

40TH PARLIAMENT



PALLIATIVE CARE IN WESTERN AUSTRALIA— PROGRESS REPORT

*Final Report of the Joint Select Committee on Palliative Care in
Western Australia*

Presented by

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and

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November 2020

Joint Select Committee on Palliative Care in Western Australia

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Government response

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The two-month period commences on the date of tabling.

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EXECUTIVE SUMMARY

- 1 The Joint Select Committee on Palliative Care in Western Australia (Committee) was established on 28 May 2020 to inquire into and report on:
 - (a) the progress in relation to palliative care, in particular implementation of recommendations of the Joint Select Committee into End of Life Choices;
 - (b) the delivery of the 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 services between metropolitan and regional areas.¹
- 2 The proposal to establish a joint select committee into palliative care arose during debate on the Voluntary Assisted Dying Bill 2019 in December 2019,² following the report of the Joint Select Committee on End of Life Choices (JSCEOLC) in August 2018, in which the JSCEOLC made a number of findings and recommendations about palliative care.³
- 3 The Committee's terms of reference necessitated a broad inquiry into the delivery of palliative care services throughout Western Australia.
- 4 Witnesses to the inquiry included the Department of Health and WA Country Health Service (WACHS), palliative care service providers, medical practitioners, volunteer organisations, aged care providers, and advocacy groups and peak bodies representing health consumers, service providers, medical practitioners and primary care workers.

Inquiry under terms of reference (a) and (b)

Issues relating to the progress of palliative care generally

- 5 In addition to addressing the implementation of the recommendations of the JSCEOLC, evidence received by the Committee raised a number of important issues in relation to the progress of palliative care service delivery, some of which were not addressed specifically by the JSCEOLC. Chapter 4 of this report sets out the evidence received by the Committee on these issues, together with associated findings and recommendations.

Implementation of the recommendations of the Joint Select Committee on End of Life Choices

- 6 Progress was noted to varying degrees on the implementation of the recommendations of the JSCEOLC.
- 7 The Committee found that implementation of the following recommendations had significantly progressed:
 - JSCEOLC recommendation 7 (the Minister for Health facilitate the establishment of an inpatient specialist palliative care hospice in the northern suburbs of Perth)

¹ Western Australia, Legislative Assembly, *Parliamentary Debates (Hansard)*, 20 May 2020, pp 2948–51; Western Australia, Legislative Council, *Parliamentary Debates (Hansard)*, 21 May 2020, pp 3047–48; Western Australia, Legislative Assembly, *Parliamentary Debates (Hansard)*, 28 May 2020, pp 3360–1.

² Hon Stephen Dawson MLC, Minister for Environment, Western Australia, Legislative Council, *Parliamentary Debates (Hansard)*, 4 December 2019, pp 9850–9852.

³ Western Australia, Legislative Assembly and Legislative Council, Joint Select Committee on End of Life Choices, report 1, *My Life, My Choice*, 23 August 2018, findings 9–28 and recommendations 7–18, pp xxxiii–xxxvii.

- JSCEOLC recommendation 9 (WA Health conduct an independent review, from a patient’s perspective, of the three models of palliative care in Western Australia)
 - JSCEOLC recommendation 11 (WA Health undertake specified measures to improve understanding of palliative care)
 - JSCEOLC recommendation 12 (policy development and improved governance structures for the delivery of palliative care by WACHS be prioritised)
 - JSCEOLC recommendation 18 (WA Health provide specific guidelines on the use of terminal sedation by health professionals for patients at the end of life).
- 8 The Committee found that there has been preliminary progress in relation to JSCEOLC recommendations 15–17 regarding ongoing professional development for health professionals about end-of-life treatment and decision-making.
- 9 The Committee received evidence that JSCEOLC recommendation 10 (WA Health implement a process to determine the unmet demand for palliative care and establish an ongoing process to measure the delivery of palliative care services) would not be progressed and instead that WA Health had determined to establish a process to determine unmet need for palliative care. The Committee found that this was appropriate.
- 10 Limited progress was noted in relation to JSCEOLC recommendation 8 (the Minister for Health ensure that community palliative care providers are adequately funded to provide for growing demand).
- 11 The progress of implementation of JSCEOLC recommendation 13 (the Minister for Health ensure regional palliative care be adequately funded to meet demand) could not be evaluated without a more detailed assessment of demand for palliative care services in regional and remote areas.
- 12 The Committee received evidence that JSCEOLC recommendation 14 (the Minister for Health appoint an independent reviewer to audit palliative care activity and spending by WA Health) will not be progressed.
- 13 The Committee’s consideration, under term of reference (b), of the delivery of services associated with palliative care funding announcements in 2019–20 overlapped to an extent with its consideration of the implementation of the recommendations of the JSCEOLC under term of reference (a). However, terms of reference (a) and (b) are discussed in separate Chapters of the report, as there were also many areas where the two terms of reference did not overlap.

Inquiry under terms of reference (c) and (d)

- 14 The Committee’s inquiry into service delivery in regional and remote areas was limited to some degree by its short reporting timeframe and restrictions imposed in response to the COVID-19 pandemic. Nonetheless, the Committee was able to receive a significant amount of evidence from a wide variety of sources and make some substantial findings and recommendations about the current state of palliative care services in regional and remote Western Australia.
- 15 Evidence was heard from regional and remote witnesses based in Albany, Newman, Busselton, Chittering, Northam, Kununurra, Derby, Broome, Geraldton and Kalgoorlie.
- 16 The Committee found that substantial progress has been made in the expansion of the WACHS multidisciplinary specialist palliative care teams, and in the improved governance structures within WACHS pursuant to recommendation 12 of the JSCEOLC. However, as noted above, the Committee was not able to evaluate the progress of implementation of

recommendation 13 without more detailed information as to the demand for palliative care services in regional and remote areas.

- 17 In its consideration of term of reference (d) (the progress on ensuring greater equity of access to palliative care services between metropolitan and regional areas) the Committee found that there had been substantial progress, particularly in improved governance within WACHS and expansion of the WACHS district-based multidisciplinary teams. The Committee noted that community palliative care services in particular remain less accessible to patients living in regional and remote areas.

Findings and recommendations

Findings and recommendations are grouped as they appear in the text at the page number indicated:

FINDING 1

Page 21

Western Australia has a 10-year palliative care strategy, which commenced in 2018.

FINDING 2

Page 21

Plans to implement the *WA End-of-Life and Palliative Care Strategy 2018–2028* vary between agencies and range from a 10-year Implementation Plan by South Metropolitan Health Service, a 5-year plan by East Metropolitan Health Service, a 3-year plan by the Department of Health, a yet-to-be complete plan by North Metropolitan Health Service and no publicly available plan by WA Country Health Service.

FINDING 3

Page 23

Whilst palliative care in Western Australia has historically been provided through three models of care, the Department of Health now recognises five models of care: Hospital—Inpatient, Hospital—Consultancy, Hospital—Outpatient, Consultative, and Community.

FINDING 4

Page 35

Residential aged care facilities are accurately characterised as settings for palliative care, not palliative care services.

FINDING 5

Page 36

There is a paucity of data quantifying the number of aged care residents requiring and/or receiving palliative care in Western Australia.

FINDING 6

Page 38

There is a paucity of data quantifying the level of involvement of general practitioners in palliative care.

FINDING 7

Page 42

Volunteers play a valuable but unquantified role in the provision of palliative care services in Western Australia.

FINDING 8

Page 44

- a) The Electronic Palliative Care Information System (ePalCIS) is a specialised palliative care data collection system in use in around 19 sites in Western Australia.
- b) The rollout of ePalCIS ceased in 2017 due to budget constraints.
- c) A subsequent investigation into the current use of ePalCIS has resulted in a recommendation for its increased rollout and use, to enable all hospital sites to accurately record palliative care activity and be funded accordingly.

FINDING 9

Page 46

The palliative care system is fragmented and its navigation is a challenge for patients.

FINDING 10

Page 47

There is a need to assess the interaction between the existing models of care and the concept of person-centred care. It remains to be seen if this will be achieved by the independent review resulting from recommendation 9 of the Joint Select Committee on End of Life Choices.

FINDING 11

Page 49

The cooperative planning and seamless transition (from a patient's perspective) between palliative care services remains a key aspiration amongst stakeholders.

RECOMMENDATION 1

Page 50

The Minister for Health facilitate the removal of administrative barriers to the smooth transition of patients between palliative care service providers.

FINDING 12

Page 50

There are gaps in the care of regional and remote palliative care patients caused by fragmentation of care and poor communication between service providers.

RECOMMENDATION 2

Page 51

The Minister for Health facilitate and monitor an improved communication protocol, and if necessary an improved communication pathway, between medical practitioners and specialist palliative care services.

FINDING 13

Page 53

- a) A system of palliative care navigators would be a welcome and valuable addition to Western Australia's palliative care services.
- b) A palliative care community hotline does not fulfil the role of a palliative care navigator but could form a useful component of a palliative care navigation system if combined with a system of individual case-management.

RECOMMENDATION 3

Page 53

The Minister for Health ensure that the scoping of a palliative care navigator model by the Department of Health is progressed.

FINDING 14

Page 55

Telehealth is a welcome adjunct to direct access to palliative care and its use has increased in part as consequence of the COVID-19 pandemic.

FINDING 15

Page 57

Following a pilot in the Wheatbelt region, the Telepalliative Care in the Home program has been expanded to all of the other regions of the WA Country Health Service, except the Kimberley and Pilbara where it is expected to be rolled out by March 2021.

RECOMMENDATION 4

Page 58

The Minister for Health commission an independent evaluation of whether telepalliative care services would be of benefit to patients in the metropolitan area.

FINDING 16

Page 60

The outcome of the current contract review with the sole metropolitan provider of community specialist palliative care will be instrumental in any goal of increased market contestability of specialist community palliative care providers.

FINDING 17

Page 62

In some areas, respite care is limited or non-existent and is an important component in fulfilling the priority that Western Australian families and carers are supported and have access to such care.

FINDING 18

Page 65

Regional palliative care patients in exceptional circumstances who do not qualify for the National Disability Insurance Scheme or the Commonwealth Home Support Program now have access to interim domiciliary homecare packages through the WA Country Health Service.

RECOMMENDATION 5

Page 65

The Minister for Health ensure that metropolitan palliative care patients who do not qualify for the National Disability Insurance Scheme or the Commonwealth Home Support Program have timely access to domiciliary homecare assistance.

FINDING 19

Page 67

The funding of volunteer services to support, train and guarantee the sustainable involvement of volunteers in the delivery of palliative care in Western Australia remains under-prioritised.

RECOMMENDATION 6

Page 68

The funding of volunteer services in palliative care be prioritised through models such as the Compassionate Communities model.

FINDING 20

Page 73

Despite the well-evidenced benefits of early and proactive referral to specialist palliative care, the change in referral culture necessary to achieve those benefits is yet to occur.

FINDING 21

Page 79

Progressing improved palliative care in residential aged care remains under-prioritised.

RECOMMENDATION 7

Page 80

The Minister for Health develop a plan to increase the number of consultation liaison psychiatrists available to palliative care patients.

FINDING 22

Page 84

In Western Australia, the:

- a) national benchmark number of specialist palliative care physicians specified in the *Palliative Care Service Delivery Guidelines* of 2.0 full time equivalent per 100 000 population has not been met
- b) number of palliative care nurses does not meet the national average of 12 full time equivalent nurses per 100 000 population according to the Australian Institute of Health and Welfare.

