Independent review – Consumer perspectives of palliative care service models

SUMMARY REPORT

November 2020

Further information from

Professor Samar Aoun
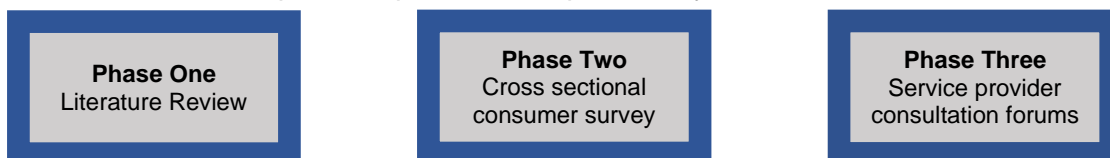
samar.aoun@perron.uwa.edu.au

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EXECUTIVE SUMMARY AND RECOMMENDATIONS

In response to Recommendation Nine of the Joint Select Committee, the WA Department of Health (DoH) commissioned this independent review of consumer perspectives of palliative care service models. The independent review was completed in three phases and findings documented in three separate reports. This report is a synthesis of all three.

Phase One Literature Review	**Phase Two** Cross sectional consumer survey	**Phase Three** Service provider consultation forums

Recommendations

From the literature review and the consumer survey findings, it is evident that receiving palliative care provides much better quality of care for people with life limiting illnesses. The following recommendations are based on key improvements suggested by consumers and service providers, to find innovative ways to deliver better quality of care not only for the 40% who receive palliative/end of life (EOL) care but also for those 60% who do not receive such services:

Nursing homes: Residential Aged Care Facilities and health care providers need to work in collaboration to address the lower standard of care experienced by residents and their family carers.

Non-cancer conditions: Partnerships between specialist and generalist services and the community are needed for a more inclusive palliative approach to care to address the lower standard of care for non-cancer conditions. Non-cancer conditions should be targeted in new models of care, such as the one outlined below.

Family carer support: to help family carers care for the ill person but also to help care for themselves. Instigate a system that assesses and addresses carer support needs, collects regular consumer feedback and co-designs service improvements. The DoH EOLC Program to facilitate the implementation based on the evidence already provided in the WA Strategy.

Grief/bereavement support: The principal providers of this support are family and friends, supported by a range of other primary care and community services. Community education and grief literacy are at least as important as direct services in this area. The DoH End of Life Care (EOLC) Program and PCWA to make available a resource list of support services, continuously updated, to health professionals and the community.
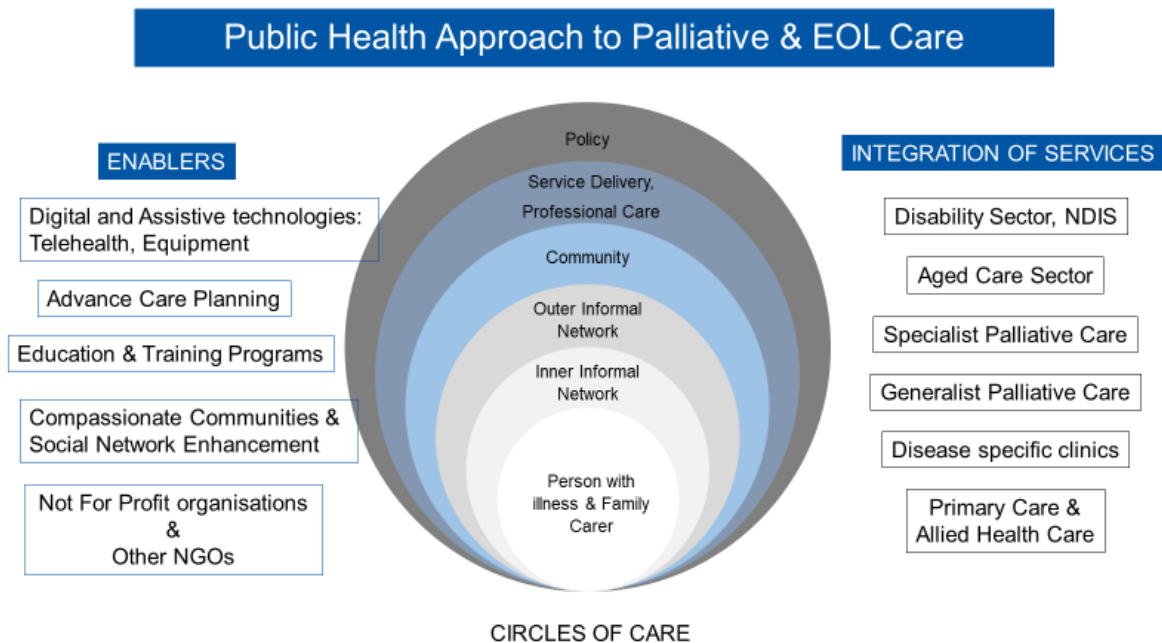
Health literacy and death literacy around end of life and palliative care: including through promoting and facilitating the uptake of tools such as Advance Care Plans, Advance Health Directives, and Goals of Patient Care. this is a shared responsibility between Palliative Care WA (PCWA), DoH, health service providers and Primary Care.

Workforce/Health professional education/training/support: Recognising that the whole health workforce contributes to quality end of life care, including bereavement support, and framing practice guidelines accordingly. Professionals need to share their training and consulting capabilities with each other and with informal caregivers in addition to their well-developed service provision and referral skills. WA Health End-of-life and Palliative Care Education and Training Framework and Resource Hub is an important tool for the sector to help achieve this.

Models of integrated care: including mobilising community options/better primary care engagement and potentially episodic care to broaden the reach of palliative care, case coordination and improved communication/clinical handover. The role of not-for-profit organisations is vital in this space. This integration is achieved by implementing the demonstration project/s described below.

Proposed Model of Palliative Care and End of Life Care

A public health approach to palliative and end of life care is proposed. This end of life care model is able to achieve an integration of tertiary, primary and community services through active consumer engagement in the design and delivery of care.

It is recommended that one or more WA Health regions (metropolitan and rural) be selected to develop and test a public health palliative care model through a demonstration project that connects the dots in the diagram. Trial sites are needed to explore the complexities of coordination, transition and communication inherent in the model by:

- Undertaking an audit of care provided for all deaths in the selected region, drawing upon as many data sources as can be usefully linked with the project.

