



Government of **Western Australia**
WA Country Health Service

WA Country Health Service Submission to the Joint Select Committee on Palliative Care in Western Australia

July 2020

Document Control

Version #	Version Date	Author(s)	Description
0.1	3 July 2020	Sinq Mndebele, Senior Project Officer, Palliative Care Program	Initial draft
0.2	6 July 2020	Steph Barrett, Program Manager, Palliative Care Program	Feedback provided
0.3	7 July 2020	Regional Feedback	Incorporated
0.4	9 July 2020	A/Prof Kirsten Auret, Clinical Director, Palliative Care Program	Reviewed
0.5	9 July 2020	Steph Barrett, Program Manager, Palliative Care Program	Reviewed
0.6	9 July 2020	Marie Norris, A/Executive Director of Nursing & Midwifery Services	Reviewed
0.7	10 July	Marg Denton, A/Chief Executive	Final Report

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Executive Summary

This submission addresses progress in the implementation of the recommendations made in the Joint Select Committee My Life, My Choice Report regarding palliative care for WA Country Health Service (WACHS). Of the 24 recommendations contained in the My Life, My Choice Report, two related specifically to Palliative Care and End of Life for WACHS, specifically recommendations 12 and 13:

- Recommendation 12 - The Minister for Health should prioritise policy development and improved governance structures for the delivery of palliative care by WA Country Health Services.
- Recommendation 13 - The Minister for Health should ensure regional palliative care be adequately funded to meet demand.

Through the 2019-2020 Budget, a total package for WACHS of \$39.7 million is provided over four years to support palliative care and end-of-life choices. This incorporates:

- \$30.2 million to expand delivery of community palliative care services in WA country;
- \$2.5 million committed to enhance clinical and program governance;
- \$2.0 million to fund community homecare packages for patients who have a potential risk of admission to hospital or residential aged care services; and
- \$5 million for the Carnarvon Aged Care facility - this additional funding supplements the existing provision of \$11.6 million to support a new 38 bed purpose-built facility.

Using this funding, a new program of palliative care is being developed in WACHS to complement current service delivery, expand provision of multidisciplinary care, develop policy and improve governance structures.

Through the program, established under the title "Palliative Care Program" (PCP), WACHS has made major steps forward in year one in progressing a comprehensive and complex rural and remote palliative care service in response to improving equity of access and end of life choices for regional Western Australians.

The regions have made significant improvements to their clinical palliative care teams in terms of expertise, including medical, social workers, clinical nurses, Aboriginal Health Workers (AHW) and a central program oversight and management is now in place.

Background

Palliative care improves the quality of life of people with life-limiting illness and their families through the prevention and relief of suffering. Palliative care recognises the person and the importance and uniqueness of their family and carers.

In WA, there is an inequity of access to quality palliative care services for rural and regional people with terminal and life-limiting illnesses. The burden of disease in rural and regional WA has implications for the provision of palliative care. People living in rural and regional areas generally experience poorer health with higher death rates.

The incidence of cancer in rural and regional WA is significantly higher than in metropolitan Perth. One in three country men and one in four country women in WA will have a cancer diagnosis before age 75. Mortality rates in rural and regional WA are significantly higher than the state average. Country Aboriginal women are 1.6 times and country Aboriginal men are 1.4 times more likely to die from cancer compared to women and men residing in Perth.

People living in rural and remote areas, in particular Aboriginal people, experience higher rates of chronic conditions such as diabetes, cardiovascular and chronic obstructive pulmonary disease than non-Aboriginal people and people living in cities. There is also a higher proportion of the elderly living in rural and regional WA with the projected population of people aged 65+ increasing by 3.5 per cent annually. Currently approximately 10 -15 paediatric palliative care patients are supported by the Perth Children's Hospital state-wide service in rural and remote WA.

Through the significant commitment by the Government, WACHS is dedicated to expanding services in rural and regional WA and providing care closer to home through improving and increasing community based palliative care services, provision of in-home palliative care support, developing and expanding innovative Telehealth services from the WACHS telehealth hub using high definition video consultation to support palliative care patients who wish to receive care at home and ensuring palliative care on-country visits are delivered including:

- The progress in relation to implementation of recommendations 12 and 13 of the Joint Select Committee into End of Life Choices; and
- The delivery of the services associated with palliative care funding announcements in 2019–2020.