FINDING 23

Page 85

Knowledge about end-of-life care and specialist palliative care across the general practitioner workforce is variable and there is significant scope to improve capability.

FINDING 24

Page 85

The establishment of a training and education resource hub by the Department of Health will be a step towards addressing education and training issues impacting palliative care in Western Australia.

RECOMMENDATION 8

Page 85

The Minister for Health explain why additional funding to increase the palliative care workforce was not allocated in the January 2020 Expenditure Review Committee submission.

RECOMMENDATION 9

Page 85

A majority of the Committee, comprising Hon Nick Goiran MLC, Mr Zak Kirkup MLA, Mr Shane Love MLA and Hon Alison Xamon MLC, recommends that the Minister for Health prioritise additional funding to increase the palliative care workforce as noted in the Department of Health's *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, page 30.

RECOMMENDATION 10

Page 85

The Minister for Health prepare a plan to:

- a) increase the palliative care workforce
- b) increase the availability of further education in palliative care and general practitioner registrar positions in palliative care.

RECOMMENDATION 11

Page 89

Palliative care units be designed in consultation with local Aboriginal community members and elders.

RECOMMENDATION 12

Page 92

The Minister for Health ensure that culturally appropriate resources are available for Aboriginal people to explain palliative care.

FINDING 25

Page 93

The development of an Aboriginal End-of-Life and Palliative Care Framework will be an important first step to support and improve equity of access to palliative care by Aboriginal people throughout Western Australia.

FINDING 26

Page 95

There is an inequity of access to appropriate and timely specialist palliative care in parts of the Perth metropolitan area, including the south metropolitan region which particularly impacts residents in and around the Rockingham and Mandurah corridor.

FINDING 27

Page 96

The report by the Joint Select Committee on End of Life Choices did not address the palliative care needs of several specific groups, namely paediatric patients, culturally and linguistically diverse communities, people experiencing cognitive decline and dementia, people with disabilities, people living with mental illness, people with degenerative neurological conditions, people experiencing homelessness, the LGBTIQ community, asylum seekers and prisoners.

FINDING 28

Page 97

The construction of a new Children's Hospice will be a welcome addition to Western Australia's palliative care infrastructure.

FINDING 29

Page 97

Despite funding increases in regional services, investment in developing a stronger process for paediatric palliative care patients in regional and remote areas has yet to occur.

FINDING 30

Page 102

Improving access to palliative care for condition-specific and other diverse groups requires the identification of access gaps and co-design of appropriate training and resources.

FINDING 31

Page 107

The progress on implementing the recommendations of the Joint Select Committee on End of Life Choices has been inconsistently communicated to key stakeholders.

RECOMMENDATION 13

Page 107

WA Health regularly communicate the progress of implementation of the recommendations of the Joint Select Committee on End of Life Choices to stakeholders in the palliative care sector, and the Department of Health include a summary of those communications in its Annual Report.

FINDING 32

Page 110

There has been substantial progress on the implementation of recommendation 7 of the Joint Select Committee on End of Life Choices (regarding the number of publicly funded beds in the northern suburbs of Perth), but this progress has not been effectively communicated to stakeholders in the palliative care sector.

RECOMMENDATION 14

Page 110

WA Health undertake an evaluation of whether the ten additional inpatient beds in the northern suburbs of Perth referred to in the funding announcement of 10 October 2019:

- a) will meet the unmet inpatient palliative care needs of the northern suburbs of Perth as identified by the Joint Select Committee on End of Life Choices
- b) constitute an 'inpatient specialist palliative care hospice' for the purposes of recommendation 7 of the Joint Select Committee on End of Life Choices.

RECOMMENDATION 15

Page 110

The North Metropolitan Health Service and the Department of Health report on the progress of implementation of recommendation 7 of the Joint Select Committee on End of Life Choices in their next Annual Reports.

FINDING 33

Page 114

The Committee was not provided with unredacted information to enable it to assess the progress of implementation of recommendation 8 of the Joint Select Committee on End of Life Choices, that the Minister for Health ensure that community palliative care providers, such as Silver Chain, are adequately funded to provide for growing demand.

RECOMMENDATION 16

Page 114

WA Health use the results of the independent review undertaken pursuant to recommendation 9 of the Joint Select Committee on End of Life Choices, and the audit undertaken pursuant to recommendation 10 of the Joint Select Committee on End of Life Choices, to quantify the funding required to enable community palliative care providers including Silver Chain to provide for:

- a) existing demand; and
- b) growing demand.

FINDING 34

Page 117

From May 2020, there has been significant progress in the implementation of recommendation 9 of the Joint Select Committee on End of Life Choices, that WA Health conduct an independent review, from a patient's perspective, of the three models of palliative care in Western Australia: inpatient, consultative and community.

RECOMMENDATION 17

Page 117

The Minister for Health table in Parliament the independent review undertaken pursuant to recommendation 9 of the Joint Select Committee on End of Life Choices, and thereafter the Government's response.

FINDING 35

Page 120

The accessibility of Medicare Benefits Schedule data remains a challenge that restricts the scope of WA Health's measurement of the delivery of palliative care services.

FINDING 36

Page 121

The Department of Health's decision to seek to determine unmet need, rather than unmet demand as recommended by recommendation 10 of the Joint Select Committee on End of Life Choices, is appropriate.

FINDING 37

Page 121

While there has been some progress in determining unmet need for palliative care pursuant to recommendation 10 of the Joint Select Committee on End of Life Choices, the current methodology adopted by WA Health does not fully measure unmet need.

RECOMMENDATION 18

Page 121

WA Health further refine the methodology for determining the unmet need for palliative care, and ensure the measure of unmet need includes:

- a) the number of those accessing palliative care for the first time very late in the trajectory of their illness and therefore not receiving timely referrals
- b) general practitioner and primary care data
- c) patients who received palliative care in the community and did not have any hospital admissions in the year prior to death.

FINDING 38

Page 121

There has been limited progress in relation to the implementation of an ongoing process to measure the delivery of palliative care services as recommended by recommendation 10 of the Joint Select Committee on End of Life Choices.

RECOMMENDATION 19

Page 122

WA Health undertake a full roll-out of the Electronic Palliative Care Information System known as ePalCIS.

FINDING 39

Page 123

If a consistent definition of palliative care has been established by WA Health pursuant to recommendation 11 of the Joint Select Committee on End of Life Choices, the communication of it to key stakeholders remains a problem.

RECOMMENDATION 20

Page 123

WA Health communicate to key stakeholders its consistent definition of palliative care established pursuant to recommendation 11 of the Joint Select Committee on End of Life Choices.

FINDING 40

Page 125

While some progress has been made to implement the part of recommendation 11 of the Joint Select Committee on End of Life Choices that WA Health 'provide comprehensive, accessible and practical information and education services about palliative care to health professionals and the community', most of the initiatives to achieve this are yet to materialise.

FINDING 41

Page 126

Addressing workforce issues is a prerequisite to facilitating capacity for palliative care specialists to share knowledge with their generalist colleagues pursuant to recommendation 11 of the Joint Select Committee on End of Life Choices.

FINDING 42

Page 127

Substantial progress has been made on the implementation of that part of recommendation 11 of the Joint Select Committee on End of Life Choices that WA Health establish a palliative care information and community hotline.

FINDING 43

Page 129

Notwithstanding the Government's stated acceptance of recommendation 14 of the Joint Select Committee on End of Life Choices in November 2018 and May 2019, recommendation 14 will not be implemented by the Department of Health, as it considers that an independent audit would not provide additional information or more granular details than what is available under the current methodology.

FINDING 44

Page 130

There has been preliminary progress on the implementation of recommendations 15, 16 and 17 of the Joint Select Committee on End of Life Choices relating to ongoing professional development.

FINDING 45

Page 131

The recommendation in recommendation 17 of the Joint Select Committee on End of Life Choices that WA Health consider how it might effectively educate the community about end-of-life decision-making, and implement appropriate health promotion in this area, is being progressed by negotiations for a five-year service agreement between WA Health and Palliative Care Western Australia.

FINDING 46

Page 133

There has been substantial progress on the implementation of recommendation 18 of the Joint Select Committee on End of Life Choices that WA Health provide specific guidelines on the use of terminal sedation by health professionals for patients at the end of life.

RECOMMENDATION 21

Page 133

The Department of Health report on the progress of implementation of recommendations 8, 10 and 11 of the Joint Select Committee on End of Life Choices in its next Annual Report.

RECOMMENDATION 22

Page 137

The Minister for Health explain how the remaining funds allocated to expanded regional palliative care services in 2019-20 will be spent.

FINDING 47

Page 158

Notwithstanding the Government's announcement that \$5 million of its five year \$41 million commitment for end-of-life choices and palliative care would be spent on the Carnarvon Aged and Palliative Care facility, it will result in two multipurpose rooms within the facility being 'flexibly allocated to palliative care'.

FINDING 48

Page 160

The volume of palliative care activity that occurs in primary care settings in regional and remote Western Australia, including services provided by general practitioners and Aboriginal community-controlled health services, is unknown.

FINDING 49

Page 162

Aboriginal community-controlled health services play an important role delivering palliative care services in regional and remote areas of Western Australia. The capacity of Aboriginal community-controlled health services and clinics to deliver palliative care services varies across the State, and there are key enablers required to support them in the delivery of those services.

FINDING 50

Page 162

Aboriginal palliative care patients are often discharged to small local hospitals in their area, with no contact made with the local Aboriginal community-controlled health services.

FINDING 51

Page 162

The WA Country Health Service is developing an inaugural Palliative Care Aboriginal Health Services Coordinator position.

FINDING 52

Page 166

Access to after-hours palliative care services is variable in regional and remote Western Australia, in contrast to the metropolitan area which benefits from Silver Chain's 24/7 palliative care nursing services.

FINDING 53

Page 166

There remains a substantial variation in community palliative care in regional and remote areas, particularly away from regional centres.

FINDING 54

Page 174

There has been significant progress on the implementation of recommendation 12 of the Joint Select Committee on End of Life Choices, that the Minister for Health prioritise policy development and improved governance structures for the delivery of palliative care by the WA Country Health Service.

FINDING 55

Page 178

The progress of implementation of recommendation 13 of the Joint Select Committee on End of Life Choices, that the Minister for Health ensure regional palliative care be adequately funded to meet demand, cannot be evaluated until a more detailed assessment of demand and/or need for palliative care services in regional and remote areas has been undertaken.

RECOMMENDATION 23

Page 180

The Department of Health undertake a detailed assessment of demand and/or need for palliative care services in regional and remote areas of Western Australia.

RECOMMENDATION 24

Page 180

The WA Country Health Service and the Department of Health report on the progress of implementation of recommendation 13 of the Joint Select Committee on End of Life Choices in their next Annual Reports.

FINDING 56

Page 185

Advance Care Planning is separate from palliative care, but is an important tool to facilitate the timely delivery of palliative care consistent with the desires of the patient.

RECOMMENDATION 25

Page 189

A Committee in the 41st Parliament monitor the progress of recommendations arising from this inquiry.



