



Government of **Western Australia**
Department of **Health**

WA Palliative Care Summit 2019 WACHS Report



Monday 19 August 2019
Royal Perth Hospital and via Videoconference

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Overview

Members of WACHS palliative care teams and services attended a Palliative Care Summit on Monday, 19 August 2019 at the Royal Perth Hospital and via Videoconference. The aim of the Summit was to discuss and reflect on the future direction of palliative care in Western Australia, in light of the End of Life Choices Joint Select Committee and Sustainable Health Review recommendations and the *WA End of Life and Palliative Care Strategy (2018–2028)*.

By the end of the Summit, the participants had:

- A greater understanding of the lived experience
- Understand the alignment across the current strategic environment for palliative care,
- Considered the priorities and next steps moving forward
- Built stronger networks and relationships
- Considered perspectives from interstate and international examples
- Discussed key Joint Select Committee recommendations and considered the Ministerial context and setting.

This Report captures the key outputs from the polling and workshop sessions.

Facilitation and reporting by Will Bessen of Tuna Blue Facilitation.



Executive Summary

The key themes from each workshopped recommendation are captured in this Executive Summary.

Recommendation 9

Independent review from a patient's perspective of the models of palliative care:

- Genuine co-design and co-production with communities at the local level from a blank sheet perspective (not just the three models)
- Consider regional and demographic differences; don't replicate metrocentric models of care
- Draw from best practice examples within WA, interstate and internationally
- Ensure access is proactive and equitable
- Flexibility is an important aspect of any future models
- Include spirituality and cultural safety.

Recommendation 11

Provide comprehensive, accessible and practical information and education services about palliative care to health professionals and the community.

Establish a palliative information and community hotline:

- Focus on the differing information needs of community, patients / families and staff audiences
- Build community awareness and literacy of palliative care and death to demystify the dying process
- Educate local GP's and clinicians on access options for palliative care, managing pain and aged care patients and complementary therapy advice
- Increase carer education, advocacy and psychosocial support
- Educate all providers in a networked and collaborative manner between primary, acute and residential care settings
- Ensure the hotline is integrated with local teams, website resources, the Telehealth Command Centre and 24/7 support for families
- Specific service provision and access improvements

Recommendation 12

Prioritise policy development and improved governance structures for the delivery of palliative care by WACHS:

- Define the model of care with more clarity, including early referrals to palliative care, risk assessments to include psychosocial, gaps between primary, hospital and specialist teams and greater incorporation of telehealth and HITH
- Remove barriers to timely care to enable nurse practitioners and generalists to provide support
- Continued collaboration and integration for the patient
- Ongoing palliative care education to communities, patients GP's and hospitals

- Better data standardisation and linkage to research and funding processes
- Know, support and recognise the local cultural practices within the community
- Provide 24/7 services to local communities, especially weekends
- Recognise and address staff burnout and turnover.

Recommendation 13

Ensure regional Palliative Care providers are adequately funded:

- Funding based on the unmet demand and strategic needs informed by data, money saving models of care and integrating care
- Care closer to home including specialised home care packages, home respite and community nursing
- Need for 7 days a week or 24/7 care options in all regions
- Linkages between regional staff and specialist WACHS teams
- Address staff burnout through adequate resourcing of services
- Support and upskilling for regional clinical staff
- Greater cultural awareness and security
- Increased access to technology solutions.

Process

The participants heard **opening talks** from:

- **Jeff Moffet**, Chief Executive WACHS
- **Hon Alanna Clohesy MLC**, Parliamentary Secretary to the Deputy Premier, Minister for Health and Mental Health.

A quick number of **polls** were conducted to engage participants in the content and test assumptions (see Polls section of this report).

The participants heard **presentations** from:

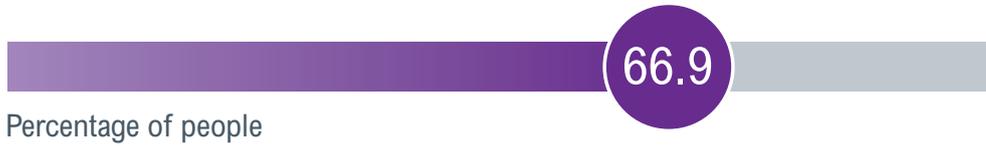
- **Kimika Lee**, regional perspective
- **Exmouth**, lived experience perspective
- **Brett Hayes**, regional snapshot
- **Kathy Eagar**, keynote presentation

A **workshop** session was held to unpack a number of key Joint Select Committee recommendations.