Progress against JSC Recommendation 12

The Minister for Health should prioritise policy development and improved governance structures for the delivery of palliative care by WA Country Health Services.

Clinical and Program Governance

WACHS was requested to prioritise policy development and governance structures to support the delivery of palliative care services to regional and rural WA.

Appropriate governance requires that systems are in place to ensure patients receive consistent, safe, high quality healthcare. Good clinical governance requires well defined roles, responsibilities, accountabilities, reporting and decision-making lines, clear direction and leadership. Good clinical governance integrates with broader corporate governance and both are integral to the governing of WACHS.

The principles that support good clinical governance in WACHS Palliative Care services include:

- Care is centered on the patient and their family/carer;
- Relevant accurate information is available and used to guide care;
- There is a team of executive and clinical staff that have the right skills to provide safe high-quality care;
- Systems are in place to manage risks and minimise harm;
- There is visible and accountable leadership;
- There is a culture of openness, collaboration and continuous improvement;

- There are reliable processes to support clinicians to provide safe care;
- There is purposeful use of data to manage performance and drive improvements; and
- There are authentic consumer partnerships.

At the time of the last JSC into End of Life Choices, areas for improvement with WACHS Palliative Care governance included:

- Inadequate clinical staffing resource with the skill set and/or flexible working arrangements to provide care to palliative care patients that were more complex / who lived further away from main regional centres / who wanted care within their home;
- Inadequate access to palliative care medicine specialists to support care planning for complex patients in the regions;
- Inconsistent approach or absence of local palliative care governance committees that included relevant partner organisations and consumers or had a clear pathway for reporting safety and quality issues; and
- Absence of central program governance.

There have already been several improvements to governance processes, and these will be further developed and embedded over the life of the investment. Clinical expertise is supported by a Palliative Care Medical Director at central level (0.2 FTE) with Palliative Care Medical Specialists recruited to each region (0.1 – 0.2 FTE per region). In five regions, experienced General Practitioners have been employed on a pilot program to interface between their designated Palliative Care Medical Specialist and their respective Regional Nursing Coordinator, who is responsible for coordinating WACHS and external palliative care activities within their region.

Governance has also been enhanced by:

- The development of the PCP 'Plan' which represents a high-level synopsis of planning and stakeholder feedback to date. The Plan is guided by project management expertise and the WACHS Project Management Framework. Since commencing the PCP in July 2019, several iterations have been completed, testing the Plan for validity in terms of the current – future state, financial scenarios, stakeholder and change management planning, key dates, resourcing, priority activities and outputs, and program logic (benefits). The Plan acknowledges that requirements will continue to evolve and as such will continue to be captured, assessed and built into future updates where relevant.
- Clear alignment with national standards, the WA End of Life and Palliative Care Strategy 2018 – 2028 and the Sustainable Health Review – Strategy 3 Great Beginnings and a Dignified End of Life.
- Articulated accountability structure for Palliative Care in WACHS.
- Clarification of the roles and responsibilities of WACHS executive to the Palliative Care outcomes including:
 - The creation of a central PCP team to guide and drive the growth of regional palliative care services;
 - The appointment of a Clinical Director of Palliative Care;
 - Creation of a full-time Nurse Practitioner position to provide clinical leadership to regions and the program;
 - Creation of a full-time Palliative Care Aboriginal Health Coordinator to provide leadership to the regions and the program; and
 - Engagement by the central PCP team with regional leaders.
- Strengthened committee structure:
 - The formation of the PCP Project Control Group;
 - The promotion of regional Palliative Care steering committees (with consumer involvement) which are now functional, or soon to be functional, in all regions;
 - New regular meetings between the Clinical Director and the WA Cancer and Palliative Care network leads;
 - New regular meetings between the central PCP staff and the WA Cancer and Palliative Care network staff; and

- Inclusion in the wider WACHS Clinical Directors' Network, led by Executive Directors of Medical Services.

An important system that supports governance for palliative care is the data and outcome measures that are available from the Palliative Care Outcomes Collaboration (PCOC). This is a national program, based at the University of Wollongong and funded by the Australian government, that uses standard clinical assessment tools across all states in Australia to measure and benchmark patient outcomes in palliative care.