CHAPTER 1

Introduction

Establishment of the Committee and terms of reference

- 1.1 The Joint Select Committee on Palliative Care (Committee) was established on 28 May 2020 to inquire into and report on:
- (a) the progress in relation to palliative care, in particular implementation of recommendations of the Joint Select Committee into End of Life Choices;
 - (b) the delivery of the 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 services between metropolitan and regional areas.⁴
- 1.2 The Committee is made up of three Members of the Legislative Assembly and three Members of the Legislative Council and is required to report to both Houses of Parliament by 19 November 2020.

Background—*Voluntary Assisted Dying Act 2019*

- 1.3 The proposal to establish a joint select committee into palliative care arose during debate on the Voluntary Assisted Dying Bill 2019 in December 2019⁵ in response to a proposed amendment to establish a joint standing committee. The Government's proposal included an undertaking that the joint select committee would be established in February 2020 with a November 2020 reporting date. As noted in paragraph 1.1, the Committee was not established until 28 May 2020,⁶ with the parliamentary secretary representing the Minister for Health advising on 13 May 2020 that the COVID-19 pandemic had significantly impacted the time line for the development and establishment of the Committee.⁷
- 1.4 The Joint Select Committee on End of Life Choices (JSCEOLC) had reported in 2018, with a majority recommending that the Western Australian government develop and introduce legislation for voluntary assisted dying.⁸ The JSCEOLC was also tasked with inquiring into the role of palliative care as a practice utilised within the medical community to assist a person to manage their end of life when experiencing chronic and/or terminal illness, and made a large number of findings and recommendations regarding end-of-life care, palliative care and advance care planning.⁹

⁴ Western Australia, Legislative Assembly, *Parliamentary Debates (Hansard)*, 20 May 2020, pp 2948–51; Western Australia, Legislative Council, *Parliamentary Debates (Hansard)*, 21 May 2020, pp 3047–8; Western Australia, Legislative Assembly, *Parliamentary Debates (Hansard)*, 28 May 2020, pp 3360–1.

⁵ Hon Stephen Dawson MLC, Minister for Environment, Western Australia, Legislative Council, *Parliamentary Debates (Hansard)*, 4 December 2019, p 9852.

⁶ As discussed at paragraph 1.16, this short timeframe contributed to the limitations of this inquiry.

⁷ Hon Alanna Clohesy MLC, Western Australia, Legislative Council, *Parliamentary Debates (Hansard)*, 13 May 2020, p 2569.

⁸ Western Australia, Legislative Assembly and Legislative Council, Joint Select Committee on End of Life Choices, report 1, *My Life, My Choice*, 23 August 2018, p 225.

⁹ *ibid.*, findings 1–28 and recommendations 1–18, pp 46–130.

- 1.5 In its final report (JSCEOLC Report), the JSCEOLC found that:
- access to specialist palliative care in the early stages of a diagnosis might improve remaining quality of life, mood, resilience, symptom management and allow for death in the patient’s preferred location. These benefits would be more readily available to patients if difficult discussions about death and dying took place earlier.¹⁰
- 1.6 The *Voluntary Assisted Dying Act 2019* was passed by the Legislative Assembly on 24 September 2019 and by the Legislative Council on 5 December 2019. The operative parts of the Act are currently scheduled to come into operation in mid-2021.¹¹
- 1.7 It is a guiding principle of the Act that:
- a person approaching the end of life should be provided with high quality care and treatment, including palliative care and treatment, to minimise the person’s suffering and maximise the person’s quality of life.¹²

Background—palliative care

Increasing need for palliative care

- 1.8 The Committee received evidence of an increasing need for palliative care services.¹³ The population of Western Australia is ageing,¹⁴ and the prevalence of cancer and other chronic diseases that accompany ageing is increasing.¹⁵
- 1.9 KPMG estimated in 2019 that the need for palliative care in Australia between 2019 and 2060 will grow faster than both the population and total deaths.¹⁶ In that period, KPMG estimated that:
- the population will increase by 60 per cent to 40.5 million individuals
 - total [annual] deaths will surge by 135 per cent to 400 000, of which 214 000 will require palliative care services.¹⁷

¹⁰ *ibid.*, finding 12, p 75.

¹¹ *Voluntary Assisted Dying Act 2019* s 2. See <https://ww2.health.wa.gov.au/voluntaryassisteddying>. Viewed 24 August 2020.

¹² *ibid.*, s 4(1)(d); recommended in the Department of Health, Ministerial Expert Panel on Voluntary Assisted Dying, *Final Report*, 2019, p xi. See: <https://ww2.health.wa.gov.au/-/media/Files/Corporate/general-documents/Voluntary-assisted-dying/PDF/voluntary-assisted-dying-final-report.pdf>. Viewed 26 October 2020.

¹³ Submission 23 from Department of Health, 10 July 2020, p 6; Submission 25 from South Metropolitan Health Service, 10 July 2020, p 6; Submission 41 from Australian Medical Association (WA), 17 July 2020, p 3; Palliative Care Australia and KPMG, *Investing to Save: The economics of increased investment in palliative care in Australia*, May 2020, p 32. See: <https://palliativecare.org.au/kpmg-palliativecare-economic-report>. Viewed 23 October 2020; Submission 34 from Bethesda Health Care, 10 July 2020, pp 2–3; Submission 6 from Family Voice Australia, 6 July 2020, p 2.

¹⁴ Submission 23 from Department of Health, 10 July 2020, p 6; Submission 25 from South Metropolitan Health Service, 10 July 2020, p 6; Submission 41 from Australian Medical Association (WA), 17 July 2020, p 3; Submission 34 from Bethesda Health Care, 10 July 2020 p 2; Submission 6 from Family Voice Australia, 6 July 2020, pp 1–2.

¹⁵ Submission 41 from Australian Medical Association (WA), 17 July 2020, p 3; Submission 34 from Bethesda Health Care, 10 July 2020, p 2.

¹⁶ Palliative Care Australia and KPMG, *Investing to Save: The economics of increased investment in palliative care in Australia*, May 2020, p 32. See: <https://palliativecare.org.au/kpmg-palliativecare-economic-report>. Viewed 23 October 2020.

¹⁷ *ibid.*

Benefits of quality palliative care

- 1.10 The benefits of palliative care are noted in the *National Palliative Care Strategy 2018* published by the Australian Department of Health (National Strategy):

People receiving palliative care have been shown to have fewer hospitalisations, shorter lengths of stay when they are hospitalised, and reduced visits to emergency departments. Those receiving palliative care at home have been shown to have increased quality of life and reduced need for hospital-based care, providing cost-savings for government.¹⁸

Conduct of the inquiry

- 1.11 The Committee advertised its inquiry and called for submissions through social media,¹⁹ in *The West Australian*²⁰ and in seven regional newspapers.²¹ The Committee also wrote directly to 178 stakeholders inviting a submission to the inquiry, as listed in Appendix 1.
- 1.12 Forty two submissions were received. All public submissions are available on the Committee's webpage at www.parliament.wa.gov.au/plc, and a list of stakeholders and submitters is set out in Appendix 1. Four of those submissions were from private citizens outlining their experiences with palliative care. The Committee thanks those submitters for sharing their personal experiences with the Committee.
- 1.13 The Committee held 25 hearings with 48 witnesses, listed in Appendix 1. Transcripts and videos of evidence given at public hearings held by the Committee are available on the Committee's webpage at www.parliament.wa.gov.au/plc. As well as witnesses based in the metropolitan area, evidence was heard in person or by video conferencing from witnesses based in the following regional locations:
- Albany
 - Newman
 - Busselton
 - Chittering
 - Northam
 - Kununurra
 - Derby
 - Broome
 - Geraldton
 - Kalgoorlie.

¹⁸ Australian Government, Department of Health, *National Palliative Care Strategy 2018*, December 2018, p 7. See: <https://www.health.gov.au/resources/publications/the-national-palliative-care-strategy-2018>. Viewed 23 October 2020.

¹⁹ Legislative Council (9 June 2020) 'Would you like to make a submission to the Joint Select Committee on Palliative Care in Western Australia?' [Facebook Post], <https://www.facebook.com/WALegislativeCouncil/photos/a.110294575676367/3212380708801056/>, Legislative Council of Western Australia.

²⁰ *West Australian*, 13 June 2020, p 34.

²¹ *Kalgoorlie Miner*, 13 June 2020; *Bunbury Herald* 16 June 2020; *Midwest Times*, 17 June 2020; *Pilbara News*, 17 June 2020; *Narrogin Observer*, 17 June 2020; *Albany Advertiser*, 17 June 2020; *Broome Advertiser*, 17 June 2020.

- 1.14 In addition, the Committee visited the Busselton Health Campus Palliative Care Unit and the Geographe Bay Centre operated by Busselton Hospice Care Inc. (BHCI),²² meeting with staff at both locations.
- 1.15 The Committee extends its appreciation to those who provided evidence and information during the inquiry. The Committee has been consistently impressed by the professionalism and dedication of those working in the delivery of palliative care services in Western Australia.

Limitations of the inquiry

- 1.16 The short timeframe overlaid with COVID-19 restrictions created some challenges for the Committee. Nonetheless, the Committee was able to receive a significant amount of evidence from a wide variety of sources and make some substantial findings and recommendations about the current state of palliative care services in Western Australia.
- 1.17 The Committee hopes that this report will constitute a starting point for further inquiry into palliative care services in the 41st Parliament, in the context of the commencement of the main provisions of the *Voluntary Assisted Dying Act 2019* in 2021.

Structure of this report

Background Chapters

- 1.18 Chapter 2 discusses the meaning and scope of palliative care, including some common misperceptions about palliative care that were raised with the Committee. The Chapter also outlines definitions of some other key terms in relation to palliative care and end-of-life.
- 1.19 Chapter 3 outlines the framework of the delivery of palliative care services in Western Australia, including the roles of the Department of Health, WA Health and the WA Country Health Service (WACHS), together with the role of other participants such as Silver Chain Group (Silver Chain) and other private providers, primary care providers, carers and volunteers.

Terms of reference Chapters

- 1.20 Chapter 4 discusses the part of Committee term of reference (a) referring to 'the progress of palliative care'. The general progress of palliative care in Western Australia is considered in relation to coordination and navigation of care; telehealth; community palliative care including the role of carers and after-hours care; community and volunteer involvement; late referrals to palliative care; palliative care in residential aged care facilities; workforce issues; palliative care for Aboriginal people and other specific groups; equity within the metropolitan and outer-metropolitan areas; and the impact of COVID-19.
- 1.21 Chapter 5 discusses the progress of implementation of the recommendations of the JSCEOLC pursuant to the Committee's term of reference (a).
- 1.22 Chapter 6 considers the delivery of services associated with palliative care funding announcements in 2019 and 2020, pursuant to Committee's term of reference (b).
- 1.23 Chapter 7 deals with the Committee's term of reference (c), 'the delivery of palliative care in regional and remote areas'. The Chapter outlines the frame work for the delivery of palliative

²² Busselton Hospice Care Inc. operated a hospice attached to the Busselton Hospital from 2000 to 2015. It no longer operates the hospice, but supplies and manages a large team of volunteers to support the palliative care unit now located within the Busselton Health Campus, completed in 2015. Busselton Hospice Care Inc. also provides a range of volunteer-based programs at its Geographe Bay Centre, located in the former hospice building (Submission 12 from Busselton Hospice Care Inc., 9 July 2020, p 1).

care services in regional and remote areas, including the role of WACHS and the involvement of other providers such as Aboriginal community-controlled health services (ACCHS) and general practitioners (GPs). Chapter 7 also discusses some of the issues arising in relation to the delivery of services in regional and remote areas, including the geographically dispersed population.