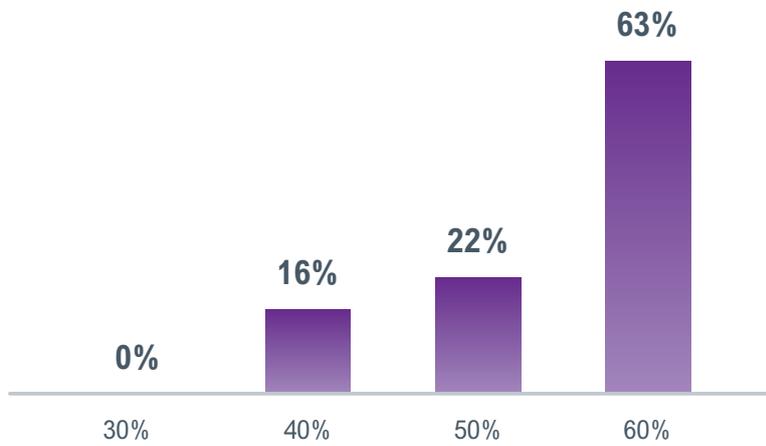
Polls

The following images capture the polls questions the participants completed.

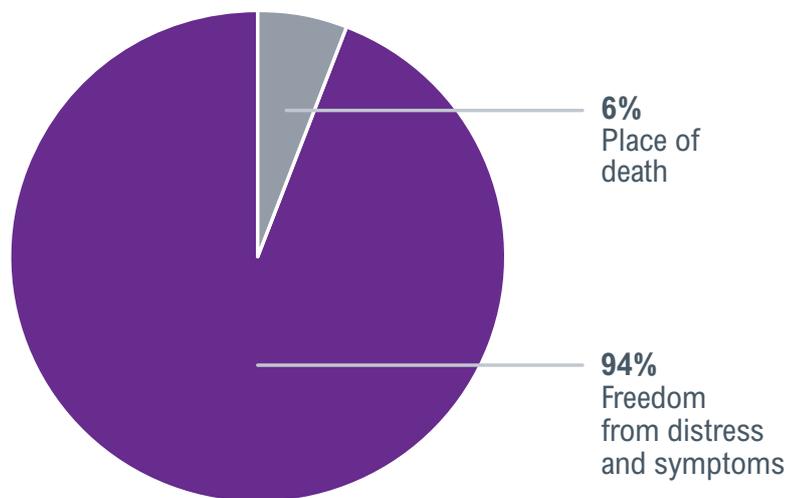
What percentage of people prefer to die in their own home?



What percentage of all deaths in Australia occur in hospitals?



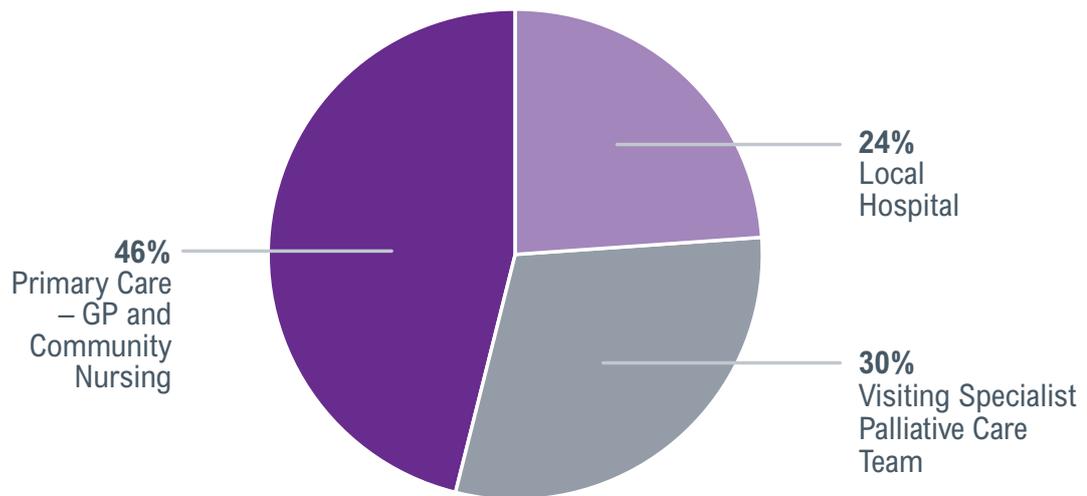
What is more important for dying patients and their families?



