Submission on the Terms of Reference Joint Select Committee on Palliative Care in Western Australia

WA Primary Health Alliance Submission

July 2020

WA Primary Health Alliance
Better health, together

phn
PERTH NORTH, PERTH SOUTH, COUNTRY WA
An Australian Government Initiative

1.Introduction

a) About Primary Health Networks

The Australian Government's Primary Health Network (PHN) program commenced from 1 July 2015 with the objective to increase the efficiency and effectiveness of medical services for patients, particularly those at risk of poor health outcomes, and to improve coordination of care to ensure patients receive the right care in the right place at the right time.

PHNs have four key roles:

- They engage with local communities to understand what primary health care services would make a difference, particularly for those at risk of poor health outcomes.
- They commission health services to meet the prioritised needs of people in their regions and address identified gaps in primary health care, to ensure community outcomes are achieved.
- Through practice support, they work closely with GPs and other primary health care professionals to continuously improve the care they provide.
- They work collaboratively within their regions to help to better integrate the local health system, and in doing so improve patient care and experience.

b) About WA Primary Health Alliance

As part of the Australian Government's PHN initiative, WA Primary Health Alliance (WAPHA) operates across the state to improve access to health care that is closer to home for those at risk of poor health outcomes. We do this by operating the state's three PHNs – Perth North, Perth South and Country Western Australia (WA). We are unique in that this coverage allows us to have a state-wide footprint.

Our mission is to shape, strengthen and sustain primary health care through partnerships and strategies that improve people's access and health outcomes. We believe a more connected health system will ultimately contribute to better individual and population health outcomes, including:

- Increased health equities;
- Fewer preventable deaths;
- Fewer preventable hospitalisations;
- Reduced health risks such as alcohol and drug use and overweight/obesity;
- More prevention behaviours such as immunisation and cancer screening;
- Better patient experience;
- Greater empowerment of individuals to manage their own health;
- More care delivered closer to home.

We invest over $140 million a year into the primary health care system in WA. As a state-wide agency, we work to systemically improve the quality and standard of primary health care across WA. Through our three PHNs, we support a population of over 2.5 million, and cover an area of almost 2.5 million square kilometres. We directly commission services, and support GPs and all primary health care workers to deliver targeted initiatives.

To achieve our mission, WAPHA's Strategic Plan 2020-23 commits us to the following strategies:

1. Commission services in a planned and targeted way

   We will think strategically and ensure each investment is focused on the needs and priorities of those communities and people who are experiencing the greatest barriers to accessing quality primary health care service.

2. Promote and prioritise an integrated health system

   We are committed to advancing the role of high quality primary health care within the wider health system.

3. Continuously improve primary care practice

   We will take a more inclusive approach to the coordination and delivery of primary care, including building deeper connections between GPs, pharmacists, nurse practitioners and allied health providers.

4. Empower people within our community

   We will help empower people across WA to be active participants in their own health and wellbeing and to capitalise on the investment called on by the Sustainable Health Review.

The 31 PHNs across the national PHN Program, including WAPHA, are supported by a Program Performance and Quality Framework that provides a structure for monitoring and assessing PHNs' individual performance and progress towards achieving outcomes. It contains indicators that measure performance across the seven priority areas for the PHN Program. These are:

- Mental Health
- Aboriginal and Torres Strait Islander Health
- Population Health
- Workforce
- Digital Health
- Aged Care
- Alcohol and Other Drugs

2. WAPHA activities related to Palliative Care

WAPHA is committed to improving access to palliative care in Western Australia and is of the view that everyone living with a life limiting illness should have equitable and timely access to evidence based palliative care, including end of life care, based on need.

The majority of WAPHA's activity related to palliative care falls within its priority areas of Aged Care. Our work includes involvement in projects that promote the uptake of Advanced Care Planning (ACP), seek to improve awareness of palliative care options and end-of-life choices, and improve co-ordination, management and support for people with chronic and life limiting conditions[1].