- 1.24 Chapter 8 discusses the progress on ensuring greater equity of access to palliative care services between metropolitan and regional areas, pursuant to the Committee's term of reference (d), including the implementation of the recommendations of the JSCEOLC in relation to regional and remote palliative care.

Additional Chapters

- 1.25 Chapter 9 discusses the role of advance care planning (ACP) in relation to palliative care, and outlines evidence received by the Committee about the importance of ACP.
- 1.26 Chapter 10 outlines the Committee's conclusions.

CHAPTER 2

Palliative care – terminology and scope

What is palliative care?

'Palliative care affirms life while recognising that dying is an inevitable part of life'

(Palliative Care Australia, National Palliative Care Standards)²³

2.1 To palliate means to 'make (a disease or its symptoms) less severe without removing the cause'.²⁴

2.2 The World Health Organization (WHO) defines 'palliative care' as:

An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification, impeccable assessment, treatment of pain and other problems, physical, psychosocial and spiritual.²⁵

2.3 Specifically, the WHO states that palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.²⁶

²³ Palliative Care Australia, *National Palliative Care Standards*, 5th edition, 2018, p 5. See: https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/11/PalliativeCare-National-Standards-2018_Nov-web.pdf. Viewed 23 October 2020.

²⁴ Department of Health, *WA End-of-Life and Palliative Care Strategy 2018–2028*, 2018, p 3, citing the Oxford Dictionary, Oxford University Press, 2016. See: https://ww2.health.wa.gov.au/~/_/media/Files/Corporate/general%20documents/Health%20Networks/Palliative%20care/WA%20End-of-life%20and%20Palliative%20Care%20Strategy%202018-2028.pdf. Viewed 23 October 2020.

²⁵ World Health Organization, 2020. See: <https://www.who.int/cancer/palliative/definition/en/>. Viewed 8 September 2020.

²⁶ *ibid.*

- 2.4 Variations on the WHO definition of palliative care are used by government agencies, service providers and other stakeholders.
- 2.5 CareSearch, the Australian online palliative care knowledge network, notes that palliative care services can include:
- relief from distressing symptoms including pain, depression, fatigue, nausea, breathlessness and anxiety
 - psychological and spiritual support
 - a support system to help patients and family live as actively as possible until death
 - support to help the family cope during the person's illness and in their own bereavement.²⁷
- 2.6 Traditionally, palliative care has been provided for patients with cancer or similar illnesses who were in the final stages of their disease.²⁸ More recently, palliative care is increasingly recognised as being appropriate for patients with other life-limiting conditions such as motor neurone disease, dementia and chronic heart and lung diseases.²⁹
- 2.7 There is also a recognition that palliative care is becoming more complex, with the increasing incidence of chronic disease and multiple co-morbidities.³⁰
- 2.8 Palliative Care Western Australia (PCWA) advised the Committee that the traditional model of palliative care 'where there is an intense amount of care provided in the last days or weeks before death' no longer suits the needs of many patients who could benefit from palliative care.³¹

²⁷ CareSearch: palliative care knowledge network, 21 August 2020. See: <https://www.caresearch.com.au/caresearch/tabid/63/Default.aspx>. Viewed 5 October 2020.

²⁸ Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question on notice 1 asked at hearing held 15 July 2020, dated 14 August 2020, p 2 and Attachment, *WA Health End-of-Life and Palliative Care, Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 22; Western Australia, Legislative Assembly and Legislative Council, Joint Select Committee on End of Life Choices, report 1, *My Life, My Choice*, 23 August 2018, p 62; Department of Health, *The End-of-Life Framework: A statewide model for the provision of comprehensive, coordinated care at end-of-life in Western Australia*, 2015, p 8. See: <https://ww2.health.wa.gov.au/-/media/Files/Corporate/general-documents/End-of-Life/PDF/The-End-of-Life-Framework.pdf>. Viewed 23 October 2020; Dr Elissa Campbell, President, Palliative Care Western Australia, transcript of evidence, 31 July 2020, p 3.

²⁹ Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question on notice 1 asked at hearing held 15 July 2020, dated 14 August 2020, p 2 and Attachment, *WA Health End-of-Life and Palliative Care, Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 22; Dr Elissa Campbell, President, Palliative Care Western Australia, transcript of evidence, 31 July 2020, pp 3–4; Submission 25 from South Metropolitan Health Service, 10 July 2020, p 4.

³⁰ Submission 25 from South Metropolitan Health Service, 10 July 2020, p 10; Dr Derek Eng, Palliative Care Physician and Member, Australian and New Zealand Society of Palliative Medicine, transcript of evidence, 30 July 2020, p 7; Department of Health, *The End-of-Life Framework: A statewide model for the provision of comprehensive, coordinated care at end-of-life in Western Australia*, 2015, p 3. See: <https://ww2.health.wa.gov.au/-/media/Files/Corporate/general-documents/End-of-Life/PDF/The-End-of-Life-Framework.pdf>. Viewed 23 October 2020.

³¹ Dr Elissa Campbell, President, Palliative Care Western Australia, transcript of evidence, 31 July 2020, p 4; See also Department of Health, *The End-of-Life Framework: A statewide model for the provision of comprehensive, coordinated care at end-of-life in Western Australia*, 2015, p 8. See: <https://ww2.health.wa.gov.au/-/media/Files/Corporate/general-documents/End-of-Life/PDF/The-End-of-Life-Framework.pdf>. Viewed 23 October 2020.

- 2.9 As well as describing an approach to care, 'palliative care' is also used to refer to the multi-disciplinary health specialty by which that care is provided. The specialty is commonly referred to as 'specialist palliative care' to differentiate it from palliative care as a concept.³²
- 2.10 The Committee heard that palliative care as a specialty is 'in its infancy' and that:
- Palliative care has a lot of growth to do. There is a lot more that we do not understand that we are beginning to understand and the challenges ahead of us will be how to better and better and better and better support people to die.³³
- 2.11 It is now recognised that palliative care can co-exist with active treatment,³⁴ and should be considered (and is on one view 'critical')³⁵ from the time of diagnosis of a progressive, incurable condition.³⁶ Associate Professor Alison Parr, Clinical Lead, Palliative Care, WA Cancer and Palliative Care Network, Department of Health, advised the Committee:
- Palliative care is about supporting people with progressive incurable illness. It is about a multidisciplinary approach. It focuses on quality of life. The prognosis for some of these people that receive palliative care may actually be years—and that is a common misconception; it is not all about end of life. They may still be receiving disease-modifying treatments alongside palliative care interventions; for example, chemotherapy, or radiotherapy, for those with cancer. It is about keeping people as well as possible for as long as possible, despite incurable illness, and it is about keeping them functioning and also supporting psychological wellbeing and practical support for those people as their illness progresses.³⁷
- 2.12 Australian Medical Association (WA) (AMA(WA)) described palliative care as embracing:
- the whole journey for those with incurable illness (planning ahead, avoiding crises and keeping people out of hospital) rather than merely the final few days of a person's life.³⁸
- 2.13 Consistent with the traditional model of palliative care, the Committee heard evidence of a misperception amongst the general public and health professionals that palliative care is solely for the elderly and imminently dying.³⁹ Other evidence received by the Committee of misperceptions in relation to palliative care included:

³² Department of Health, *WA End-of-Life and Palliative Care Strategy 2018–2028*, 2018, p 3. See <https://www2.health.wa.gov.au/~media/Files/Corporate/general%20documents/Health%20Networks/Palliative%20care/WA%20End-of-life%20and%20Palliative%20Care%20Strategy%202018-2028.pdf>. Viewed 23 October 2020.

³³ Brett Hayes, Wheatbelt Palliative Care Manager, WA Country Health Service, transcript of evidence, 3 September 2020, p 13.

³⁴ Western Australia, Legislative Assembly and Legislative Council, Joint Select Committee on End of Life Choices, report 1, *My Life, My Choice*, August 2018, p 62; Palliative Care Australia, *Palliative Care Service Development Guidelines*, January 2018, p 12. See: https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/02/PalliativeCare-Service-Delivery-2018_web2.pdf. Viewed 23 October 2020; Submission 36 from Palliative Care Western Australia, 10 July 2020, p 23.

³⁵ Submission 41 from Australian Medical Association (WA), 17 July 2020, p 7.

³⁶ *ibid.*; Dr Elissa Campbell, President, Palliative Care Western Australia, transcript of evidence, 31 July 2020, pp 3–4.

³⁷ Assoc Prof Alison Parr, Clinical Lead Palliative Care, WA Cancer and Palliative Care Network, transcript of evidence, 15 July 2020, p 3.

³⁸ Submission 41 from Australian Medical Association (WA), 17 July 2020, p 7.

³⁹ Submission 41 from Australian Medical Association (WA), 17 July 2020, p 7; Prof Megan Galbally, Chair, WA Branch Committee, Royal Australian and New Zealand College of Psychiatrists, Answer to question on notice asked at hearing held 30 July 2020, dated 13 August 2020, p 3; Submission 17 from Aged and Community Services Australia, 10 July 2020, p 7; Submission 26 from Health Consumers' Council (WA), 10 July 2020, p 6; Submission 38 from the Aboriginal Health Council of Western Australia, 13 July 2020, p 6.

AMA(WA):

A key objective of palliative care reform in Western Australia should be to shift the public and professional views of palliative care. There is a pervading erroneous belief that palliative care is solely for the elderly and imminently dying. It is paramount that this misperception is corrected to facilitate better access. Palliative care is not just care of the imminently dying, it is critical from the point of diagnosis of a progressive, incurable condition. Palliative care embraces the whole journey for those with incurable illness (planning ahead, avoiding crises and keeping people out of hospital) rather than merely the final few days of a person's life.⁴⁰

Associate Professor Alison Parr, Clinical Lead, Palliative Care, WA Cancer and Palliative Care Network:

That is something that I think people do not recognise and do not realise that our focus is actually on wellbeing and living well, rather than people's perception, which is that we are all about dying. There is a big issue there, both amongst the public and professionals, in recognising what palliative care can potentially achieve.⁴¹

TPG Aged Care:

Taboos around the concept of death and dying are entrenched in our community as too is the understanding of the word 'palliative'.⁴²

Health Consumers' Council (WA):

While it's challenging that people think of palliative care as only being about end of life – which stops some people taking it up or being willing to be referred to it – that it's likely this may always be some people's perception and so we need to work with that. HCC has often advocated for a different term such as comfort care.⁴³

Aboriginal Health Council of WA:

Too often, the perception is that palliative care is about providing medication for pain, and end-of-life care for 'cancer' rather than for other lifelimiting conditions such as renal failure and other chronic diseases.⁴⁴

Bethesda Health Care:

We observe that some associate palliative care with lesser levels of care, choice and hope.⁴⁵

⁴⁰ *ibid.*

⁴¹ Assoc Prof Alison Parr, Clinical Lead Palliative Care, WA Cancer and Palliative Care Network, transcript of evidence, 15 July 2020, p 3.

⁴² Submission 24 from TPG Aged Care, 10 July 2020, p 1.

⁴³ Submission 26 from Health Consumers' Council (WA), 10 July 2020, p 6.