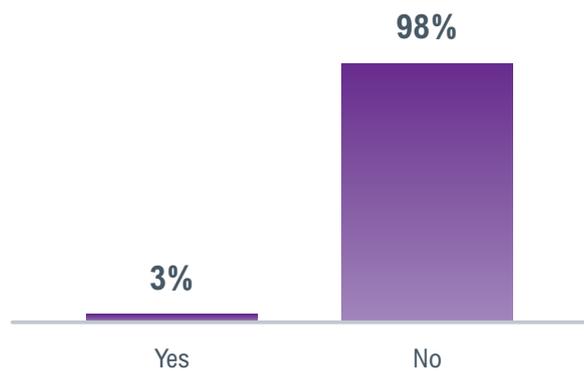
Of the people who could benefit from palliative care in Australia, what are the percentage that receive it?



Assign 100 points to how you think palliative care should be divided in regional WA



Palliative care is only available when you're in the last days of dying



Workshop

The participants considered four recommendations from the Joint Select Committee Report *My Life, My Choice*:

- **Rec 9** – Models of Care Review
- **Rec 11** – Information, Education and Hotline
- **Rec 12** – Policy and Governance Structures for WACHS
- **Rec 13** – Adequate Funding.

Recommendation 9

Independent review from a patient's perspective of the models of palliative care

- What are the benefits of the models of palliative care?
- What are the risks of the models of care?

The key themes are:

- Genuine co-design and co-production with communities at the local level from a blank sheet perspective (not just the three models)
- Consider regional and demographic differences; don't replicate metrocentric models of care
- Draw from best practice examples within WA, interstate and internationally
- Ensure access is proactive and equitable
- Flexibility is an important aspect of any future models
- Include spirituality and cultural safety.

The responses in detail are:

Genuine co-design and co-production with communities at the local level from a blank sheet perspective (not just the three models)

- What is the commitment to innovatively co-design and co-produce models of palliative care at a local level? The community have many of the answers that are required
- Risk if you don't involve the community in rural and regional, palliative care will fall down
- Consideration of models for the entire 'family unit' and not only the patient
- Are these the right three models? Surely there is a chance to start from a blank sheet and truly put people, not funding models at the centre
- Family/carer/unit perspective

Consider regional and demographic differences; don't replicate metrocentric models of care

- Each region's needs are quite diverse and it doesn't look the same
- The models are probably not detailed enough to capture the needs of rural communities and consumers
- Give some consideration to demographics e.g. age, living situation

- Must include what this also looks like from a rural hub and remote perspective which is quite different from metrocentric care
- Benefits include the community and regional model

Draw from best practice examples within WA, interstate and internationally

- What might innovation look like? There is a need to look at a broad base of international evidence and great examples from within rural work
- Access to culturally appropriate care, Medicare rebated access to traditional healers and bush medicine, as in South Australia
- We need to be considering the very exciting model that is currently operating in the Great Southern out of Albany using compassionate communities and communities of practice that are capacity building with primary care GP's
- Include Compassionate Communities family/community approach

Ensure access is proactive and equitable

- Need to look at strategic utilisation of new WACHS budget. New direction should not just be about adding new team members, it should really be considering sustainability and innovative practice
- How we deliver palliative care needs to dramatically change from a responsive model to a proactive model and the patients perspective must be central
- Equitable access to allied health across the three models
- Palliative care to be made available to all diseases.

Flexibility is an important aspect of any future models

- Flexibility to provide the care where it is needed
- What patients need to happen when preferences change
- Community care to be appropriately staffed in a flexible fashion
- Risk is the lack of continuity of care and sharing of information as a patient moves between the three models.

Include spirituality and cultural safety

- In the multidisciplinary team, what and how is the spirituality going to be provided
- Death and dying is a social/community event.
- Need to be inclusive of cultural safety.

Other comments

- Need a good model to support out of hours on-call care support across the state
- Flagging system for patients with a palliative care plan or EoL care plan to notify the team involved when they present to ED for symptom management issues 24/7
- How are we going to better look after the paediatric palliative care patient, they have very complex needs that in regional and rural country are very challenging
- Where and how does respite care fit in for the carers, can we do this better, can it be funded?
- How do we ensure the journey from in-hospital to community is smooth

- Limited access to equipment such as beds to enable and improve community care
- More staff on the ground
- Staffing and training
- Standardised approach to whatever model is implemented
- Timely fashion
- Formal and informal network of care.