A summary of WAPHA's strategic engagement with key partners and investment in programs and services relating to palliative care is provided below:

- WAPHA membership of the **Voluntary Assisted Dying Implementation Leadership**

[1] Health Care Homes The Department of Health. Available at: http://www.health.gov.au/internet/main/publishing.nsf/Content/health-care-homes

Taskforce, providing primary care input and advice relating to Voluntary Assisted Dying (VAD) and its important linkages to End of Life Care.

- WAPHA membership of the **Voluntary Assisted Dying Implementation Project** that has formal oversight through an internal WA Department of Health Steering Committee, the End of Life Care Projects Steering Committee. This steering committee also oversees the Palliative Care and Advanced Health Directives (AHD) project work.

- WAPHA membership of the **End of Life Palliative Care Advisory Committee** that provides operational support to implement and communicate initiatives in the areas of Advance Care Planning, End of Life Choices and Palliative Care and Voluntary Assisted Dying including progressing the WA End-of-life and Palliative Care Strategy 2018-2018.

- Delivery of the **Advance Project.** WAPHA, in conjunction with Hammond Care, support practice nurses, practice managers and general practitioners (GPs) initiate ACP and palliative care in everyday general practice. This Commonwealth funded project uses a free, evidence-based toolkit and training package to initiate ACP conversations and assess patients' and carers' palliative and supportive care needs.

- Collaboratively developing and updating **HealthPathways WA** specific Palliative Care pathways to help clinicians easily navigate their patients through the complex primary, community and acute healthcare system. HealthPathways is an enabler that increases capacity across the primary, secondary and tertiary health sectors related to end-of-life and specialist palliative care management and appropriate referral pathways with GPs, practice nurses and allied health professionals.

- Commissioning **psychological treatment for people with mental illness living in Residential Aged Care Facilities (RACFs)** to enable residents of RACFs with mental illness to access psychological treatment services similar to those available in the community through the Medicare Benefit Scheme Better Access. Evidence based psychological treatment is accessed by GP referral and provided by registered and clinical psychologists onsite in the RACFs. This is being rolled out on a planned phased basis and will be accessible to all RACFs across WA by 2022. RACF residents engaged with the Metropolitan Palliative Care Consultancy Services are now able to access psychological treatment through this initiative if it is appropriate to meet their needs.

- Establishing **Greater Choice at Home Palliative Care Compassionate Communities** project in Country WA PHN (City of Albany, Great Southern Region) to start and shape conversations around dying, death and loss to improve end-of-life care, support and experience. The project works with aged care services and communities to improve the early uptake of ACP and to improve awareness of palliative care options and choices. There is also work being undertaken to develop a palliative care roadmap for the South West Region of Country WA.

- WAPHA has commissioned Chorus to pilot a program aimed at **increasing social connectedness for older Australians** residing in Perth South PHN who are experiencing isolation and loneliness. This program, coordinated by the Australian College of Mental Health Nurses, works with general practices within the Mandurah region to identify eligible clients for referral into the program.

- Supporting **Comprehensive Primary Care, Integrated Team Care and GP Shared Care** arrangements help improve the lives of all Western Australians access quality palliative and end-of-life care. In addition, the Perth North PHN is an implementation site for the Commonwealth's Health Care Homes initiative to provide Australians with improved co-ordination, management and support for their chronic conditions[2].

[2] Health Care Homes The Department of Health. Available at: http://www.health.gov.au/internet/main/publishing.nsf/Content/health-care-homes

- Training for GPs promoting the **Palliative Care Approach** and work with Palliative Care WA and the Cancer Council to provide Advance Care Planning Workshops. In addition, WAPHA has provided funding for a regional GP studying part-time towards a Clinical Diploma of Palliative Medicine provided through the Rural Clinical School of WA within The University of Western Australia and awarded through RACGP.

- WAPHA has commissioned the **Tackling Barriers to increase access to Aged Care Assessment and early Advanced Care Planning** project which aims to improve access to integrated assessment services for older people with complex needs. Activity includes:

  - identification of real and perceived barriers to aged care assessment
  - identifying ways to better integrate complex care across the continuum
  - exploring ways to increase access to Advanced Care Planning (inclusive of Goals of Patient Care).