- Mapping existing end of life care assets and gaps in care provision, with particular attention to:

    - The illness journey for all deaths, particularly transitions in site and provision of care over the last year of life.

    - Patterns of formal end of life care, in particular the relationship between specialist palliative care, generalist palliative care, primary care, aged care, community care.

    - Patterns of informal end of life support, including social networks, information about the community programs and organisations that provide support, and the type of support provided.

"Palliative care is so important and when you've had good palliative care it makes a huge difference to your experience. Cancer patients that I've spoken with who have palliative care seem to have a much better experience than those who go without. But it's not just the patient … the family too cope better when there's a pall care team involved. They have someone to call and they have a plan - there is support." (Cancer patient).

INTRODUCTION

The WA Parliament's Report of the Joint Select Committee on End of Life Choices, 2018 and the Sustainable Health Review 2019 both highlighted challenges in the delivery of palliative care across Western Australia. As part of the WA Department of Health's response to these two processes, the WA Cancer and Palliative Care Network developed the WA End of Life and Palliative Care Strategy 2018-2028 which outlines six priorities for the delivery of palliative care services across Western Australia. In response to Recommendation Nine of the Joint Select Committee, the WA Department of Health commissioned this independent review of consumer perspectives of palliative care service models.

METHODOLOGY

The independent review was completed in three phases and findings documented in three separate reports:

> **Phase 1: A Literature Review** that looked at consumer preferences for receiving palliative care (at home, hospital, hospice, nursing home) and also reviewed the usefulness of different models with a focus on what can be adapted for the WA setting.

> **Phase 2: A cross sectional consumer survey** using a tailored questionnaire to ask patients with a life limiting illness and current and bereaved family carers (both users and non-users of palliative care services - in total six surveys) reported on what is working and not working (or what has or has not worked or could have worked better) for them within the framework of the six priorities of the WA End of Life and Palliative Care Strategy 2018-28, with metropolitan/rural and cancer/non-cancer conditions comparisons.

> **Phase 3:   Four service provider consultation forums** were held with metropolitan, regional and rural service providers (and relevant health care professionals) to present the results of the consumer survey and ask them about the challenges in responding to the needs of consumers, the benefits and risks and how the delivery of palliative care can be improved from their perspectives.

This fourth report is a consolidated summary of all three phases leading up to a proposed model of palliative and end of life care for WA. Project team and reference group members are listed in Appendix 1.

SUMMARY OF FINDINGS

The **literature review** addressed the consumers' needs and preferences at end of life, the end of life needs in particular settings and the utility of different models in responding to consumer need. The literature review found that there was insufficient information on patients' overall illness journeys because consumer experience of palliative care has been poorly

investigated, and consumer contribution to service and policy design was limited and selective. The review highlighted that, in addition to competent treatment, information about the illness experience and strategies for managing that experience are important to patients and their family carers. It is important to distinguish needs that are patient/carer centred and are independent of care settings from needs created by particular care settings themselves that can be addressed through structural changes.

This literature supports a move toward a patient journey perspective, although the current evidence comes mainly from cancer patients. Taking a patient journey perspective requires that services be integrated across the illness course. The trends found in the international literature are to a large extent reflected in Australian policy documents and service guidelines. While a role for active consumer engagement was virtually absent from documents produced a decade ago, it has in recent years been consistently included. These contributions are, however, uneven. Recent documents acknowledge the importance of community involvement or engagement although few expand on how this engagement might take place. Despite support for community engagement and involvement of informal carers, most current models still fall short because their integration is limited to formal health services, with consumers consulted as clients rather than partners in the co-design of services. In light of these gaps, the review highlighted different approaches to be considered such as public health models of care.

Public health approaches to end of life care (EOLC) have potential to enhance integration of services and provide a comprehensive approach that engages the assets of local communities. Moreover, they offer frameworks in which partnerships can be developed with patient communities with distinctive end of life needs, such as those with non-cancer conditions, and thus provide a more inclusive approach to EOLC. To achieve this, we need to hear directly from the consumers about their experiences of unmet needs and how these can be met with better partnerships between the health services and the community, with the consumer involved in the co-design.

The **consumer survey** provided detailed exploration of experiences during the caregiving journey through to bereavement, what worked well and what could have worked better. It also provided a useful indication to services where they are delivering well in the framework of the six priorities of the Strategy and where there are still unmet needs as experienced by the consumers (Appendix 2). Definitions of several used terms in the field were included for survey respondents to refer to (Appendix 3). The methodological considerations and strengths and limitations of the consumer survey are detailed in the related full report.

Although 430 on-line surveys were received, following data cleaning and quality assurance, we were able to utilise 82% of surveys or 353, 68% (n=239) were users of palliative care services and 32% (n=114) non-users. The largest group responding were bereaved carers, equating to 71% of the valid sample: 30.2% of users had a non-cancer condition, and 31% of users were from regional and rural areas. The most reported setting for care was home (43%) followed by hospital (26%), hospice (23%) and nursing home (8%). About 60% of non-users had a non-cancer condition.

Sixty-two individuals registered for the four **service provider consultation forums** and 50 people attended from 30 services. Appendix 4 presents the format of discussions.

The following findings are grouped under the six priorities combining the opinion of consumers and service providers.

Priority one: care accessible to everyone, everywhere

What is working well for users of Palliative Care (PC)?

The quality indicators during the illness were generally high for the overall sample: about 80% for quality of care (home setting receiving the highest rating), accessing care as soon as needed (home setting receiving the highest rating) and relief of pain (hospice and hospital settings receiving the highest ratings); about 70% for relief of symptoms other than pain (nearly equal for home, hospital and hospice) and practical assistance (home and hospital); The quality indicators at EOL were rated high at over 80% for the quality of EOL care and receiving enough help *at the actual time* of death from services, particularly for home and hospital settings. Quality of care rated high and similar at about 80% in both metropolitan and rural areas.

What is not working so well for users of PC?

Overall, only 60% reported receiving as much support as wanted *before* death (hospital, home, hospice). The nursing home was reported to have a lower performance than the other three settings particularly for receiving as much support as wanted (44%) and for relief of pain and other symptoms (50%). Only about 50% of respondents felt they received enough help *after* their relative's death. Across most indicators, quality indicators for non-cancer rated lower than cancer.

Differences

Metropolitan/rural: metropolitan people had slightly better access to care as soon as needed and relief of pain. However, the rural setting did better on the following indicators: relief of other symptoms (significant difference for home), practical assistance, quality of EOL care, receiving enough help at time of death from services.

