based upon helping a patient carer assistant know how to be with the patient. Nurse Practitioner can do by themselves, or can be enforced by the facility. Nationally available. ▪ Volunteer model – a lot of organisations have volunteer models (Cancer Council in their lodge have volunteer models, Forget Me Not model, Eden principle – principle of care that this is their home, and look after resident by bringing community to them, house like feel).
10	Palliative Care Rounds and PACOC Development	<ul style="list-style-type: none"> ▪ Palliative Care Rounds and PACOC development - combining both screening, assessment and point of care outcome measures of PACOC with dedicated Nurse Practitioner / Specialist Palliative Care case assessment, evidence based. ▪ 'Needs' rounds, identified within the ACT Inspired model. Critical for quick turnaround times of key decisions.
11	State-wide Extension of ACP/ VEM Model	<ul style="list-style-type: none"> ▪ State-wide extension of the ACP/ VEM model linking hospitals, paramedics, RACFs/hospices.
12	Aged Care (or long term hospice)	<ul style="list-style-type: none"> ▪ Aged Care or long term hospice at an established facility leveraging (and repurposing) existing staff, administration and capacity of existing facility.
13	Palliative Care Locum After-Hours GP/NP service, Family/Carer Support	<ul style="list-style-type: none"> ▪ Palliative Care Locum After-Hours GP/NP Service, Family/Carer Support Project and/or nationally recognised certification (non-registered carer workforce) in RACF providing resources, access, phone and telehealth support to care for patients.

- **Patients and Advance care planning:**
 - Equitable access to palliative care
 - Number of dedicated staff coordinating quality ACP/AHD
 - Level of patient involvement in informed decision making
 - Quality of death index
 - Dying in preferred place
 - Number of people who received end of life care at home
 - Number of people transferred to hospital within 10 days of dying
 - Family grieving staff (number of families called two weeks after death)
 - Quality of life
 - Symptom distress / severity
 - Timeliness of service
 - Patient vulnerability, cultural sensitivity
 - Patient/Family/Carer experience/satisfaction survey results by LGA/community
 - Increased quality of life / PREM (engagement in activities, enjoyment of meals) and PROM (quality of life)
- **Governance:**
 - Policy processes and procedures enabling real-time decisions to be made and patient choice honoured
 - Internal culture reviews
 - Transboundary and inter-service assessments linking palliative care
 - Availability of quality real time systems and data including data integrity
 - Consistency of information
 - Integration of other health services i.e. mental health, renal, dementia
 - Funding and investment focus
 - Equitable palliative care available across the States
- **Service delivery:**
 - Place of death
 - Presentation to ED / ED-Admission
 - Avoidable hospital transfer- feedback loop from ED
 - LOS / reduction in average LOS
 - Workforce satisfaction
 - Benchmarked palliative care workforce against population
 - Burden of disease, complexity of service
 - Timing of referrals versus duration of palliative care services
 - Number of transfers and/or services a patient receives
 - Staff retention
 - PACOC scoring matrix
 - Partner and provider reviews
 - Shared care / GPs, families
- **Education:**
 - Multi-disciplinary models of care
 - Community / public awareness campaigns
 - PC specialist carer qualification nationally recognised (advanced carer qualification for palliative care)
 - Non-registered carers receiving 'new' carer qualification
 - CaLD training measure
 - Credentials – expertise acknowledge and verified and transferrable to other services / states etc.
 - PEPA Program- part of induction / training- all staff- annual training
 - All staff recognising deteriorating patient - families would see all staff well trained / doing the same thing