3. WAPHA's Submission to the Joint Select Committee on Palliative Care in Western Australia

WAPHA welcomes the work of the Joint select Committee on Palliative care in Western Australia which will address:

(a) The progress in relation to palliative care in particular the recommendations of the Joint Select Committee into End of Life Choices;

(b) The delivery of services associated with palliative care funding announcements in 2019-2020;

(c) The delivery of palliative care into regional and remote areas; and

(d) The progress on ensuring greater equity of access to palliative care between metropolitan and regional areas.

WAPHA is in favour of the Terms of Reference, and is particularly pleased to see inclusion of items c) The delivery of palliative care into regional and remote areas; and d) The progress on ensuring greater equity of access to palliative care between metropolitan and regional areas.

We acknowledge that progress has been made since the publication of *MY LIFE, MY CHOICE The Report of the Joint Select Committee* (The Select Committee Report) in August 2018. WAPHA notes that palliative care was the single biggest issue examined during the inquiry and that discussion tends to focus on voluntary assisted dying and end of life issues.

WAPHA supports the development of the WA End-of-life and Palliative Care Strategy 2018-2028 and the recent release of the Strategy's Implementation Plan One (2020-2022) (IP1). WAPHA provided a submission on development of the Strategy in December 2017 supporting the Strategy's focus on patient centred care; incorporating patients and families in co-designing care with health teams; the strengthening of referral pathways between end-of-life and specialist care teams; increasing the capacity of the generalist healthcare workforce; and improving practical advice and support for families, and community awareness.

In July 2020, WAPHA attended a consultation convened by Palliative Care WA (PCWA) to inform development of PCWA's submission to the Joint Select Committee. The focus of discussion was on consumers and carers, advanced care planning and advanced health directives.

WAPHA is pleased to provide its own submission, which includes particular emphasis on the role of primary care in palliative care and support for progress to be made in ensuring greater equity of access to palliative care between metropolitan and regional areas.

a) Role of General Practice in Palliative Care

WAPHA notes that the Joint Select Committee Report into End of Life Choices makes limited reference to the role of general practice and the wider primary care team in palliative care. In addition, the
WA Government's 2019-2020 announcement of palliative care funding and service delivery does not make specific reference to general practice.

GPs and other primary health practitioners are a vital part of the integrated continuum of care – playing a significant role in palliative care across community, transition care, acute care and designated inpatient care settings. WAPHA believes strongly in an integrated health care system with capacity to deliver person-centred, best practice care and is committed to driving a collective focus on delivering care in the most appropriate setting through formalised, cohesive relationships across the system and encouraging the use of multi-disciplinary teams.

As part of the Inquiry, WAPHA recommends the Joint Select Committee further consider:

- The role of general practice in improving access to palliative care;
- The role of the broader primary health care workforce in palliative care which includes pharmacists, nurse practitioners, Aboriginal health workers and other allied health providers in addition to GPs;
- How general practice and other primary health care providers can be equipped and enabled to provide good quality palliative and end-of-life care no matter where they are located across WA.

The Royal College of General Practitioners (RACGP) Aged Care Clinical Guide (Silver Book)[3] describes palliative care as 'a fundamental component of general practice'. General practice can and should play an increasingly important role in delivering services in the community that positively contribute to the quality-of-life for patients and their families approaching end-of-life.

Studies indicate that 60-70% of Australian's wish to die at home[4] and that community-based local approaches to end-of-life care are often preferred, particularly by Aboriginal people. GPs, along with other primary care providers are an integral part of supporting this wish, however require the skills, linkages and, importantly, the confidence to do so effectively.

Knowledge about end-of-life care and specialist palliative care across the GP workforce is variable and there is significant scope to improve capability. Recent studies have shown that Australian GPs have identified a lack of confidence in providing palliative care in general practice[5]. Common reasons for this included patient complexity, inadequate training, insufficient resources, lack of experience or knowledge, inability to provide 24-hour care, and lack of information or poor communication and links between healthcare providers and specialist palliative care services[6].

These findings mirror previous national and international findings and point to an opportunity to improve access to quality care. In addition, some GPs have expressed concern related to the medico-legal implications of palliative care, potentially limiting their engagement with education and training that could improve the quality of end-of-life care they provide for their patients.