Cancer/non-cancer: There were differences across settings and the nursing home showed an opposite trend on most indicators, where the non-cancer group did much better, though the numbers were too small. The most significant differences between the two groups on nearly all indicators before and after death were in the hospice setting. The significant difference in overall quality of care was in the home and hospice settings where the cancer group had better quality indicators. The quality of EOL care was significantly better in the hospice for the cancer group (97% vs 50%).

Comparison with Non-Users of PC

All priority one quality indicators for non-users were lower than those reported by users, and in particular the largest differences were in the quality of end of life care (83% users vs non-users vs 38%), receiving enough help at the time of death (84% users vs 59% non-users), receiving practical assistance (75% users vs 56% non-users), receiving as much help as needed before the death (61% vs 40%), relief of pain (77% vs 62%) and other symptoms. However, the support received after death was equivalent to that of users (47% vs 45%).

"Everyone with a life limiting illness should automatically be seen by palliative care to start the relationship and then be available whenever they are needed"
(patient).

Table 1 presents the opinion of consumers (from survey) and service providers (from consultation forums) about what needs to improve the quality indicators in priority one.

	Improvements suggested by consumers	Improvements suggested by service providers
P R I O R I T Y O N E	• Accessing care earlier/when required. • Increasing staffing levels in existing services. • Increasing number of services (in both rural and metropolitan areas). • Better after-hours care, support and access. • Providing sufficient support to stay in the setting of choice (e.g. home). • Better information and support at the initial diagnosis of a life limiting illness. • Better palliative care delivery for neurological conditions. • Navigation of referral and access-admission process • More adequate pain relief/reduce delays in achieving pain relief. • Information on how to manage changes in medication as the patient's ability to swallow deteriorates. • Streamline and improve access to NDIS services. • Increase regional services: 24-hour care at home/ community palliative care.	• Increase staff numbers/funding for services. • Simplify referral criteria and reduce wait times, particularly those related to Aged Care Assessment Team (ACAT) and National Disability Insurance Scheme (NDIS). • Introduce a directory of services. Knowing where to look for information about community providers. • Move towards shared models of care, with incentivised funding to ensure collaboration and integration across the continuum of care. • Improve equity of care both across regions (funding and staff numbers) and across different disease groups (cancer vs non-cancer conditions). • Improve health and death literacy of consumers. • Improve staff retention in rural areas. • Explore ways to improve timely delivery of pain relief and other support to remote patients. • Reduce burden of chronic disease in rural areas. • Introduce funding options for EOL care for people < 65 years ineligible for NDIS.

Table 1: Improvements suggested for Priority One - Care accessible to everyone, everywhere.

Priority two: care is person-centred

What is working well for users of PC?

The following quality indicators during the illness were generally high (above 80%) for the overall sample for all settings except nursing home: Respect for values, culture and spiritual beliefs. Regarding EOL wishes documentation, 60% of respondents reported having one or more of these documents, 70% reported that the services checked if they have any of these documents and 80% reported that their wishes have been taken into account. Patients were included in care decisions (70%) in most settings and to a lower extent in nursing home (50%). 80% felt that family carers were involved in decision making at EOL and only 16% reported that decisions were made about their relative's care that they would not have wanted. The ratings for respect for values and culture were nearly the same in both areas as well as wishes in Advance Care Planning (ACP) documents being fulfilled.

What is not working so well for users of PC?

Spiritual and emotional support for the patient were rated lower at about 60% rating it excellent/good across settings and even lower for nursing home. Less than 60% of respondents were able to discuss their fears and worries as much as wanted. Across most indicators, non-cancer rated lower than cancer.

Differences

Metropolitan/rural: Rural areas did better in services asking about existence of EOL wishes documentation, inclusion of patients in care decisions during illness and EOL. Spiritual beliefs were more respected in metropolitan areas.

Cancer/non-cancer: Across most indicators, cancer rated higher than non-cancer, especially in values/culture/spiritual beliefs, EOL wishes fulfilled, could discuss worries/fears, spiritual and emotional support for patient. The differences were particularly significant in the hospice setting. The nursing home showed an opposite trend to other settings on most indicators, where the non-cancer group fared better (but the numbers in this setting are small).

Comparison with Non-Users of PC

The most pronounced differences were in the following quality indicators where the non-users fared worse: carer involved in decisions as wanted (80% users vs 45% non-users), inclusion of patient in care decisions (72% vs 58%), spiritual support of patient (61% vs 37%), could discuss worries/fears (58% vs 40%), being asked if they had EOL wishes documentation (69% vs 48%). Twice as many non-users had decisions made but they were not wanted (16% users vs 38% non-users).

In general, service providers felt that "person centred care is done well within palliative care but not so well outside palliative care".

Table 2 presents the opinion of consumers (from survey) and service providers (from consultation forums) about what needs to improve the quality indicators in priority two.

	Improvements suggested by consumers	Improvements suggested by service providers
P R I O R I T Y T W O	• Improving their knowledge and education and making it easier to complete EOL wishes documents: Advance Care plans, Advance Health Directives, Goals of Care. • Flexibility to accommodate individual wishes of patients (e.g. day release, engaging activities, visiting access). • Patients and family/carers more involved in decisions (and given sufficient information). • Improve services' physical environment to be more sensitive. • Improve consumer knowledge: Flow chart for families – who's who and contact details. • More weekend services (doctor, spiritual needs, counselling and grief support). • More in-home support (not just personal care) for people wishing to stay in their home. • Tailored mental health support services for dementia patients.	• Improve the ACAT/ NDIS interfaces. • Improve the access, processes and systems for patients that don't have access to ACAT funding. • Ensure clear pathways between different settings and within metropolitan/rural transfers. • Explore how technology can support patients isolated by distance (e.g. iPads in the home program). • Improve health literacy and death literacy to change perceptions of palliative care and promote the value of palliative care to consumers.

Table 2: Improvements suggested for Priority Two - Care is person-centred

Priority three: care is coordinated

What is working well for PC users?

87% reported that health professionals involved in their care worked well together within settings except nursing home. The referral process to these settings was easy (about 75%) but lower for nursing home. 74% of respondents were satisfied with the 'out of hours' services they received. Metropolitan/rural differences were not pronounced for this priority.

What is not working so well for PC users?