Recommendation 11

Provide comprehensive, accessible and practical information and education services about palliative care to health professionals and the community

Establish a palliative information and community hotline

- What are the rural and remote training and education needs for end-of-life and palliative care?

The key themes are:

- Focus on the differing information needs of community, patients/families and staff audiences
- Build community awareness and literacy of palliative care and death to demystify the dying process
- Educate local GP's and clinicians on access options for palliative care, managing pain and aged care patients and complementary therapy advice
- Increase carer education, advocacy and psychosocial support
- Educate all providers in a networked and collaborative manner between primary, acute and residential care settings
- Ensure the hotline is integrated with local teams, website resources, the Telehealth Command Centre and 24/7 support for families
- Specific service provision and access improvements.

The responses in detail are:

Focus on the differing information needs of community, patients/families and staff audiences

- Enable better hotline support for three groups clinicians, patients and families and broader community support e.g. advance care planning
- Focus on the differing information needs of the community
- The understanding of what palliative care is, is still very misunderstood, this needs further education to the public and health professionals
- Palliative care education is mandatory across all levels of health provision

Build community awareness and literacy of palliative care and death to demystify the dying process

- Better information and support for community in understanding what palliative care services are available and what they provide
- Death cafes and death/dying demystification for people
- Community awareness and a national approach that could include schools
- www.mycommunitydirectory.com needs to be populated and used

- Health literacy education in community about when can palliative care be accessed and how?
- WACHS education resources and development capacity could be a useful resource for specifically contributing to education around issues of particular relevance and interest to rural communities and all interested rural clinicians. Ease of access to information about, and to e-learning programmes, from outside the WA Health intranet system would be essential.
- We ALL need death literacy
- Demystify the process of dying and the stages
- Understanding the dying process
- Enable greater choices for the patient.

Educate local GP's and clinicians on access options for palliative care, managing pain and aged care patients and complementary therapy advice

- Resourcing the mentoring and capacity building of local staff more formally
- Re-education of public and hospital staff towards early acceptance of palliative care services and how to talk about palliative care services to clients.
- Education of key clinicians (i.e. specialists) to enhance a timely referral to Palliative care during their treatment pathway
- How do we support the clinicians to access this
- Supporting aged care staff to better manage palliative patients
- Education and resources for GP's in rural areas re prescribing of medications
- Improved training opportunities for regional, remote and rural GP's palliative care
- Pain nurse education
- Ability to provide advice to complementary therapies (i.e. massage for patients and carers)
- Information on costs involved
- Encourage organisations to promote continuous education for their staff.

Increase carer education, advocacy and psychosocial support

- Carer education and advocates to communities
- Carer feedback
- Psychosocial advice for carers patients and staff
- Support for families
- Carer support education
- What education and resources are available to staff to share with family and for themselves to have the difficult conversations around palliative care.

Educate all providers in a networked and collaborative manner between primary, acute and residential care settings

- Regions have been working for a long time historically with the Network to develop and really embrace a vision for really statewide palliative care including modelling and service planning
- The need to consider the building of formal linkages between primary and acute care and residential care
- Interagency collaboration and education

- Engagement and partnerships between NGO's and AMS's to deliver culturally appropriate palliative care
- Potential to involve tertiary and other education institutions with acknowledged interest in rural health to contribute to development and provision of rural focussed palliative care education resources
- GP's, residential facilities and chronic disease coordinators all need to be death literate and enhanced by formal and informal networks of care
- How to keep communication consistent with a transient workforce
- Multidisciplinary support for all aspects of patient care team
- Care coordination between community carers and health services

Ensure the hotline is integrated with local teams, website resources, the Telehealth Command Centre and 24/7 support for families

- Is a hotline the best way to spend funding? What about a good website that is easily accessible and cheaper to run?
- Broader Knowledge to inform outside medical services in the community to refer to the hotline to empower the patient
- Hotline expansion... where does telehealth command centre fit into this model?
- 24/7 phone or VC support for family and carers to access as needed (also for Health Care Professionals)
- Contradiction between local team and hotline
- Could there be algorithms developed so that responses to questions are consistent and evidence based advice, similar to Health Direct
- Ability for this hotline to then populate the Commonwealth home support applications (i.e. My Aged Care and NDIS) and give information about the services.