[3] https://www.racgp.org.au/getattachment/55aea74c-fbe9-4d01-8cbc-425948225cb8/Palliative-care.aspx
[4] Foreman LM, Hunt RW, Luke CG, Roder DM. Factors predictive of preferred place of death in the general population of South Australia. Palliat Med 2006; 20: 447-453.
[5] https://www.racgp.org.au/afp/2017/januaryfebruary/palliative-care-in-general-practice-gp-integration-in-caring-for-patients-with-advanced-cancer/
[6] Le et al AFP vol. 46 No 1-2 Jan-Feb 2017

A significant role for PHNs is to empower and support GPs and other primary care providers and WAPHA does this by:

- improving linkages between primary health care professionals (GPs, practices nurses, Residential Aged Care staff, Aboriginal health workers) and both community and inpatient palliative care services;
- co-ordinating access to resources for primary health care providers regarding palliative care services; and
- co-ordinating access to quality palliative care education for health care professionals.

Data on the extent to which palliative care-related services are delivered by GPs is difficult to establish from existing MBS data as currently there are no specific palliative care items that can be used by GPs or other medical specialists who may be providing palliative care (such as oncologists). It is likely that GPs use other MBS items, for example, those for chronic disease management and home visit items, when providing patients with palliative care[7].

Given the absence of dedicated MBS items, GP remuneration for palliative and end-of-life care can be challenging. Furthermore, several of the key activities known to contribute to effective end-of-life care do not attract a payment within the MBS, such as service co-ordination, family consultations, consultations with practice nurses, and case conferences. Alternative funding models to address this gap require consideration as a lever to increase the level of support available via general practice.

Consistent with the intent of Recommendation 10 of the Joint Select Committee Report on End of Life Choices, *MY LIFE, MY CHOICE* further consideration should be given to the completion of an in-depth exploration of the barriers and enablers for WA GPs to deliver high quality palliative care across the State and WAPHA is well place to assist with this.

b)Advance Care Planning and Advanced Health Directives

WAPHA notes the lack of progress towards implementing Recommendation 5 of *MY LIFE, MY CHOICE* relating to a Medicare rebate for the preparation of ACPs or AHDs with GPs and requests that the Joint Select Committee inquiry reaffirms their commitment to supporting amendments to the MBS.

WAPHA is committed to encouraging general practice and primary care to use ACP as a tool to improve the quality of care provided to their patients. ACP is a concept that is often raised in the context of annual health assessments, chronic disease management plans or as part of the ongoing care of older patients by general practice. However, at present there are no separate MBS item numbers for the preparation of ACPs or AHDs.

As noted by the RACGP[8], ACP is a process of reflection, discussion and communication that enables a person to plan for their future medical treatment and other care, for a time when they are not competent to make, or communicate, decisions for themselves. Although often about end-of-life care (the last 12 months) or terminal care (the last days to weeks of life), ACP is a process that all patients, and especially those who are at risk of deterioration in health, can benefit from. ACPs will often lead to the completion of an ACD.

Consistent with Recommendations 1 and 2 from the Joint Select Committee Report *MY LIFE, MY CHOICE* some progress has been made with WAPHA's Advance Project, a practical, evidence-based toolkit and a training package, specifically designed to support Australian general practices to implement a team-based approach to initiating ACP and palliative care into everyday clinical practice.

[7] https://www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/contents/palliative-care-in-general-practice
[8] https://www.racgp.org.au/running-a-practice/practice-resources/practice-tools/advance-care-planning

However, there remain real challenges around health professionals and community understanding of ACPs, AHDs, enduring powers of guardianship, ACPs and goals of patient care, and around how ACPs and AHDs are documented, stored and enacted. WAPHA is hopeful that the Joint Select Committee can explore in more detail opportunities to provide greater clarity for health professionals, consumers and the community more broadly.

c) Equity, access and integration across metropolitan and regional areas

Consistent with Recommendations 11, 12 and 13 from Joint Select Committee Report *MY LIFE, MY CHOICE* WAPHA supports specific consideration being given to how better and more equitable palliative care services for people can be provided. WAPHA is pleased that the Joint Select Committee will focus on those residing in regional, rural and remote parts of WA and would encourage that the Inquiry continue to look at ways to ensure that culturally relevant requirements are addressed and preferences of patients, their families and the communities are considered.