Only 8-12% (range across settings) of ED admissions were coordinated and planned. 66% thought the services in a particular setting worked well with GPs and other services external to these settings.

Differences

Cancer/non-cancer: Referral process was easier and staff worked better together within a setting and with others outside the setting for cancer, the largest significant difference being

in the hospice setting (95% vs 73%); the percent of planned and coordinated ED admissions were slightly higher for non-cancer.

Comparison with Non-Users of PC

The referral process to services was not as easy for the non-users (52% non-users vs 75% users), the teams did not work as well together (78% non-users vs 87% users). However more of the non-users' ED admissions were coordinated or planned (15% non-users vs 9% users) and their services worked well with the GP similarly to the users.

Table 3 presents the opinion of consumers (from survey) and service providers (from consultation forums) about what needs to improve the quality indicators in priority three.

P R I O R I T Y T H R E E	Improvements suggested by consumers	Improvements suggested by service providers
	• Better coordination of care across different providers and teams. • Single professional responsible for the overall care of each patient – who can coordinate all the other agencies. • Utilising other disciplines in care planning. • Short-term support for medical treatment (at home) that does not require hospital admission.	• Care coordination linked to the client and their support network, independent of any single provider. Palliative care should not become the default case manager. • Better communication between services and greater understanding of the limitations and value of services and between professionals (e.g., GPs, palliative care services, specialists).

Table 3: Improvements suggested for Priority Three - Care is coordinated

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"I was never convinced that communication between the medical service teams was all that great. It was up to me to update them and connect the dots". (family carer, user)

"Services used are not necessarily connected or communicating. As a carer I oversight communication between them and coordination across them." (family carer, non-user).

Priority four: families and carers are supported

What is working well for PC users?

About 80% of family carers reported that the patient was involved in decision making at EOL as much as wanted. Metropolitan/rural differences were not pronounced for this priority.

What is not working so well for PC users?

Emotional support to family carer and being provided with information about their relative's condition both rated relatively low at about 60% with the nursing home rating the lowest. Support for the family carer at bereavement was poor, rating about 40-50% for having the opportunity to talk to services about their experience of illness and death, being offered

information about grief and bereavement services and 42% being contacted within 3-6 weeks from death (contact even lower at 6 months, 16%). Across most indicators, non-cancer rated lower than cancer.

Differences

Cancer/non-cancer: There was a significant difference in the emotional support to family carer in the hospice setting with more provided to the cancer group (73% vs 40%), while the opposite in support occurred in nursing homes.

Comparison with Non-Users of PC

Only 50% of non-users reported that patient was involved in decisions at EOL compared to 78% of users. 31% of non-users received information on grief and bereavement services compared to 53% of users. 44% of non-users reported family carer receiving emotional support compared to 62% of users.

"I think that as soon as someone is diagnosed there should be a referral for domestic and health help at home for the carer. not wait for the family to initiate at the end or when things get too much". (family carer, non-user)

"A caring follow-up call from palliative care would have been helpful but when it did occur months later, it was done as a perfunctory task which lacked empathy and was unhelpful." (family carer, user)

Table 4 presents the opinion of consumers (from survey) and service providers (from consultation forums) about what needs to improve the quality indicators in priority four.

	Improvements suggested by consumers	Improvements suggested by service providers
P R I O R I T Y F O U R	• Information at the time of diagnosis (illness trajectory; how palliative care can help). • Increase the level of family carer support. • Grief and bereavement support. • Respect for the role of the enduring guardian. • Regular case reviews/ communication with family about day to day care delivered.	• Routine assessment of carers' needs should be undertaken separately to patients to reduce carer strain during the caregiving period and for better bereavement outcomes. • The use of an 'app' where users can complete some standard information (e.g., location, illness, existing supports/networks) as a filter which then provides them with a list of services and supports applicable to their circumstances. • Increase personal care funding and improve out of home respite options. • Improve symptom control over the illness trajectory to enable people to remain at home longer. • Provision of bereavement support is better provided by other specialist organisations. • improving knowledge/information/ health literacy on disease trajectories, services, and the benefits of palliative care.

Table 4: Improvements suggested for Priority Four – Families and carers are supported

"Families are often shocked when they reach the palliative care stage because of their lack of understanding of illness trajectory". (Service Provider)

"There is an understandable scepticism about the potential for 'system' adaptation. For example, 'collaboration' is a genuine desire of many but our 'systems' make that a job in itself and we are all time poor in our roles". (Service Provider)

Priority five: all staff are prepared to care

What is working well for PC users?

Possibly the highest overall ratings were in this priority where about 90% of respondents reported being treated with respect/dignity and compassion/kindness and that staff were competent. The ability to obtain information when needed was as high as 80% across most settings. Family being dealt with in a sensitive manner after relative's death was high at 86% across most settings. Metropolitan/rural differences were not pronounced for this priority overall.

What is not working so well for PC users?

Nursing home ratings for all these quality indicators were lower at 60%. The non-cancer group ratings were lower.

Differences

Metropolitan/rural: Metropolitan hospitals were better at providing information when needed; rural settings dealt more in a sensitive manner overall (92% vs 84%) and especially in hospice setting.

Cancer/non-cancer: Generally, the cancer group rated more favourably on all indicators across settings except at nursing home.

Comparison with Non-Users of PC

Being treated with respect/dignity, with compassion/kindness (89% for users and 82% for non-users) and staff competence (91% users vs 88% non-users) were quite similar for the two groups. The most pronounced difference is if they were dealt with in a sensitive manner (89% users vs 59% non-users).

> *"Junior staff tried their best but clearly no institutional culture to support education and practice of palliative care. Senior staff uneducated and seemingly unaware of own knowledge and practice inadequacies. Senior nursing staff in particular had no knowledge of principles of patient centre care, professional standards or good palliative care." (family carer, non-user)*

Table 5 presents the opinion of consumers (from survey) and service providers (from consultation forums) about what needs to improve the quality indicators in priority five.

PRIORITY FIVE	Improvements suggested by consumers	Improvements suggested by service providers
	• Staff knowledge and training including: Swallowing, Specific diseases (e.g. Motor Neurone Disease (MND), dementia), basics of death and dying, Communication skills, Wound care management, Empathy, Catheter care. • Staffing levels: Palliative care teams needing more staff on weekends and after hours.	• Provide training on palliative care to non-palliative care services - the palliative approach to care. Disease specific specialists could provide training on disease specific information to general palliative care providers and the upskilling of health staff in non-cancer disease groups (e.g., MND education workshops delivered by the MND Association to all health professionals). • Improve the support/caring of frontline staff, in terms of debriefing opportunities and professional supervision. • Improve GP knowledge and capacity of palliative care, including the use of Health Pathways.