Specific service provision and access improvements

- Review of role and responsibilities for regional palliative care nurse managers to ensure effective care coordination
- Increased funding for mobile respite care in the home
- Increased funding for respite centres to allow for carer support
- Availability of social workers
- Improve availability of palliative care education for rural and remote GP's
- Increased access and advice from the allied health team
- Increase volume and opportunity for staff to specialise in palliative care, including for AHW's, support staff and post graduate studies
- Difficulty being remote and having no Wi-Fi or telephone connection
- Broad range of clinical support
- Services that can be provided
- Eligibility to palliative care support.

Recommendation 12

Prioritise policy development and improved governance structures for the delivery of palliative care by WACHS

- What would you change with rural and remote palliative care governance?

The key themes are:

- Define the model of care with more clarity, including early referrals to palliative care, risk assessments to include psychosocial, gaps between primary, hospital and specialist teams and greater incorporation of telehealth and HITH
- Remove barriers to timely care to enable nurse practitioners and generalists to provide support
- Continued collaboration and integration for the patient
- Ongoing palliative care education to communities, patients GP's and hospitals
- Better data standardisation and linkage to research and funding processes
- Know, support and recognise the local cultural practices within the community
- Provide 24/7 services to local communities, especially weekends
- Recognise and address staff burnout and turnover.

The responses in detail are:

Define the model of care with more clarity, including early referrals to palliative care, risk assessments to include psychosocial, gaps between primary, hospital and specialist teams and greater incorporation of telehealth and HITH

- Defining what is the model of care
- Early referrals to the regional palliative specialists team
- Allow remote health services to provide nursing and medical support
- Explore direct admission to Hospice from Community/Home
- Greater acceptance of early referral to palliative care
- Development of risk assessment for complex palliative care to include psychosocial and medical similar to commonwealth maternity
- Practical support, equipment and access to social work via telehealth for psychosocial support
- Gap in the GP Model of Care vs WACHS Hospital guidelines and palliative care support for community based patients
- Review of the medical practitioner model; how can we utilise telehealth to increase service delivery in an innovative way while maintaining clinical governance
- As palliative advances and we are better equipped to provide the care in the home, how is policy going to recognise Hospital in the Home (HITH).

Remove barriers to timely care to enable nurse practitioners and generalists to provide support

- Take away WACHS barriers to providing end of life care (e.g. staff can't complete or sign Advanced Health Directives)
- Increase role of, or positions for, NP's in rural community settings to help access to prescription of medications

- Bread and butter palliative care is generalists
- Community nursing able to provide rapid response
- Community services from palliative nursing down to support workers.

Continued collaboration and integration for the patient

- WACHS should build upon the work commenced by the regions and the Network
- How to support primary and acute care better integrate and work seamlessly for patient
- Encourage collaboration
- Clear roles and responsibilities and accountability
- Greater links and partnerships with primary health and GPs.

Ongoing palliative care education to communities, patients GP's and hospitals

- Provide continued education to health services, GP's and carers
- Consumers need to be enabled to better inform service and funding models
- Greater education to staff about palliative care in regional hospitals. Perhaps funding of palliative care provider (e.g. GP or clinical nurse within regional hospitals)
- Provide community education on what is palliative care to remote and regional communities on the ground (be seen)
- PCOC and Care of Dying pathway and carers education already implemented statewide through WACHS.

Better data standardisation and linkage to research and funding processes

- Need more linkage of evaluation of programs with research
- Need to review the abundance of palliative care and aged care data
- Standardisation of data collection
- Wider use of the PCOC tool for all health care providers to know how we collaborate patient centred care.

Know, support and recognise the local cultural practices within the community

- Support local community
- Knowing the community
- Recognising local cultural practices for appropriate care.

Provide 24/7 services to local communities, especially weekends

- Increase in community services and increase in palliative hours
- Provide funding to implement 24-hour service to local communities
- Increase community services and increase in palliative hours (i.e. weekends).

Recognise and address staff burnout and turnover

- Increase the importance from the top in regards to compassion and self-care to reduce burnout in staff
- I believe staff turnover is an issue.

Recommendation 13

Ensure regional Palliative Care providers are adequately funded

- What do you think are the funding priorities for palliative care for regional palliative care?