WACHS utilises ePalCIS in some of the regions, the approved statewide palliative care information system to electronically capture clinical assessments for palliative care patients. The five assessment tools are part of routine clinical care and are inclusive of the patient, family and carer. They include:

- Palliative Care Phase (stable, unstable, deteriorating or terminal);
- Resource Utilisation Groups Activates of Daily Living (measure of four key activities for daily living);
- Australia-modified Karnofsky Performance Status (measure of patient function);
- Palliative Care Problem Severity Score (clinician rating of problem severity in four domains); and
- Symptom Assessment Scale (for the seven most common experienced symptoms including pain, fatigue and breathing problems).

This information is then analysed by PCOC and reports are produced for WACHS which provide a six-month high-level profile of the patients that received care. These reports support WACHS to participate in continuous quality improvement activities with the goal of improving patient and family care outcomes as part of our quality improvement cycles. WACHS is committed to implementing the use of ePalCIS in all seven regions and has commenced a specialised education and rollout program as part of the PCP.

WACHS is developing a new suite of policies and guidelines to support the delivery of palliative care in the community and ensuring the compliance with WA Health and WACHS system-wide policies that include:

- WA Cancer & Palliative Care Network Evidence based clinical guidelines for adults in the terminal phase;
- MR723.1 State Care Plan for the Dying Person (CPDP) Community – Care Plan for the Dying Person;
- WACHS Medication Administration Policy;
- WACHS Working in Isolation – Minimum Safety and Security Standards for All Staff Policy;
- WACHS Recognising the Importance of Carers Policy;
- WACHS Medication Safety for Palliative Carers at Home Procedure - under revision;
- New WACHS Complex Medications in Palliative Care Guideline (in development);
- New WACHS Palliative Community Homecare Procedure (in development);
- New WACHS Goals of Patient Care (Adult) Guideline; and
- Production of palliative care models of care for COVID.

Work is in progress to develop an online WACHS palliative care “dashboard” to report clinical palliative care data and quality improvement and safety information, that will provide an improved approach to reporting palliative care service activity. The dashboard will help to identify quality issues, drive process improvement and support visibility of Palliative Care activity to WACHS Executive and Clinical / Program Management.

New quality improvement plans have been identified and are currently underway. “WACHS Community Palliative Care Clinical Documentation Audit” has been developed and currently being implemented. It is a community palliative care audit tool that assesses the standard and compliance of documentation of recorded clinical care as specified in the Community Clinical Palliative Care Practice Standards and Guidelines, to facilitate improved processes and governance around palliative care services.

Albany health campus in the Great Southern region has recently completed a “Quality of Dying Audit” as part of the 20 health centers that are participating in the National Health Roundtable. This audit reviewed physical care, symptom management and communication with the patient and family/carer. The focus was on the last 48 hours of life (or the whole admission if in hospital for less than 48 hours).

These audits and other quality improvement initiatives seek to improve quality of life and quality of death for palliative care patients and families/carers.

Other additional supportive governance work includes the development of the WACHS palliative care intranet site, supporting consumer feedback through 'Care Opinion' and a 'Good News/ Areas of Improvement Register'.

Progress against JSC Recommendation 13

The Minister for Health should ensure regional palliative care be adequately funded to meet demand.

WA Health has provided additional funding to WACHS over a four-year period to 30 June 2023 to expand and deliver palliative care services in the seven WACHS regions. The expanded program complements current service delivery to best fit the diverse geographic environment of rural and remote WA and improve equity of access to quality palliative care and end of life choices for regional Western Australians.

The pre-existing nurse-led palliative care services have been identified as key enablers of program activity and implementation. The nurse-led teams are now well-established and actively support palliative care service delivery within regions.

The Palliative Care Regional Coordinator is the central clinical services coordination and reference point for each region. The regional palliative care teams comprise clinical nurses, social workers, Aboriginal Health Workers, support staff and locally residing experienced general practitioners (in five regions). For more complex care management, palliative care physicians (Medical Consultants, fly or drive in and out) have been recruited to each region, reporting to their regional medical director and supported by the Palliative Care Clinical Director in WACHS. In the Southwest, palliative care physician support is provided through a service level agreement with St John Of God, Bunbury.

New Models of Palliative Care

Specialist District Based Multidisciplinary Teams

WACHS is undertaking a phased delivery approach across the four years for the PCP. Currently work is near completion on a comprehensive review of existing models of service delivery for palliative care across the regions, to analyse and determine the models of care that best support the needs of those patients with potential access challenges and ensure respect for regional differences.