Table 5: Improvements suggested for Priority Five – All staff are prepared to care

Priority six: the community is aware and able to care

What is working well for PC Users?

The vast majority of respondents received informal support similarly across all settings before (95%) and after (93%) bereavement mainly from family/friends/neighbours. Also, the vast majority reported that this informal support was helpful before (91%) and after (87%) bereavement. Overall, those bereaved who have cared for their relative at home rated the helpfulness of support to be more helpful. Metropolitan/rural differences were not pronounced for this priority.

What is not working so well for PC Users?

Nothing to report here.

Differences

Cancer/non-cancer: The helpfulness of the informal support before bereavement was rated higher for the cancer group. The informal support received by the bereaved when relative was cared for at home or hospital was higher for the cancer group, similar at hospice for both groups and higher for non-cancer in the nursing home (though numbers are very small). The helpfulness after death was higher for those whose relatives had non-cancer and were in hospice setting.

Comparison with Non-Users of PC

Both groups received the same extent of informal support. The non-users reported lower ratings for the helpfulness of informal support before death (70% vs 92%) and after death (76% vs 93%).

[unhelpful] Doctors and specialists who are usually unable to point one towards a needed support. How difficult would it be for doctors/specialists to at a minimum have some business cards at the counter for voluntary groups such as the prostate support groups?" (patient, non-user)

Nearly a third of bereaved carers in both groups did not respond to the questions on actual or preferred place of death. While 26.5% of users and 17.8% of non-users died at home, 45% of users and 33% of non-users had preferred death to be at home. The majority of non-users died at hospital, while users died in nearly equal proportions at home or hospice. More details in the following summary table.

	USERS		NON-USERS	
Place of death	actual	preferred	actual	preferred
Home	26.5	44.6	17.8	33.3
Hospital	12.3	3.4	32.1	0
Nursing Home	4.4	1.0	13.3	0
Hospice	23.5	7.4	0	9.0

Summary Table: Actual and preferred place of death for users and non-users (%)

Table 6 presents the opinion of consumers (from survey) and service providers (from consultation forums) about what needs to improve the quality indicators in priority six.

P R I O R I T Y S I X	Improvements suggested by consumers	Improvements suggested by service providers
	• Community understanding of the benefits of timely end-of-life and palliative care. • Public awareness on how to informally support others within their own community. • Formal services need to work in partnership with informal networks to maximise capacity of support. • Clear and concise information and assistance to complete Advance Health Directives. • Use of completed Goals of Patient Care more widely.	• Continue community programs to educate and empower consumers, carers, and families on advance care planning and the range of services available. • Community education on how to support others within their community through life limiting illnesses as well as grief support for families and their carers, before and after death. • Better publicity for existing services, such as the recently introduced palliative care support line, and the role of not-for-profit organisations.

Table 6: Improvements suggested for Priority Six – The community is aware and able to care
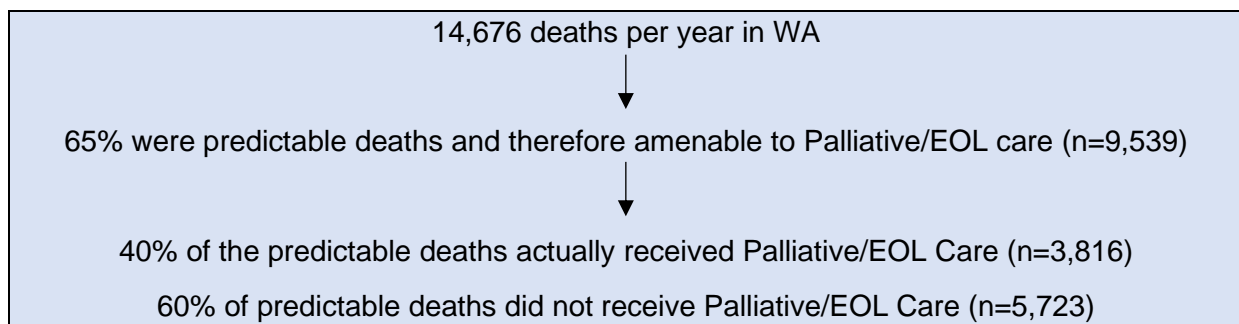
> *Friends and neighbours who just dropped around to help normalise my life after spending over 3 weeks in hospital, lend books, bring food, help with the garden. Family who would video conference from overseas in support. (patient, non-user)*

CONCLUSION

WA Health, in commissioning this systematic exploration of consumer experience, leads the field nationally and in many respects internationally, in particular because the review seeks information about the end of life experience of non-users as well users of palliative care.

The findings confirm that palliative care services improve the quality of patients' and families' experience of end of life care when compared with that of non-users of palliative care. It is clear that the palliative approach to care provided by general health services contributes to that quality of care. But it is also clear that palliative care is most effective for cancer patients and their families and that, if a palliative approach is to be extended more widely to non-cancer conditions, familiarity with end of life needs for those conditions needs to be improved. This means reaching out to the 5,723 patients who have predictable or expected deaths, but who currently receive 'care at end of life' and not 'End of Life Care' (Figure 1). Overall, the end of life care system needs to be bolstered by systematic and consistent education and training for general health professionals to enhance collaboration and ease the pressure on specialist palliative care services.

Figure 1: Palliative and EOL Care in 2019 in Western Australia

14,676 deaths per year in WA

65% were predictable deaths and therefore amenable to Palliative/EOL care (n=9,539)

40% of the predictable deaths actually received Palliative/EOL Care (n=3,816)

60% of predictable deaths did not receive Palliative/EOL Care (n=5,723)

Source: Presentation by Prof Kathy Eagar, Perth,19 August 2019

It is evident that family carers assumed the vital role of 'connecting the dots" in liaising with several treating teams and maintaining communication about and coordination of care. In the absence of formal case managers, family carers must be supported to develop their capacity in this role if care is to be as effective as possible. It should be noted that the importance of systematically assessing and addressing carer support needs has been recognised in WA strategy since 2018, but no steps have as yet been taken to operationalise this matter.