⁴⁴ Submission 41 from Australian Medical Association (WA), 17 July 2020, p 3.

⁴⁵ Dr Neale Fong, Chief Executive Officer, Bethesda Health Care, Answer to question on notice asked at hearing held 30 July 2020, dated 28 August 2020, p 2.

Importance of shared definitions

- 2.14 The Committee heard evidence about the importance of shared definitions in end-of-life and palliative care, and a common understanding amongst health professionals of what is involved in end-of-life and palliative care.⁴⁶
- 2.15 The JSCEOLC noted that during its inquiry:
- the terms 'end of life care', 'palliative care' and 'specialist palliative care' were often used interchangeably. This often made it difficult to gain an accurate understanding of what people meant when they described palliative care. This was further complicated by a general lack of consensus amongst the evidence as to when palliative care should commence and the nature of the clinical services that it should encompass.⁴⁷
- 2.16 Similarly, the *National Consensus Statement: Essential Elements for Safe and High-quality End-of-life Care* stated in 2015:
- Clarity and agreement are lacking about the meaning of many terms that are commonly used in relation to end-of-life care. It is important for all those involved in providing end-of-life care to have a common understanding of what such terms mean in practice.⁴⁸

Definitions of key terms

- 2.17 The Committee noted a range of definitions of key terms used in relation to palliative care. For the purposes of this report, the Committee uses the definitions adopted by the Department of Health as noted in paragraphs 2.18–2.32.

Palliative care

- 2.18 In its report, the JSCEOLC noted 'a marked lack of consistency in the use of the term palliative care by both professionals, patients and families, including the nature and extent of the clinical activities it encompasses and how early it should begin'.⁴⁹ Consequently, the JSCEOLC recommended that WA Health establish a consistent definition of palliative care to be adopted by all health professionals.⁵⁰
- 2.19 Similarly, evidence to the Committee has revealed the use of a range of definitions of palliative care.
- 2.20 In the *WA End-of-life and Palliative Care Strategy (WA Strategy)*, the Department of Health advised the Committee that it now consistently applies the following definition of palliative care:

⁴⁶ Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 7.

⁴⁷ Western Australia, Legislative Assembly and Legislative Council, Joint Select Committee on End of Life Choices, report 1, *My Life, My Choice*, August 2018, p 58.

⁴⁸ Australian Commission on Safety and Quality in Health Care, *National consensus statement: essential elements for safe and high-quality end-of-life care*, 2015, p 32. See: <https://www.safetyandquality.gov.au/sites/default/files/migrated/National-Consensus-Statement-Essential-Elements-for-safe-high-quality-end-of-life-care.pdf>. Viewed 26 October 2020.

⁴⁹ Western Australia, Legislative Assembly and Legislative Council, Joint Select Committee on End of Life Choices, report 1, *My Life, My Choice*, August 2018, pp 57–8.

⁵⁰ *ibid.*, recommendation 11, p 79; See paragraphs 5.85–5.107 of this report.

Palliative care is an approach that improves the quality of life of individuals, including their family/carer, facing problems associated with life-threatening illness/condition, through the prevention and relief of suffering. Palliative care recognises the person and the importance and uniqueness of their family/carer. It serves to maximise the quality of life and considers physical, social, financial, emotional, and spiritual distress. Such distress not only influences the experience of having a life-limiting illness but also influences treatment outcomes.⁵¹

Specialist palliative care

2.21 In the WA Strategy, the Department of Health distinguishes the concept of palliative care, as defined above, from the multidisciplinary specialty (which it refers to as 'specialist palliative care').

2.22 The Department of Health advised that it has adopted the following definition of 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. The role of the specialist palliative care services includes providing consultation services to support, advise, educate and mentor specialist and non-specialist teams to provide end-of-life and palliative care and/or to provide direct care to people with complex palliative care needs.⁵²

End-of-life

2.23 'End-of-life' is defined by the Department of Health as:

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 approaching end-of-life will be considered likely to die during the next 12 months.⁵³

2.24 Several other witnesses agreed that the appropriate timeframe for 'end-of-life' is the last 12 months of life.⁵⁴

End-of-life care

2.25 The Department of Health defines 'End-of-life care' as follows:

End-of-life care is care needed for people who are likely to die in the next 12 months due to progressive, advanced or incurable illness, frailty or old age. During this period, people may experience rapid changes and fluctuations in their

⁵¹ Submission 23 from Department of Health, 10 July 2020, p 12; Department of Health, *WA End-of-Life and Palliative Care Strategy 2018–2028*, 2018, p 3. See:

https://ww2.health.wa.gov.au/~/_/media/Files/Corporate/general%20documents/Health%20Networks/Palliative%20care/WA%20End-of-life%20and%20Palliative%20Care%20Strategy%202018-2028.pdf. Viewed 23 October 2020.

⁵² *ibid.*

⁵³ *ibid.*

⁵⁴ Dr Derek Eng, Palliative Care Physician and Member, Australian and New Zealand Society of Palliative Medicine, transcript of evidence, 30 July 2020, p 10; Assoc Prof Alison Parr, Clinical Lead Palliative Care, WA Cancer and Palliative Care Network, transcript of evidence, 15 July 2020, p 3; Submission 40 from WA Primary Health Alliance, 17 July 2020, p 6; Brett Hayes, Wheatbelt Palliative Care Manager, WA Country Health Service, transcript of evidence, 3 September 2020, p 11; Michele Harvey, Nurse Practitioner—Chronic Disease, Ord Valley Aboriginal Health Service, transcript of evidence, 3 September 2020, p 3.

condition and require support from a range of people, including health services, as well as family and carers.⁵⁵

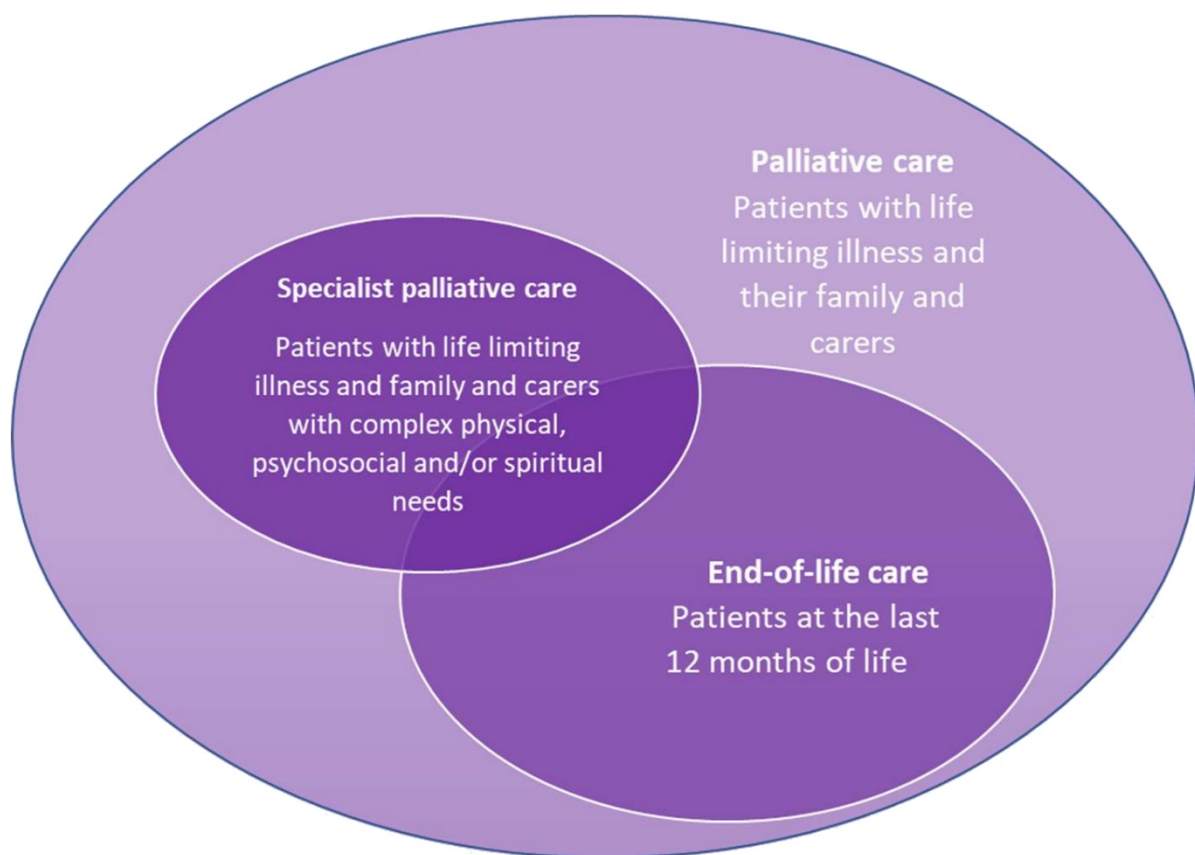
2.26 In addition, the National Strategy defines 'End-of-life care' as including:

physical, spiritual and psychosocial assessment, and care and treatment delivered by health professionals and ancillary staff. It also includes support of families and carers, and care of the patient's body after their death.⁵⁶

2.27 The Department of Health provided the diagram set out in Figure 1 to explain the interaction between palliative care, end-of-life care and specialist palliative care.

2.28 Figure 1 recognises that palliative care and if required, specialist palliative care, may be appropriate and necessary for longer than the 'end-of-life' period of the last 12 months of life.

Figure 1. *Palliative care, specialist palliative care and End-of-life care*



[Source: Department of Health, *Palliative Care in WA*, Powerpoint presentation, tabled by Angela Kelly, Acting Director General, Department of Health, during hearing held 15 July 2020, p 6.]

⁵⁵ Department of Health, *WA End-of-Life and Palliative Care Strategy 2018–2028*, 2018, p 3. See: https://ww2.health.wa.gov.au/~/_media/Files/Corporate/general%20documents/Health%20Networks/Palliative%20care/WA%20End-of-life%20and%20Palliative%20Care%20Strategy%202018-2028.pdf. Viewed 23 October 2020.

⁵⁶ Australian Government, Department of Health, *National Palliative Care Strategy 2018*, December 2018, p 29. See: <https://www.health.gov.au/resources/publications/the-national-palliative-care-strategy-2018>. Viewed 23 October 2020.

Terminal care

- 2.29 The Department of Health defines 'terminal care' as care of the dying in the last days or hours of life,⁵⁷ or 'the care of a person in the last days or weeks before they die (i.e. the final part of palliative care)'.⁵⁸

Life-limiting illness

- 2.30 The Department of Health defines 'life-limiting illness' as:

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.⁵⁹

- 2.31 The National Strategy states that:

a person with life-limiting illness may die prematurely. ['Life-limiting illness'] is often used for people living with a chronic condition that may seem life-threatening but can continue for many years or even decades.⁶⁰

Primary, secondary and tertiary care

- 2.32 The Department of Health defines primary, secondary and tertiary care as:

Primary care

The care the person receives at first contact with the healthcare system, usually involving coordination and continuity of care over time.

Secondary care

Care provided by a specialist or facility upon referral by a primary care physician.

Tertiary care

Care provided by a facility that includes highly-trained specialists and often advanced technology.⁶¹

Hospice

- 2.33 During its inquiry, the Committee noted different usages of the term 'hospice'.