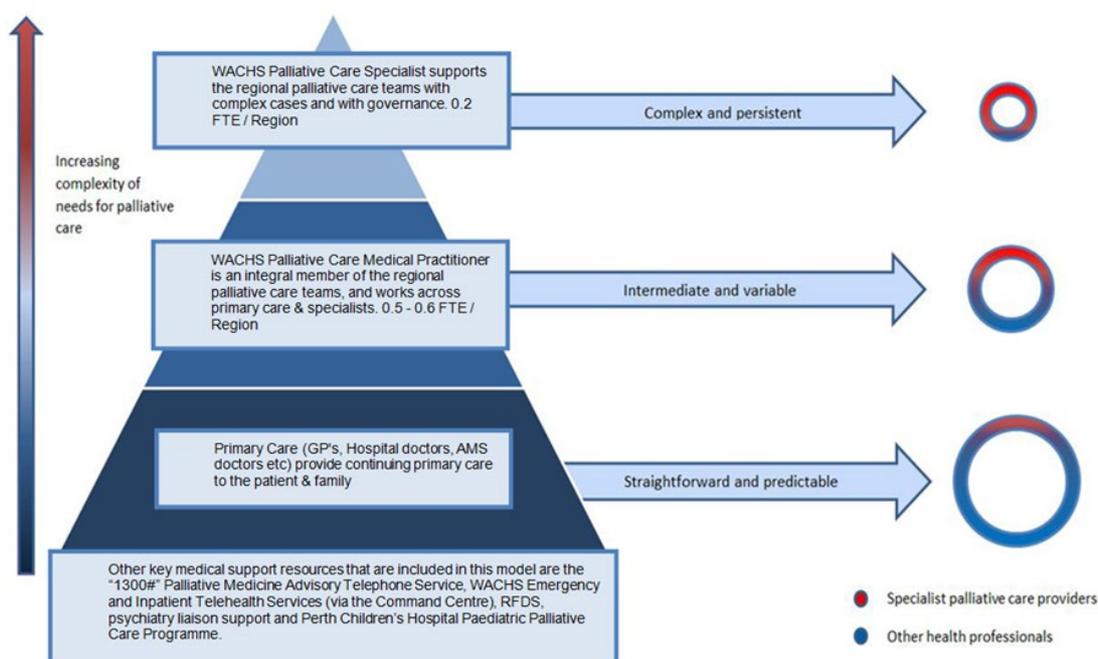
The model includes the development of nurse-led district-based multidisciplinary palliative care teams within each region, consisting of medical, nursing, allied health staff, Aboriginal Health Workers (AHW) and administration staff to deliver palliative care. The new model of care will be sustainable and culturally appropriate whilst continuing to support the provision of high-quality palliative care that responds to the physical, psychological, social and spiritual needs of patients and carers, promotes understanding of cultural sensitivity and empowers those based locally to give care closest to home.

Progress has been significant with all seven regions having access to multidisciplinary palliative care teams and 29.8 new FTE recruited in the year to 30/6/20.

Palliative Care Medical Workforce

WACHS has prioritised recruiting a palliative care medical workforce to develop capacity. A team of palliative care medical specialists support complex patient management and provide clinical support and guidance to the regional palliative care teams.

Whilst regions have now a dedicated palliative care medical specialist aligned to each region, they are part-time (0.2 FTE / region) and operate under a fly or drive-in / out model. To bridge the difference between metropolitan and regional on-the-ground access to medical specialists in palliative care, recruitment of locally residing General Practitioners (GPs) has been identified as a solution and also a way to increase capacity in the primary care workforce. A pilot team of GPs has now been recruited to work closely with their regional palliative care medical specialist and with the Clinical Director. All regional medical workforce report to their own Regional Medical Director.



The medical capacity currently in place to support regional palliative care is captured in the model illustrated above. The Pilbara experienced challenges in recruiting medical specialists and other clinical staff to this remote area of Western Australia. To improve access to palliative care services, Bethesda Healthcare has been contracted to provide an innovative support service for twelve months.

Aboriginal Health Workforce

The PCP's vision to improve access to quality palliative care for Aboriginal people is significant with a clear focus on:

- Developing and delivering culturally respectful and appropriate care for Aboriginal people and their families in their place of choice;
- Working collaboratively with Aboriginal Health Workers and services;
- Having a greater understanding of beliefs and values at end-of-life; and
- Collaborating with DoH on the developing Aboriginal End-of-Life and Palliative Care Framework.