WA is a leader in palliative care outcomes with around 70% of Western Australians who receive community based palliative care able to die at home. This is higher than the national average where only 14% of the 70% of Australians who want to die at home are able to do so[9].

Although WA is nationally renowned for its home-based palliative care service, this is a service that has only been historically provided in full in the metropolitan Perth area. WA has the lowest number of in-patient beds per capita and access to specialist end-of-life and palliative care – across inpatient, consultative and community services – is limited across the state, particularly in regional and rural areas.

Furthermore, the availability of culturally appropriate services close to home for Aboriginal people is particularly limited. Aboriginal and Torres Strait Islander peoples are generally underrepresented in the palliative and end-of-life care patient population[10] and a report from the Palliative Care Outcomes collaboration[11] found that only 1.4% of Aboriginal and Torres Strait Islander people accessed specialist palliative care services.

Quality care at the end of life is realised when it is culturally appropriate to the particular needs of individuals and groups. The consequences of culturally inappropriate care can include psychological distress and unnecessary suffering for patients, their families and carers[12]. Feedback from a WAPHA stakeholder workshop with Aboriginal women in the Kimberley suggested that very few Aboriginal people actually die on country due to lack of access to services and it often becomes challenging for families and carers to cope. Participants spoke of patient's rights and wishes to remain at home; the complexities of allowing for this to happen in a remote setting; and the support required to keep people mentally, emotionally and physically healthy and resourced to care for people during this stage of life.

WAPHA supports consideration of opportunities to expand the Aboriginal health workforce and the engagement of Aboriginal people in the design of appropriate palliative and end-of-life care options for local communities.

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[9] H. Swerissen and S. Duckett (2015) "Dying Well", Grattan Institute.

[10] K Sullivan, L Johnston, C Colyer, J Beale, J Willis, J Harrison & K Welsh, National Indigenous palliative care needs study: final report, Prepared for the Australian Government Department of Health and Ageing, Canberra, 2003.

[11] Palliative Care Outcomes collaboration. (2018). *Patient outcomes in palliative care: national report July-December 2017*. Wollongong, NSW: Palliative Care Outcomes collaboration.

[12] https://palliativecare.org.au/wp-content/uploads/2015/08/PCA-Palliative-care-and-Indigenous-Australians-position-statement-updated-16-8-11.pdf

In response to workforce shortages and the maldistribution of primary care practitioners across WA, WAPHA works collaboratively with key partners and stakeholders across the primary care sector to develop models of care that seek to overcome service gaps through the use of technology and multidisciplinary approaches. Given its state-wide footprint, WAPHA is well placed to contribute to the design of potential solutions for regional and remote areas.

As part of WAPHA's work in developing a South West WA Palliative Care Strategy and Roadmap there was strong consensus on what constitutes good palliative care service design – person centered care, accessibility, evidence base and information sharing, multiple levels of care, early planning and the importance of family, carers and the community. This development of this strategy was an outcome of the Compassionate Communities Program in the Great Southern region and identified key barriers to accessing good palliative care. These included a lack of community understanding of what palliative care is and how to access it. Stakeholders also reported limited access to services and supports for:

- patients aged under 65
- patients based outside of the Bunbury area
- patients with non-cancer diagnoses
- Aboriginal patients who require culturally secure service delivery.

The Joint Select Committee may wish to examine the draft South West WA Palliative Care Strategy and Roadmap component of the Compassionate Communities Program as exemplar model of improving community and health professional understanding of palliative care and how WAPHA is working with WA Country Health Service to collaborate and improve access to and the quality of palliative care services in regional areas.

WAPHA appreciates consideration of our submission. If you wish to discuss anything in more detail, contact Chris Kane General Manager Strategy and Engagement via email chris.kane@wapha.org.au.