The two stand-out issues to be addressed in achieving the six priorities are the lower standard of care for non-cancer conditions, and in nursing home settings for any condition. Non-cancer conditions can greatly benefit from a more inclusive palliative approach based on partnerships between specialist and generalist services that also involve the community. Improving care in the nursing home settings needs to be addressed by several players in the field, including the Metropolitan Palliative Care Consultancy Service (MPaCCS), residential aged care facilities and other service providers.

The other areas of unmet need reported in the surveys are emotional and spiritual support for patient and family before death, and bereavement support. Although these aspects are part of the holistic approach of palliative care, there seems in practice to be a disconnect between what the sector portrays and encourages the community to expect and what is actually delivered due to time and resource constraints. As one service provider commented *"the medical model of care is not holistic".* It seems that there was not enough time allowed in some services to discuss consumers' issues or expectations, concerns or fears. There were

comments from service providers on the "*inadequate time to communicate well with one another as service providers*" and also *"insufficient time for good emotional support for patients and their family carers".* Who can fill this gap? One strategy is better referral pathways to not-for-profit support organisations who are able to dedicate the time to have these conversations with better resourcing. But alongside this is the need to upskill the community networks that support people throughout the illness journey. The preferred model is one grounded in community upskilling/ knowledge, supported consistently by generalist palliative care, with specialist palliative care providing 'episodic' care as particular needs arise during the illness journey.

RECOMMENDATIONS

From the literature review and the consumer survey findings (illustrative quotes from consumers included), it is evident that receiving palliative care provides much better quality of care for people with life limiting illnesses. The following recommendations are based on key improvements suggested by consumers and service providers, to find innovative ways to deliver better quality of care not only for the 40% who receive palliative/EOL care but also for those 60% who do not receive such services:

Nursing homes: Residential Aged Care Facilities and health care providers need to work in collaboration to address the lower standard of care experienced by residents and their family carers.

"*I don't know what it takes for a nursing home to claim they offer palliative care … did not have adequate numbers of staff who were trained and experienced in this area".*

"The aged care provider was often poorly resourced, slow to react, beset with staffing issues and were compelled to employ staff sometimes poorly trained and with language issues".

Non-cancer conditions: Partnerships between specialist and generalist services and the community are needed for a more inclusive palliative approach to care to address the lower standard of care for non-cancer conditions. Non-cancer conditions should be targeted in new models of care, such as the one outlined below.

"Our experience has been heartbreaking and we are still in the midst of it. My dad is being moved from hospital to hospital and finding palliative care is impossible. The system is broken and needs to be fixed. MND is a diagnosis that needs its own system to help understand the impact."

"Considering the number of people impacted by Dementia, there should be a lot more support and services for patients and carers, especially for Younger Onset."

Family carer support: to help family carers care for the ill person but also to help care for themselves. Instigate a system that assesses and addresses carer support needs, collects regular consumer feedback and co-designs service improvements. The DOH EOLC Program to facilitate the implementation based on the evidence already provided in the WA Strategy.

"*It was such a shock for my husband to be in palliative care and I was totally unprepared and didn't know what to expect"*

"More hours of in-home support to make caring easier. Honestly, if he had lasted another 3 days, I am not sure we could have survived. Literally a whole family effort to keep him comfortable".

Grief/bereavement support: The principal providers of this support are family and friends, supported by a range of other primary care and community services. Community education and grief literacy are at least as important as direct services in this area. The DOH EOLC Program and PCWA to make available a resource list of support services, continuously updated, to health professionals and the community.

"The [not for profit organization] grief counsellors- it was like they were working off a checklist and if you didn't fit, it was too hard".

"*There needs to be a situation where de-brief is allowed. … Life has to continue for the bereaved, but life won't continue the same and this needs to be acknowledged, supported and valued."*

Health literacy and death literacy around end of life and palliative care: including through promoting and facilitating the uptake of tools such as Advance Care Plans, Advance Health Directives, and Goals of Patient Care. This is a shared responsibility between PCWA, DOH, health service providers and primary care.

"*We have found it very difficult to find clear and concise information on how to complete Advance Health Directives. The information is all general and guidance with no examples/samples of the type of wording to be used. We have spent weeks trying to get to a stage where it makes sense and clearly explains our wishes."*

Workforce/Health professional education/training/support: Recognising that the whole health workforce contributes to quality end of life care, including bereavement support, and framing practice guidelines accordingly. Professionals need to share their training and consulting capabilities with each other and with informal caregivers in addition to their well-developed service provision and referral skills. WA Health End-of-life and Palliative Care Education and Training Framework and Resource Hub is an important tool for the sector to help achieve this.

"*Skills training for nursing staff in communication. Improved assessment skills training. Additionally, a senior nursing staff member broke down following my dad's death and said that the care we provided as a family was the sort of care she would have liked provided to her own father. I felt that she could have benefited from an opportunity to talk with a skilled team member to debrief. The frequency with which we were told staff were working under pressure was concerning".*

"Mandatory training for all staff on the basics of death and dying. Increase palliative care beds at our public hospitals, increase the number of staff who specialised in palliative care".

Models of integrated care: including mobilising community options/better primary care engagement and potentially episodic care to broaden the reach of palliative care, case coordination and improved communication/clinical handover. The role of not-for-profit organisations is vital in this space. This integration is achieved by implementing the demonstration project/s described in next section.

"Improve the integration of care and ensure the emphasis is on compassionate care for all those patients who are facing their one and only death".

"Liaison, communication and coordination between doctors, [RACF], palliative and family is very poor. We are constantly seeking information, updates etc. No one provider is 'in charge' of my Dad's care. It makes it very difficult for the family to know where to turn for information."

PROPOSED MODEL OF PALLIATIVE CARE AND EOLC FOR WA

International research indicates that a solely clinical model of palliative care (mainly focusing on symptom management) is inadequate to address the multiple comorbidities and access issues that characterise modern palliative care. If palliative care is to successfully address challenges of unequal access, continuity of care, and the narrow focus in which health services attend to EOLC, new practice models need to be identified, debated and tested.

A review of the literature (see Phase 1 report) finds no evidence to recommend a particular organisational model of palliative care on the basis of clinical effectiveness or cost-effectiveness. The literature however provides clear evidence-based guidelines concerning the quality of end of life care that should be provided in all settings, and strategies by which these qualities can be realised.