The AHW is an important member to the multi-disciplinary palliative care team and this is supported by the expansion of the Palliative Care AHW position within the PCP from one to twelve and the development of inaugural WACHS Palliative Care Aboriginal Health Services Coordinator position. At the end of year one, all regions have appointed some FTE to the AHW position.

The PCP is partnering with PEPA (Program of Excellence in the palliative Care Approach) to develop a culturally sensitive orientation and education package in palliative care for AHWs and will be offered in October 2020 and will further explore opportunities to partner with the Aboriginal Health Council of Western Australia.

New and Expanded Digital and Telehealth Innovations

The use of innovative technology can connect patients and their family/carer to teams providing their care. The TelePalliative Care in the Home service is expanding to provide patients and their family/carer within the regions the opportunity to choose to access palliative care and support at home, to help patients remain at home longer. iPads have been procured and distributed to patients opting to receive care at home so that they can connect with palliative care staff through video conference. Currently operational in the Great Southern, Goldfields, Midwest, South West and Wheatbelt regions, planning has commenced for expansion of the service to the remaining two regions.

Expected benefits include reducing hospital admissions, increasing the ability for patients to remain within the home for as long as possible, improved confidence levels for carers in assisting patients to remain within the home, and increased contact with patients and carers during the terminal phase of life. An important developing addition to support the TelePalliative service is the “caring@home” resources. The caring@home resources are for community service providers, health care professionals and carers to provide support and help manage breakthrough symptoms safely using subcutaneous medicines. The PCP is reviewing and editing the resources to ensure compliance with WA Health and WACHS system-wide policies.

WACHS is progressing development of Telehealth services to provide coordinated central after-hours nursing support from the WACHS telehealth hub using high definition video consultation, ensuring regional healthcare staff, patients and their families/carers will have access to 24-hour nursing support for patients who wish to die at home. Planning has commenced with the pilot of the Telehealth Palliative Care Medical Officer position and support secured with WACHS Command Centre.

Delivery Community Based Homecare Services

In July 2018 the Home and Community Care (HACC) Program transitioned to the Commonwealth Home Support Program (CHSP). The CHSP Program does not provide access for patients under 65 to domiciliary care services. The current waiting times for Level two to four packages is up to 12 months. Palliative care and National Disability Insurance Service (NDIS) is a very complex area. NDIS maintain that palliative care is a health responsibility. They will fund supports related to disability but not to palliative care (including domiciliary supports).

Palliative care is an approach that improves the quality of life of individuals, their families and considers physical, social, financial, emotional, and spiritual distress. This includes respite care for the family (shopping, paying bills and to take some time for self-care), bedside care, medication assistance, showering, toileting, personal care, assistance with daily living, preparation of meals, cleaning domestic assistance.

The regions are identifying palliative care patients who are at risk of hospital or residential aged care admission because of a lack of domiciliary care services. By providing funding to receive domiciliary care services in a responsive timeframe patient, carers/family are supported to remain at home, 14 packages have been provided to date.

Carnarvon Residential Aged Care Facility

A \$5M capital contribution to the Carnarvon residential aged care facility supplements existing funding to support the new 38-bed facility and provide residential local palliative care options. The tender for the facility attached to the Carnarvon Health Campus has been awarded and construction is due to commence soon.

Innovative Partnerships

Bethesda Healthcare will provide a specialist palliative care service to the Pilbara region via an in-reach model of care. The service will consist of a Palliative Care Medical Specialist Team and a comprehensive program of assistance including building palliative care capacity for the region to provide quality care and the collection of data for Palliative Care Outcomes Collaboration (PCOC). The service provides the Pilbara region immediate access to experienced palliative care nursing and clinical specialists with an in-reach team visiting the region on a three-monthly basis.

Next Steps

- Appoint Palliative Care Nurse Practitioner / Clinical Nurse Consultant.
- Appoint Palliative Care Aboriginal Health Services Coordinator.
- Expand the multi-disciplinary palliative care teams to operate in multiple districts in each region.
- Expand the role of Specialist Palliative Care nurses to provide community care Monday to Sunday.
- Expand 7-day telehealth support after-hours (6pm to 8am).
- Increase the number of on-the-ground Palliative Care General Practitioners.

Regional Submissions to the JSC for Consideration

Kimberley

The Kimberley encompasses an area of 424,517 square km and is a complex landscape that represents one sixth of Western Australia's land mass. Culturally rich, approximately half of the population comprises Aboriginal people who live across its four Local Government Areas and over 150 Aboriginal Communities. The Kimberley region is remote and sparsely populated, with an estimated 36,000 residents in 2018.