⁵⁷ Department of Health, *WA End-of-Life and Palliative Care Strategy 2018–2028*, 2018, p 19. See: <https://ww2.health.wa.gov.au/~media/Files/Corporate/general%20documents/Health%20Networks/Palliative%20care/WA%20End-of-life%20and%20Palliative%20Care%20Strategy%202018-2028.pdf>. Viewed 23 October 2020.

⁵⁸ Submission 23 from Department of Health, 10 July 2020, p 12; Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 7.

⁵⁹ Department of Health, *WA End-of-Life and Palliative Care Strategy 2018–2028*, 2018, p 18. See: <https://ww2.health.wa.gov.au/~media/Files/Corporate/general%20documents/Health%20Networks/Palliative%20care/WA%20End-of-life%20and%20Palliative%20Care%20Strategy%202018-2028.pdf>. Viewed 23 October 2020.

⁶⁰ Australian Government, Department of Health, *National Palliative Care Strategy 2018*, December 2018, p 29. See: <https://www.health.gov.au/resources/publications/the-national-palliative-care-strategy-2018>. Viewed 23 October 2020.

⁶¹ Department of Health, *WA End-of-Life and Palliative Care Strategy 2018–2028*, 2018, p 19. See: <https://ww2.health.wa.gov.au/~media/Files/Corporate/general%20documents/Health%20Networks/Palliative%20care/WA%20End-of-life%20and%20Palliative%20Care%20Strategy%202018-2028.pdf>. Viewed 23 October 2020.

2.34 In its submission, the Liam James McLaughlin Memorial Hospice stated:

We note that while there is a lack of formal definition of “hospice” in the Australian context, we believe that it would be community’s expectation that this would mean the care is provided in a setting that is not an acute hospital setting. We understand in Western Australia that hospice care is considered to refer broadly to palliative care, whether it is provided in a standalone facility or not.⁶²

2.35 Similarly, PCWA submitted that there is a significant difference between a hospice and an acute care setting.⁶³

2.36 In the view of the Department of Health:

Hospice care is an approach to care and is not tied to a specific place. It can be offered in a person’s home or in a facility like a hospital. In a hospital the terms ‘hospice’ or ‘palliative care unit’ may be used interchangeably; it is not the same as a usual hospital ward, it is usually quieter and calmer with staff who are specially skilled in palliative care so that they can meet the physical, social, spiritual and emotional needs of patients and their families.⁶⁴

Glossary terms

2.37 The definitions adopted by the Department of Health of the terms discussed in this Chapter are included in the Glossary at the end of this report.

⁶² Submission 28 from Liam James McLaughlin Memorial Hospice, 10 July 2020, p 5.

⁶³ Submission 36 from Palliative Care Western Australia, 10 July 2020, p 21; Lana Glogowski, Palliative Care Western Australia, Answer to question on notice 6 asked at hearing held 31 July 2020, dated 24 August 2020, p 3.

⁶⁴ Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 32, dated 18 September 2020, p 7.

CHAPTER 3

Delivery of palliative care services in Western Australia

- 3.1 This Chapter sets out the system for the delivery of palliative care services in Western Australia, as advised to the Committee during its inquiry. It forms the background to Chapters 4 to 8, which discuss issues arising from the Committee's terms of reference.
- 3.2 Specifically, this Chapter outlines:
- the principle of person-centred care
 - 'generalist' and 'specialist' palliative care
 - the role of the Department of Health and WA Health
 - the models of care adopted by the Department of Health
 - telehealth
 - palliative care and aged care
 - the role of primary care providers
 - palliative care workforce
 - community and volunteer involvement
 - data collection and outcomes assessment.

Person-centred care

- 3.3 'Person-centred care' is a key concept in the WA Strategy⁶⁵ and the Department of Health's 2019 *Sustainable Health Review: Final Report to the Western Australian Government* (Sustainable Health Review).⁶⁶
- 3.4 Palliative Care Australia's *Service Development Guidelines* (Service Development Guidelines) note that:

Palliative care should be strongly responsive to the needs, preferences and values of people, their families and carers. A person and family-centred approach to palliative care is based on effective communication, shared decision-making and personal autonomy.⁶⁷

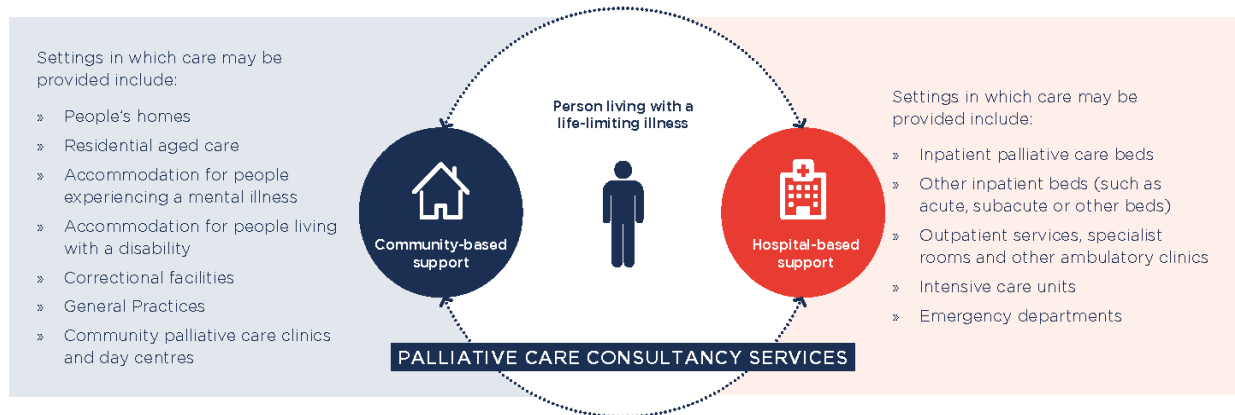
⁶⁵ Department of Health, *WA End-of-Life and Palliative Care Strategy 2018–2028*, 2018, Priority 2, p 9. See: https://ww2.health.wa.gov.au/~/_/media/Files/Corporate/general%20documents/Health%20Networks/Palliative%20care/WA%20End-of-life%20and%20Palliative%20Care%20Strategy%202018-2028.pdf. Viewed 23 October 2020.

⁶⁶ Department of Health, *Sustainable Health Review: Final Report to the Western Australian Government*, 2019, Strategy 4, p 75. See: https://ww2.health.wa.gov.au/~/_/media/Files/Corporate/general-documents/Sustainable-Health-Review/Final-report/sustainable-health-review-final-report.pdf. Viewed 27 October 2020. See also Department of Health, *Palliative Care in WA*, PowerPoint presentation, tabled by Angela Kelly, Acting Director General, Department of Health, during hearing held 15 July 2020, p 6; Christine Kane, WA Primary Health Alliance, Answer to question on notice 1 asked at hearing on 30 July 2020, dated 13 August 2020, *Draft South West WA Palliative Care System Strategy*, 30 May 2019, p 1.

⁶⁷ Palliative Care Australia, *Palliative Care Service Development Guidelines*, January 2018, p 6. See: https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/02/PalliativeCare-Service-Delivery-2018_web2.pdf. Viewed 23 October 2020.

- 3.5 The Service Development Guidelines provide the following illustration of the delivery of person-centred palliative care services (including but not limited to specialist palliative care) in various settings:

Figure 2. *Map of palliative care service settings*



[Source: Palliative Care Australia, *Palliative Care Service Development Guidelines*, p 13.]

'Generalist' and 'specialist' palliative care

- 3.6 In the Service Development Guidelines, Palliative Care Australia distinguishes between specialist and generalist palliative care:

All health professionals who provide care to people living with a life-limiting illness, their families and carers should have minimum core competencies in the provision of palliative care. PCA refers to this type of care that is provided by other health professionals, including general practitioners, as 'palliative care' (although it is also sometimes known as 'generalist palliative care') ...

People with more complex needs should be able to access care provided by specialist palliative care services comprising multidisciplinary teams with specialised skills, competencies, experience and training in palliative care. PCA refers to this type of care that is provided by specialist palliative care services as 'specialist palliative care'.⁶⁸

- 3.7 Specialist palliative care is multidisciplinary in approach, with involvement of various disciplines including medical practitioners, nurses and allied health practitioners.⁶⁹

Workforce

- 3.8 According to the Australian Institute of Health and Welfare (AIHW), the palliative care workforce is 'made up of a number of health professional groups including specialist palliative medicine physicians, nurses, general practitioners, pharmacists, other medical specialists (such as oncologists and geriatricians), as well as other health workers,

⁶⁸ *ibid.*, p 7.

⁶⁹ Assoc Prof Alison Parr, Clinical Lead Palliative Care, WA Cancer and Palliative Care Network, transcript of evidence, 15 July 2020, p 3.

support staff and volunteers'.⁷⁰ In 2018,⁷¹ there were 30 specialist palliative medicine physicians⁷² and 375 palliative care nurses⁷³ in Western Australia.⁷⁴

3.9 Table 1 sets out key data on the Western Australian palliative care workforce in 2018.

Table 1. *Palliative care workforce, Western Australia, 2018*

	Specialist palliative medicine physicians	Palliative care nurses
Number	30	375
Average hours worked per week	37.0	30.8
Average clinical hours worked per week	31.8	28.9
Full-time equivalent (FTE)	27.8	304.1
Clinical FTE	23.8	284.8
FTE per 100,000 population	1.1	11.7
Clinical FTE 100,000 population	0.9	11

[Source: Commonwealth of Australia, *Palliative care services in Australia*, report prepared by the Australian Institute of Health and Welfare, September 2020. See: www.aihw.gov.au/getmedia/a1ee1399-739f-41c0-8064-b1e12b9fa1d9/Palliative-care-workforce-2018.xlsx.aspx. Viewed 15 October 2020.]

3.10 The full-time equivalent (FTE) numbers for specialist palliative medicine physicians and palliative care nurses have changed over time, as shown in Figure 3.

⁷⁰ Commonwealth of Australia, *Palliative care services in Australia*, report prepared by the Australian Institute of Health and Welfare, September 2020. See: <https://www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/contents/palliative-care-workforce>. Viewed 15 October 2020.

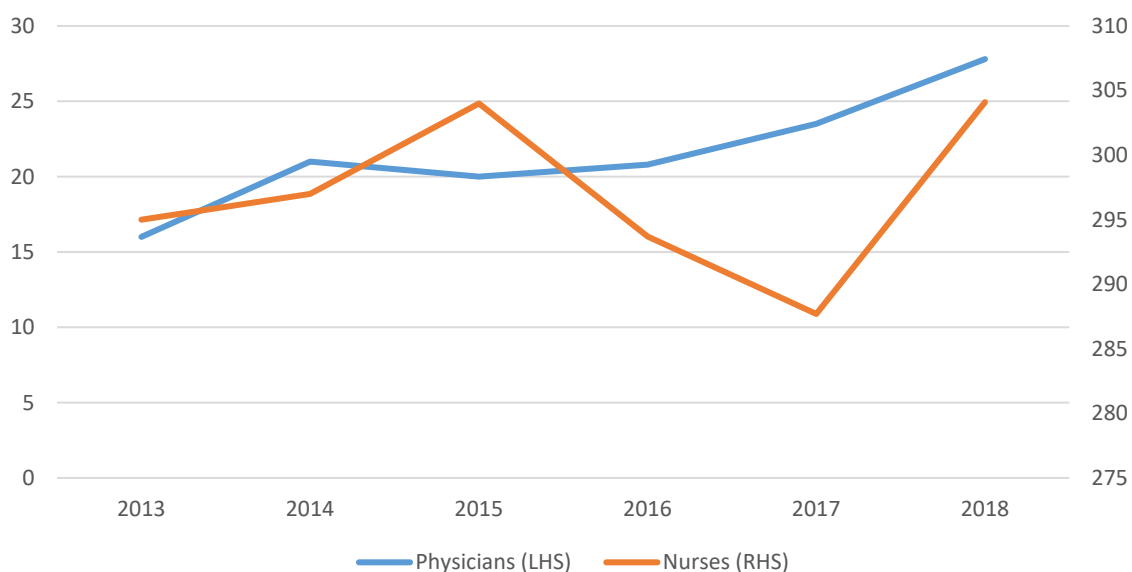
⁷¹ The latest available data.