There is strong evidence that the effectiveness, including cost-effectiveness, of palliative care provision can be improved by developing models that integrate specialist and generalist palliative care. There is an increasing body of evidence that supports the contention that the effectiveness of this integration will be further improved by forming partnerships with community services and consumers' social networks using a public health approach.

A public health approach to palliative and end of life care in the broadest sense encompasses a primary care approach involving generalist healthcare workers providing initial assessment, support, intervention and ongoing support; a tertiary care approach involving specialist healthcare providers and inpatient facilities such as hospitals, clinics, or hospices; and a population health approach involving education and community development. The latter is the least-developed aspect of palliative care service development. Hence the distinctive focus of a public health approach to end of life care today is that it views the community as an equal partner in the long and complex task of providing quality healthcare at the end of life.

This approach must recognise the 'patient and social network' (Circles of Care depicted in Figure 2). The 'inner' and 'outer' circles of care, and neighbourhood supports are the main foundation of resilient networks caring for people at home. Together they form a Compassionate Community. However, these systems must also ensure that professional care, service delivery and policy enhance the care provided by the person's social network.
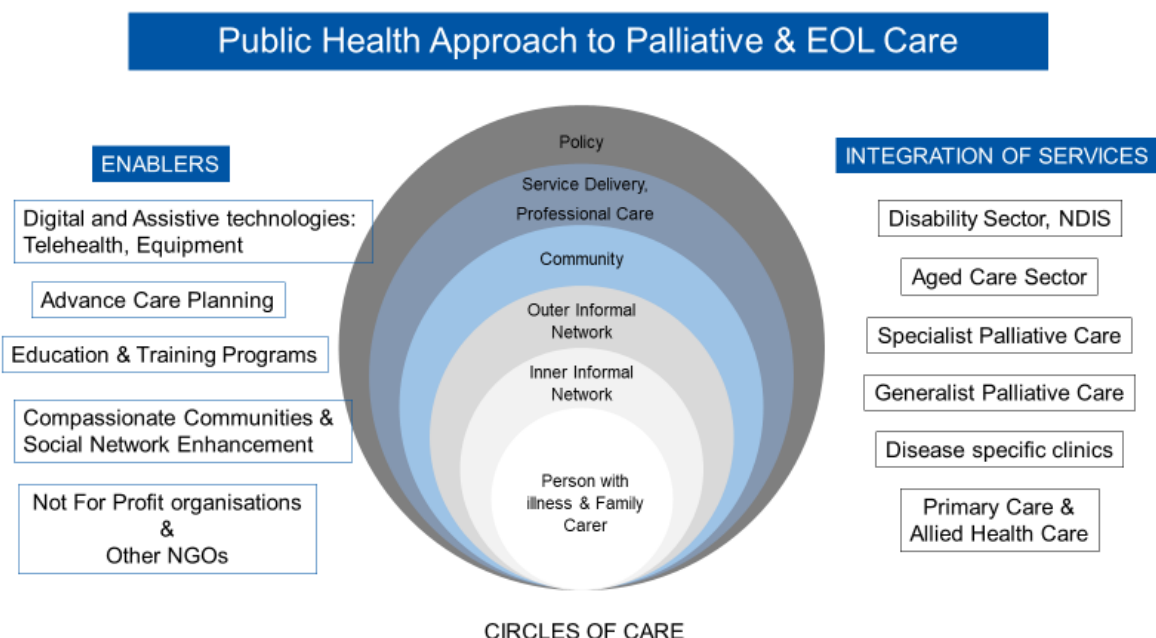
Incorporating public health frameworks and palliative approaches to care, a proposed model, building on 'Circles of Care', is depicted in Figure 2. The model can be used as a practical guide about how care can be done in communities and how different formal and informal services coordinate with each other and the communities they serve.

Figure 2 also captures the scope and complexity of a public health approach to palliative and end of life care. It shows the scope of an end of life care model able to achieve an integration of tertiary, primary and community services through active consumer engagement in the design and delivery of care. The model depends upon several elements:

1. A consensus, preferably at the national or international level, on quality standards and practice guidelines to implement those standards.

2. Health policy at state level that can facilitate the integration of primary care and tertiary care services.

3. Policy at state level that can facilitate collaboration between health services and community services, including services provided by local government.

4. Strategies for regular, systematic state-wide consumer feedback on end of life care provision.

5. A public health framework endorsed at local and state government levels to facilitate co-design of services in regions.

Element 1 is already in place with Australian Commission on Safety and Quality in Health Care (ACSQHC) standards and guidelines such as those provided by National Institute for Health and Care Excellence (NICE). With regard to elements 2 and 3, the capacity of WA health and community care policies to facilitate service integration and foster collaboration across sectors needs to be explored under practice conditions. Element 4 could be met by implementing an earlier recommendation to use the FAMCARE-2 tool for collecting information on families' experience of EOLC, while models are available for Element 5, such as the South West Compassionate Communities Connector project in partnership with WA Country Health Service (WACHS). Obviously, a range of issues need to be resolved, including case management, which at the moment defaults to the primary carer or, in some cases, the palliative care service as mentioned in the consultation forums.

Figure 2: A proposed Public Health Approach to Palliative and EOL Care in WA

RECOMMENDATION FOR A MODEL OF CARE

That one or more WA health regions (metropolitan and rural) be selected to develop and test a public health palliative care model through a demonstration project that connects the dots in Figure 2. Trial sites are needed to explore the complexities of coordination, transition and communication inherent in the model.

Ideally such a project would begin with an audit of care provided for all deaths in the selected region, drawing upon as many data sources as can be usefully linked with the project. This audit would map existing end of life care assets and gaps in care provision, with particular attention to:

- The illness journey for all deaths, particularly transitions in site and provision of care over the last year of life.

- Patterns of formal end of life care, in particular the relationship between specialist palliative care, generalist palliative care, primary care, aged care, community care.

- Patterns of informal end of life support, including social networks, information about the community programs and organisations that provide support, and the type of support provided.

On the basis of this information, a representative group of consumers, providers and civic leaders would commence a process of co-designing and implementing strategies that build collaboration between current palliative care services, primary care and aged care services, social and community services, and the informal care networks and organisations identified in the audit process. Public health palliative care planning and evaluation frameworks are available to guide this work. Implementation and evaluation should identify policy and practice issues to be resolved at the service provision level in this and other regions within WA and provide examples of local end of life care solutions that can be models for other regions. The outcome of the trial should be a regional end of life care system reframed around consumer experience, not clinical needs alone, understood and described in ways that facilitate the transfer of this learning to other regions.