Derby has a palliative care service delivered through the Derby Aboriginal Health Service with the option for WACHS to develop strong partnerships with local services and strengthen local teams, this is the preferred approach. Investment is required to provide adequate education and training based on a culturally safe approach to end of life care, this should be offered to all Palliative Care staff and other clinical staff in the Kimberley Health Service.

Consideration needs to be given to the smaller sites of Halls Creek and Fitzroy Crossing with flexibility within the model of care that would meet both the patient and the clinical staff availability as these areas have difficulty maintaining a stable clinical workforce. The option may be a visiting service as required however a better model would incorporate Aboriginal Health Workers who can work alongside Registered Nurses should that be required. In any event a team approach is required. Travel distances in the region to reach palliative care patients can be significant. Flights should be utilised between major centres to liberate time to provide clinical care and support palliative care services on the ground and included in the model going forward.

As the teams in the Kimberley are developing it has been identified there is a need to secure appropriate office and equipment storage accommodation particularly in locations such as Kununurra Halls Creek and Fitzroy Crossing.

Midwest

The Midwest covers 470 000 square kilometers and has an extremely diverse population. The Midwest health service consists of 17 health services inclusive of regional resource centre, multi-purpose sites and single nursing posts with varying clinical knowledge and expertise. The fractional FTE allocated to Palliative Care Medical Specialist and Senior Medical Officer will go part way to supporting the level of demand but will be challenged by geographical distance and dispersed populations. The requirement for increased Allied Health, in particular Social Work is also identified by the Midwest.

South West (SW)

The increase of palliative care funding has been warmly welcomed into the SW. The implementation of the funding has encountered some difficulty in the recruitment of suitably qualified and experienced clinicians particularly with the impact of COVID 19. An Aboriginal Health Worker has commenced. The SW service is well established, in comparison to other regional areas and staff have been seconded to other regions to assist them to establish their services.

Demand for allied health services (Social Work and Occupational Therapy) has been identified as one of the greatest areas of need. The increase of Social Work resource (recruited in January 2020) has resulted in an increased uptake of Advanced Health Directive (AHD) documentation across the region. Purchase of equipment has aided to fill equipment gaps and replace outdated stock. Storage of the extra equipment has proven difficult. It has been identified that there is no provision for palliative clinical pharmacy support, which could compliment the teams and aid to reduce hospital admissions.

The region has two Palliative Care Specialists who are well regarded and fully utilised across the region. It has been identified that greater palliative care training and awareness is required for general hospital staff. The recent appointment of a specific Motor Neurone Disease (MND) worker will improve the patient journey. Identified gaps in age appropriate residential options for patients with chronic degenerative diseases (i.e. Motor Neurone, Huntington's etc.) and who require intensive support continue to be housed in Residential Aged Care Facilities or move to Perth to access more appropriate support. Despite eligibility for NDIS, the timely access to intensive services remains a barrier.

SJOG Bunbury has agreed to expand access to their Palliative Care Ward (Granada) for children. A local Paediatrician will provide medical management of patients. A working party will be progressing this concept, including providing upskilling for Granada nursing staff.

Busselton and Bunbury now provide a permanent on-call nursing service at all times intended for unstable/terminal patients. Other sites within the region offer on-call to unstable patients as required.

Wheatbelt (WB)

The new funding has so far, within the Wheatbelt region, allowed a modest staffing increase with the most valuable being the addition of medical support to a previously nurse-led palliative care service. The Wheatbelt has seen an increase in nursing, social work, Aboriginal health, and medical workforce.

The Wheatbelt's looks forward to further investment to enable expansion of the teams, however still expect growing demand to outstrip resources.

Future sustainability requires further consideration of appropriate funding models.

Summary

WACHS has prioritised clinical and program governance and policy initiatives within the palliative care framework and has concentrated on the expansion of the district based multidisciplinary specialist teams with a total of 29.8 new FTE commencing in year one.

The new and expanded regional teams are further improving access and equity and bringing service provision closer to that provided to metropolitan consumers.

Consumer engagement efforts through roadshows and meetings is evolving. Engaging consumers has been instrumental in understanding palliative care service needs in the regions. An investigation of the impact of remoteness, aboriginality, population, death rate, disease burden and activity is currently being applied to guide future resource allocation and funding priorities.