⁷² A specialist palliative medicine physician must complete post-graduate specialist training and are required to have completed three years of full-time equivalent training under the supervision of a palliative medicine physician (Commonwealth of Australia, *Palliative care services in Australia*, report prepared by the Australian Institute of Health and Welfare, September 2020. See: www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/contents/palliative-care-workforce. Viewed 15 October 2020).

⁷³ A palliative care nurse is a registered nurse who has completed Master's level education and endorsed by the Nursing and Midwifery Board (ibid.)

⁷⁴ Commonwealth of Australia, *Palliative care services in Australia*, report prepared by the Australian Institute of Health and Welfare, September 2020. See: www.aihw.gov.au/getmedia/a1ee1399-739f-41c0-8064-b1e12b9fa1d9/Palliative-care-workforce-2018.xlsx.aspx. Viewed 15 October 2020.

Figure 3. *Specialist palliative care workforce in Western Australia, full-time equivalent*, 2013 to 2018*



[Source: Commonwealth of Australia, *Palliative care services in Australia*, report prepared by the Australian Institute of Health and Welfare, various years.]

* Physician FTE is based on a 40-hour working week in 2017 and 2018. All nurse data and physician data prior to 2017 is based on a 38-hour working week.

3.11 Issues relating to the palliative care workforce are discussed further in Chapter 4.⁷⁵

Department of Health and WA Health

Range of providers and settings

3.12 According to the Department of Health:

Palliative care in WA is delivered by a range of providers including primary care, public and private hospitals, nongovernment organisations and private sector organisations.

Palliative care can be delivered in a number of different settings including: a person's home; community settings such as primary care practices and residential care facilities including aged care, disability and correctional facilities; and hospital-based settings.

While some end-of-life and palliative treatment requires an acute hospital setting, for a large proportion of patients a hospital is not the most comfortable or appropriate setting for this care.⁷⁶

3.13 Publicly funded specialist palliative care services are provided by the following Health Service Providers (HSPs) under service agreements with the Department of Health:

- North Metropolitan Health Service (NMHS)
- South Metropolitan Health Service (SMHS)
- East Metropolitan Health Service (EMHS)

⁷⁵ Paragraphs 4.186 to 4.209.

⁷⁶ Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 8.

- WACHS
 - Child and Adolescent Health Service (CAHS).⁷⁷
- 3.14 The Department of Health contracts with private providers for the provision of publicly funded palliative care services. These include:
- St John of God Healthcare
 - Ramsay Health Care
 - Bethesda Healthcare (Bethesda)
 - Silver Chain.
- 3.15 Privately funded specialist palliative care services are provided by various providers including:
- St John of God Healthcare
 - Bethesda
 - Ramsay Health Care
 - Primary care providers including GPs and ACCHS.

Department of Health and WA Health

- 3.16 The Department of Health is the 'system manager' of the WA health system, providing leadership and management of the health system as a whole,⁷⁸ setting strategic directions and system-wide strategy and policy.⁷⁹
- 3.17 The term 'WA Health' is used to collectively describe the Department of Health, NMHS, SMHS, EMHS, WACHS, CAHS, Health Support Services, PathWest and the Quadriplegic Centre.⁸⁰
- 3.18 The governance structure of WA Health is illustrated in a diagram provided by the Department of Health which is reproduced in Appendix 2.⁸¹

Role of WA Country Health Service

- 3.19 WACHS delivers acute and primary health services to regional and remote Western Australia and is organised into seven regions: Kimberley, Pilbara, Midwest, Goldfields, Wheatbelt, South West and Great Southern.⁸²
- 3.20 WACHS also operates a 'command centre', located in Royal Perth Hospital,⁸³ which consists of a team of experts who provide 24-hour telephone and video support to WACHS clinical staff on the ground.⁸⁴

⁷⁷ Department of Health, *Palliative Care in WA*, PowerPoint presentation, tabled by Angela Kelly, Acting Director General, Department of Health, during hearing held 15 July 2020, p 2.

⁷⁸ Department of Health. See: <https://ww2.health.wa.gov.au/About-us>. Viewed 14 September 2020.

⁷⁹ Angela Kelly, Acting Director General, Department of Health, transcript of evidence, 15 July 2020, p 2.

⁸⁰ Department of Health. See: <https://ww2.health.wa.gov.au/About-us>. Viewed 14 September 2020.

⁸¹ Department of Health, *Palliative Care in WA*, PowerPoint presentation, tabled by Angela Kelly, Acting Director General, Department of Health, during hearing held 15 July 2020, p 2.

⁸² WA Country Health Service, 2011. See: <http://www.wacountry.health.wa.gov.au/index.php?id=961>. Viewed 17 September 2020.

⁸³ Jeffrey Moffet, Chief Executive, WA Country Health Service, transcript of evidence, 18 September 2020, p 10.

⁸⁴ *ibid.*, p 7. As part of the 2020-21 Budget, the Government approved \$10.3 million to relocate and expand the command centre to a fit-for-purpose facility. (Government of Western Australia, *2020-21 Budget, Budget Statements, Budget Paper No. 3*, report prepared by the Department of Treasury, 8 October 2020, p 146).

Location of specialist palliative care services

3.21 Maps produced by the Department of Health showing specialist palliative care services in:

- metropolitan Perth
- regional and remote WA

are reproduced in Appendix 3.

Strategic documents

The End-of-Life Framework

3.22 The Department of Health's *End-of-Life Framework* (End-of-Life Framework) was published in 2015 and arose from 'an identified need for further reform in end-of-life care, particularly in the development of a statewide, coordinated approach to advance care planning'.⁸⁵

3.23 The framework is supported by an explanatory document, *The End-of-Life Framework: A statewide model for the provision of comprehensive, coordinated care at end-of-life in Western Australia* (End-of-Life Framework document), which outlines the vision and scope of the End-of-Life Framework and discusses challenges and gaps in the health system for the delivery of palliative care and end-of-life care.⁸⁶

3.24 The End-of-Life Framework is shown in Appendix 4.

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

3.25 The WA Strategy, published by the Department of Health, supports the End-of-Life Framework and sets out six overarching priorities for the delivery of palliative care in Western Australia from 2018 to 2028, together with the 'building blocks' required for realisation of each priority. The six priorities are:

1. Care is accessible to everyone, everywhere.
2. Care is person-centred.
3. Care is coordinated.
4. Families and carers are supported.
5. All staff are prepared to care.
6. The community is aware and able to care.⁸⁷

3.26 The Department of Health has analysed the alignment of these priorities with recommendations 7 to 18 of the JSCEOLC Report and listed those alignments in its *WA End-of-Life and Palliative Care Strategy 2018–2028 Implementation Plan One 2020–2022*.⁸⁸ That list is reproduced in Appendix 5 of this report.

⁸⁵ Department of Health, *The End-of-Life Framework: A statewide model for the provision of comprehensive, coordinated care at end-of-life in Western Australia*, 2015, p 2. See: <https://ww2.health.wa.gov.au/-/media/Files/Corporate/general-documents/End-of-Life/PDF/The-End-of-Life-Framework.pdf>. Viewed 23 October 2020.

⁸⁶ *ibid.*, p 3.

⁸⁷ Department of Health, *WA End-of-Life and Palliative Care Strategy 2018–2028*, 2018, p 2. See: https://ww2.health.wa.gov.au/~/_media/Files/Corporate/general%20documents/Health%20Networks/Palliative%20care/WA%20End-of-life%20and%20Palliative%20Care%20Strategy%202018-2028.pdf. Viewed 23 October 2020.

⁸⁸ Department of Health, WA Cancer and Palliative Care Network, *WA End-of-Life and Palliative Care Strategy 2018–2028 Implementation Plan One 2020–2022*, 2020, Appendix 3, p 33. See: <https://pch.health.wa.gov.au/>

FINDING 1

Western Australia has a 10-year palliative care strategy, which commenced in 2018.

Implementation Plans

- 3.27 The Department of Health, SMHS and EMHS have published Implementation Plans, which aim to guide implementation of the WA Strategy at both statewide and local levels. They are:
- Department of Health, *WA End-of-Life and Palliative Care Strategy 2018–2028 Implementation Plan One 2020–2022* (Implementation Plan One)⁸⁹
 - SMHS, *Implementation Plan for the “WA End-of-Life and Palliative Care Strategy 2018–2028”*⁹⁰
 - EMHS, *End-of-Life and Palliative Care Strategy Implementation Plan 2019–2024*.⁹¹
- 3.28 NMHS advised that it is currently consulting on its Implementation Plan, which is expected to be completed by the end of 2020.⁹²
- 3.29 WACHS does not have a publicly-available Implementation Plan.

FINDING 2

Plans to implement the *WA End-of-Life and Palliative Care Strategy 2018–2028* vary between agencies and range from a 10-year Implementation Plan by South Metropolitan Health Service, a 5-year plan by East Metropolitan Health Service, a 3-year plan by the Department of Health, a yet-to-be complete plan by North Metropolitan Health Service and no publicly available plan by WA Country Health Service.

National Strategies and Standards

- 3.30 At a national level, the following documents provide strategic direction and standards in relation to the delivery of specialist palliative care services:
- *National Palliative Care Strategy 2018*, published by the Australian Department of Health, which is:
 - intended to be used by all Australian governments, as well as organisations and individuals, in guiding the improvement of palliative care across Australia so that people affected by life-limiting illnesses get the care they need to live well. The National Strategy provides a shared direction and an authorising environment for the continual improvement of palliative care services throughout Australia.⁹³
 - *National Consensus Statement: essential elements for safe and high-quality end-of-life care* (2015), published by the Australian Commission on Safety and Quality in Health

</media/Files/Corporate/Reports-and-publications/End-of-life/end-of-life-palliative-care-strategy-IP1.pdf>. Viewed 27 October 2020.

⁸⁹ *ibid.*

⁹⁰ South Metropolitan Health Service, *Implementation Plan for the ‘WA End-of-Life and Palliative Care Strategy 2018–2028’*, May 2019 (Attachment to submission 26 from South Metropolitan Health Service, 10 July 2020).

⁹¹ East Metropolitan Health Service, *End-of-Life and Palliative Care Strategy Implementation Plan 2019–2024*, September 2019 (Attachment to submission 8 from Dr Derek Eng, 8 July 2020).

⁹² Paula Morellini, Director, Clinic Planning, North Metropolitan Health Service, transcript of evidence, 18 September 2020, p 45.