ACKNOWLEDGEMENTS

Appendix 1

PROJECT TEAM

Name	Role
Prof Samar Aoun	Chief Investigator - Perron Institute and La Trobe University
Robyn Richmond	Project Officer - Perron Institute
A/Prof Bruce Rumbold	Associate Investigator - La Trobe University
A/Prof Lauren Breen	Associate Investigator - Curtin University
Leanne Jiang	Data Analyst - Perron Institute

REFERENCE GROUP

Name	Organisation/Role
Julie Bartley	WA Cancer and Palliative Care Network, DoH
Wendy Blomberg	Consumer/Carer representative
Pip Brennan	Health Consumers' Council
Jason Burton	Alzheimers WA
Rob Daniel	Consumer/Carer Representative
Dr Jacquie Garton-Smith	Department of Health
Ed Gaudoin	Metropolitan Palliative Care Consultancy Service
Lana Glogowski	Palliative Care WA
Will Hallahan	Metropolitan Palliative Care Consultancy Service
Gabriella Jerrat	WA Cancer and Palliative Care Network, DoH
Lyn Johnson	Consumer/Carer Representative
Melanie Marsh	CISS Director, Cancer Council WA
Kate McLaughlin	Consumer/Carer representative
Tish Morrison	Silver Chain Hospice Service
Kylie Pettit	WA Country Health Service
Paul Rogers	Carers WA

Appendix 2

Priority 1. Care is accessible to everyone, everywhere: Overall quality of care; access to care as soon as needed; received as much help from services as needed; relief of pain; relief of symptoms other than pain; practical assistance; quality of end of life (EOL) care; received enough help at time of death and after death from service providers.

Priority 2. Care is person-centred: Support to stay where the person with illness wanted to be (preferred place of care); values respected; cultural background respected; spiritual beliefs respected; spiritual support to patient; emotional support to patient; asked about Advance Care Planning; End of life wishes taken into consideration; able to discuss worries/fears; inclusion of patient in care decisions; carer as involved in decisions as they wanted to be; and decisions made about care that patient would not have wanted.

Priority 3. Care is coordinated: Ease of referral process; health professionals involved in care are working well together; services are working well with the General Practitioner, Emergency Department admissions and out of hours.

Priority 4. Families and carers are supported: Emotional support to family/carer; information on their relative's condition; patient involvement in end of life decisions; able to talk to health and/or social services about their experience of the death of the person with illness; offered information about grief and bereavement; contacted after death.

Priority 5. All staff are prepared to care: Being treated with respect/dignity; being treated with compassion/kindness; staff competence; obtaining information when needed; dealt with in a sensitive manner.

Priority 6. The community is aware and able to care: Achieving preferred place for death from the patient and carer perspective, the extent and nature of support received from the social and informal networks before and after death of person with illness and the helpfulness of informal support before and after death.

Appendix 3

End-of-Life

End-of-life is the timeframe during which a person lives with, and is impaired by, a life limiting/fatal condition, even if the prognosis is ambiguous or unknown. Those approach end-of-life will be considered likely to die during the next 12 months.

End-of-life care

Care that improves the quality of life of people and their family/carer facing problems associated with life-limiting illness. End-of-life care, supportive care, anticipatory care, comfort care, symptom management and palliative approach are sometimes used interchangeably.

End-of-life care encompasses a palliative approach to care and recognises that it is the responsibility of public, private, community and non-government health sectors to provide quality end-of-life care for their patients. It also recognises that support of people and their family/carer is most effective with a team approach through a network of healthcare professionals.

Family Carer/Informal Carer

Those who provide ongoing unpaid care and support to a family member or friend who has a disability, chronic condition, mental illness, terminal illness or general frailty. This includes parents and guardians caring for children.

Family

Those who are closest to the person in knowledge, care and affection. This may include the biological family, the family of acquisition (related by marriage or contract), and the family and friends of choice.

Life-limiting illness

An illness or condition that can be reasonably expected to cause the death of a person within the foreseeable future. This definition is inclusive of both malignant and non-malignant illness.

Palliative care

An approach that improves the quality of life of people and their family/carer facing the problems associated with life-limiting illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems – physical, psychosocial and spiritual.

Palliative Care Unit (PCU) / Hospice[1]

A PCU is a facility from which both inpatient and outpatient specialist palliative care is provided and coordinated. A PCU has a multidisciplinary team of healthcare providers who are knowledgeable and skilled in all aspects of the caring process relating to palliative care and their discipline of practice (holistic care). A PCU is not limited to care for patients at the end-of-life nor those with a cancer diagnosis; rather it is available to patients and families throughout the illness (malignant and non-malignant causes) and bereavement experiences. In summary, PCUs provide a coordinated, integrated and patient-focused model of care, which includes respite and other supportive services to carers.

Each PCU should be an integral clinical service within a hospital and be housed within a purpose-designed unit to facilitate the implementation of a palliative approach across the hospital whilst retaining the valued ethos of care in traditional hospices within the unit itself. These services should be integrated with the wider clinical system to achieve the best outcomes for patients and families.

Specialist palliative care

Specialist palliative care is undertaken by a professional palliative care team or service with recognised qualifications or accredited training in palliative care. They provide direct care to people, and their family/carer with complex palliative care needs and/or provide consultation services to support, advise and educate specialist and non-specialist teams providing end-of-life care.

While every Western Australian with life-limiting illness has a right to a quality palliative approach through end-of-life care, not everyone requires specialist palliative care.

All definitions taken from the WA End-of-Life and Palliative Care Strategy 2018-2028, WA Department of Health except those noted below

1-Taken from Palliative Care in Western Australia, Final Report December 2005

Appendix 4

FORMAT OF SERVICE PROVIDER CONSULTATION FORUMS

- An introduction to the project.

- An overview of key learnings from the literature review.

- An overview of the survey results, emphasising what is working well or what is not working so well, and improvements suggested by consumers (focussing on users of palliative care services).

- A discussion in breakout groups of the survey results, current challenges, areas of improvement, and transition between services/settings.

- A breakout session where workshops attendees, in groups, looked at the priority areas within the WA End of Life and Palliative Care strategy to identify current challenges/gaps and potential solutions.