The key messages are:

- Funding based on the unmet demand and strategic needs informed by data, money saving models of care and integrating care
- Care closer to home including specialised home care packages, home respite and community nursing
- Need for 7 days a week or 24/7 care options in all regions
- Linkages between regional staff and specialist WACHS teams
- Address staff burnout through adequate resourcing of services
- Support and upskilling for regional clinical staff
- Greater cultural awareness and security
- Increased access to technology solutions.

The detailed responses are:

Funding based on the unmet demand and strategic needs informed by data, money saving models of care and integrating care

- Need to understand the unmet demand and the need
- Better care coordination needs to be prioritised across each of the regions, we also need to consider more flexible approaches to care
- Which priorities for funding will make the greatest bang for buck, this really needs to be unpacked with clinicians that are currently doing the work
- Need for significant overhaul in governance across the state, regional and remote relies on the goodwill of clinicians which is not sustainable...
- Capturing the data to inform and influence future funding and strategy
- Not all about the spend, it is about better strategy
- Be mindful of the things that save money (e.g. models that reduce hospital admissions/ambulance transport)
- Evaluate funding options for repatriation options, in particular a service for providing flights home for patients with pain; can funding be allocated and managed via WACHS Link and regional teams to consider all factors in travel (pain, time, cost, patient position)
- Ongoing monitoring of where and how well palliative care services are provided will be important to ensure equitable access to services
- Recurrent funding to be secured for long term sustainability
- \$30M is a good start but not enough (there will still be large gaps in services)
- Needs to be funded in a way that crosses Federal and State boundaries
- Investment in ensuring rural and remote services are supported in capturing palliative care activity.

Care closer to home including specialised home care packages, home respite and community nursing

- Home respite
- Community nursing from the WACHS regional hospital
- Funding for Palliative Nurse Practitioners
- Mobile palliative care 'hospice truck' for rural and remote
- Improve services with nurse practitioners to enhance holistic specialised care given
- More resources for increased staff to provide care where patients want it
- Palliative care needs access to its own specialised home care packages (geographically diverse)
- To be able support early intervention and communication with Palliative Care patients and their carers
- Provision of community nursing (regional/remote)
- Increased money for physical resources (equipment etc.) to provide care in the home.

Need for 7 days a week or 24/7 care options in all regions

- Funding for specialist regional palliative care teams operating 7 days a week, not just Monday to Friday
- Funding for 24/7 care
- Funding to provide 24 hour support for all regions
- Increased capacity for on the ground staff members, with a focus on 24 hour service provision
- Ensure continuity of resources to fund 24 hour support across all areas of the region
- Requires ability to have 24/7 local support for patients and care givers.

Linkages between regional staff and specialist WACHS teams

- WACHS owned services to ensure flow of activity based funding back to the regions
- Regional palliative care teams have a link to a WACHS palliative care direct care team in the regional centres
- Palliative care referral at diagnosis/relapse in rural areas
- Targeted teams are needed to respond to in-home support throughout the region
- Increase collaboration with services.

Address staff burnout through adequate resourcing of services

- Palliative care needs to be recognised in the Award as a specialist health service in order to class Aboriginal Health Workers as Senior positions in this field. Current award provisions limit AHW to level 2
- Funding support needs to ensure that burnout is reduced with regional positions
- Improve funding to respite services across regional areas to assist prevention of burnout
- Palliative care needs to be recognised in the Award as a specialist health service in order to class Aboriginal Health Workers as Senior positions in this field. Current award provisions limit AHW to level 2
- Funding support needs to ensure that burnout is reduced with regional positions

Support and upskilling for regional clinical staff

- Upskilling and support for clinicians who care for palliative paediatric patients
- Support for clinical staff on the ward who may not have palliative care skills.

Greater cultural awareness and security

- Support for Indigenous patients and their cultural beliefs in the dying process. Also support and funding for Aboriginal health workers in this area
- More cultural awareness training face to face.

Increased access to technology solutions

- ETS palliative care available for all regional and remote areas
- Technology needs to be provided and funded adequately.

Other comments

- Access to air transport for terminal patients rather than a painful trip by road ambulance
- Bereavement support to be adequately funded
- Population health/public health and primary health funding, not just specialist services
- Funding for carer support and allied health (e.g. access to full time social worker in palliative care teams).

This document can be made available in alternative formats on request for a person with disability.

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