⁹³ Australian Government, Department of Health, *National Palliative Care Strategy 2018*, December 2018, p 4. See: <https://www.health.gov.au/resources/publications/the-national-palliative-care-strategy-2018>. Viewed 23 October 2020.

Care, which sets out guiding principles and essential elements in the delivery of safe, timely and high-quality end-of-life care,⁹⁴ for the use of clinicians, health service executives and managers, clinical education and training providers, regulation and accreditation agencies and planners, program managers and policy-makers.⁹⁵

- *National Palliative Care Standards* (2018), published by Palliative Care Australia, (National Standards) which sets out nine broad standards designed to be used by Specialist Palliative Care services to support the delivery of high quality palliative care for the person receiving care, their family and carers.⁹⁶
- *Palliative Care Service Development Guidelines* (2018), published by Palliative Care Australia, which set out the expectations of Palliative Care Australia for:
 - the range of palliative care services that should be available to people living with a life-limiting illness, their families and carers
 - the workforce and system capabilities required to deliver an effective network of palliative care services using a population-based and geographic approach to service planning.⁹⁷

Models of specialist palliative care

Models of care adopted by the Department of Health

3.31 Specialist palliative care is provided in a number of different settings. The JSCEOLC noted:

palliative care services are focused around “episodes of care”, which are periods of contact between a patient and a palliative care service occurring in a single setting. An episode of care ends when the setting of care changes.⁹⁸

3.32 The Department of Health advised the JSCEOLC that palliative care is provided through ‘inpatient’, ‘community’ and ‘consultancy’ models of care:

Inpatient – episodes of care are those for which the intent of the admission was for the patient to be in hospital overnight. This includes those patients who were admitted and died on the day of their admission.

Community care – episodes where the patient received palliative care either in their home or a residential aged care facility.

Consultancy – Palliative care consultancy services are teams of specialist doctors and nurses who provide palliative care advice to assist treating teams across all areas of the hospital. Palliative care consultancy advice may include: pain and symptom management, including emotional and spiritual distress; assistance with decision-making and family/patient communication; discharge planning; linking in

⁹⁴ Australian Commission on Safety and Quality in Health Care, *National consensus statement: essential elements for safe and high-quality end-of-life care*, 2015. See: <https://www.safetyandquality.gov.au/sites/default/files/migrated/National-Consensus-Statement-Essential-Elements-for-safe-high-quality-end-of-life-care.pdf>. Viewed 26 October 2020.

⁹⁵ *ibid.*, p 3.

⁹⁶ Palliative Care Australia, *National Palliative Care Standards*, 5th edition, 2018, p 9. See: https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/11/PalliativeCare-National-Standards-2018_Nov-web.pdf. Viewed 23 October 2020.

⁹⁷ Palliative Care Australia, *Palliative Care Service Development Guidelines*, January 2018, p 5. See: https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/02/PalliativeCare-Service-Delivery-2018_web2.pdf. Viewed 23 October 2020.

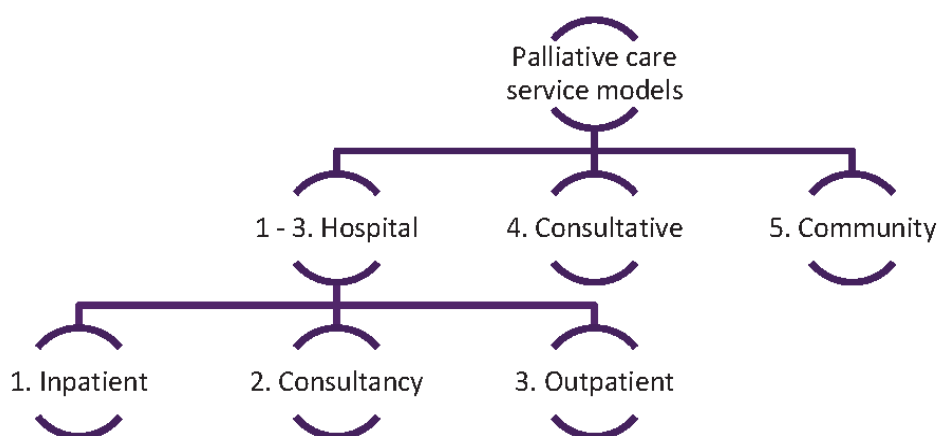
⁹⁸ Western Australia, Legislative Assembly and Legislative Council, Joint Select Committee on End of Life Choices, report 1, *My Life, My Choice*, 23 August 2018, p 64.

with community palliative care services and/or possible admission to the hospital's palliative care unit.⁹⁹

3.33 These three models formed the basis of JSCEOLC recommendation 9, that WA Health 'conduct an independent review, from a patient's perspective, of the three models of palliative care in Western Australia: inpatient, consultative and community'.¹⁰⁰

3.34 The Department of Health advised the Committee that it now identifies five key specialist palliative care service models, as illustrated in Figure 4.

Figure 4. *Specialist palliative care service models*



[Source: Department of Health, *WA End-of-Life and Palliative Care: Current State of WA palliative care service provision and key findings: Working paper*, June 2020, p 8.]

3.35 The Department of Health advised that the five models were identified as part of the Department's analysis of current service delivery, and that:

Unpacking the hospital element into the Hospital inpatient, hospital consultancy and hospital outpatient more clearly articulates how services are delivered in a hospital setting.¹⁰¹

3.36 The Committee was advised that, while hospices are not listed separately in the diagram, 'hospice' and 'palliative care unit' are used interchangeably within the hospital setting.¹⁰²

3.37 For the purposes of its discussion of the delivery of palliative care services, the Committee has adopted the 5-model framework set out in Figure 4. Service provision under these five models is discussed in paragraphs 3.43–3.87.

FINDING 3

Whilst palliative care in Western Australia has historically been provided through three models of care, the Department of Health now recognises five models of care: Hospital—Inpatient, Hospital—Consultancy, Hospital—Outpatient, Consultative, and Community.

⁹⁹ *ibid.*, pp 64–5.

¹⁰⁰ *ibid.*, p 74. See paragraphs 5.56–5.61.

¹⁰¹ Amanda Bolleter, Project Director, End of Life Care, Department of Health, email, 2 November 2020, Attachment 1, Answer to question 1.

¹⁰² Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 32, dated 18 September 2020, p 7.

Criticism of the models of care

3.38 In its submission to the inquiry, the Health Consumers' Council (WA) (HCC) expressed concern:

that there is an assumption that these are the three models. How grounded is this in what people actually want?¹⁰³

3.39 Similarly, the Department of Health's *WA Palliative Care Summit 2019 Report* noted a response from a participant in the Summit that:

We need to be more open minded – the three models of care reflect the system, not patient and family choices. We have to meaningfully include the wider community in designing services, and across WA.¹⁰⁴

3.40 The Department of Health advised:

The service models describe the different settings in which care can be provided, noting the language is reflective of the literature when describing how health care services are delivered. These settings are described in the *WA End of Life and Palliative Care Strategy 2018–2028*. At the center of service provision is access to the right care, at the right time, by the right team and in the right place.

People, families and carers are at the center of care. Work currently underway exploring service delivery models and the independent review into patient preferences will serve to merge the notion of care setting and patient centred delivery to bridge the gap between planning models and people's experience of palliative care.¹⁰⁵

Funding across models of care

3.41 Figure 5 illustrates the breakdown of the WA Health funding allocation for palliative care in 2018–19 between:

- inpatient palliative care in public hospitals
- inpatient palliative care in publicly-funded private hospitals
- outpatient services
- community services
- consultative services.¹⁰⁶

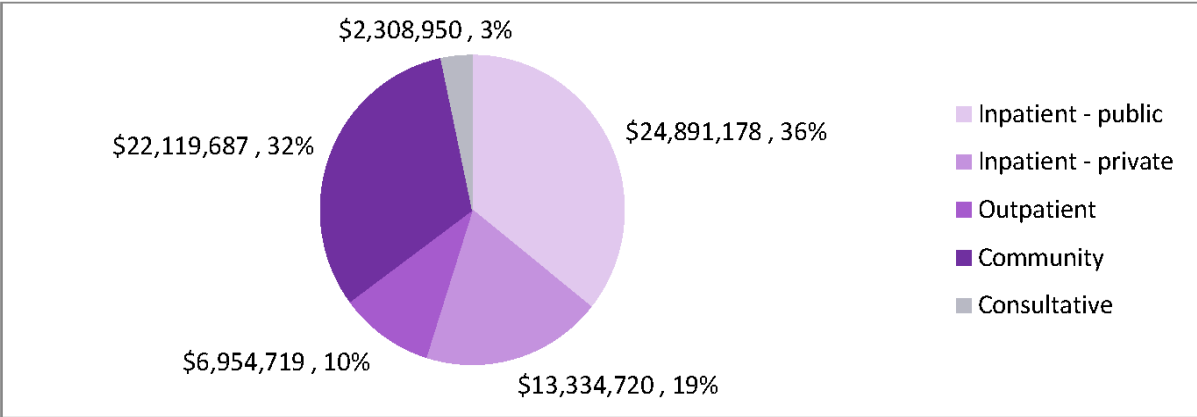
¹⁰³ Submission 26 from Health Consumers' Council (WA), 10 July 2020, p 5.

¹⁰⁴ Department of Health, *WA Palliative Care Summit 2019 Report*, 24 August 2019, p 21. See: https://ww2.health.wa.gov.au/~/_/media/Files/Corporate/general%20documents/Palliative/13697%20Palliative%20Care%20Summit%20Report.pdf. Viewed 26 October 2020.

¹⁰⁵ Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 31, dated 18 September 2020, p 7.

¹⁰⁶ The Department of Health clarified that the 'Inpatient—public' and 'Inpatient—private' categories in Figure 5 include services provided under the 'Hospital—consultancy' model (Amanda Bolleter, Project Director, End of Life Care, Department of Health, email, 2 November 2020, Attachment 1, Answer to question 2).

Figure 5. Funding allocated to palliative care services in Western Australia for 2018–19



Note: Community and Consultative categories do not include all services

[Source: Department of Health, *WA End-of-Life and Palliative Care: Current State of WA palliative care service provision and key findings: Working paper*, June 2020, p 21.]

Independent review of the models of care

3.42 The Department of Health advised in its submission that findings from the independent review of palliative care service models under JSCEOLC recommendation 9¹⁰⁷ will identify patient and community preferences for how palliative care is received and gaps in current service provision.¹⁰⁸

Community specialist palliative care services

‘everyone should have the choice to receive palliative care services at home, wherever their home is located’

(Aboriginal Health Council of WA)¹⁰⁹

What is community specialist palliative care?

- 3.43 Community care refers to care provided by health professionals in a community setting, rather than in hospital.¹¹⁰
- 3.44 Community specialist palliative care is provided in a variety of settings, including a person’s home and other community settings such as primary care practices and residential care facilities including aged care, disability and correctional facilities.¹¹¹
- 3.45 The Committee has noted that different issues arise according to the setting in which community palliative care is provided. In addition to community palliative care generally, this section will also discuss issues specific to:
 - in-home palliative care (provided in private homes)
 - palliative care provided in residential aged care facilities (RACF).

¹⁰⁷ See paragraphs 5.55–5.61.
¹⁰⁸ Submission 23 from Department of Health, 10 July 2020, p 9.
¹⁰⁹ Submission 38 from the Aboriginal Health Council of Western Australia, 13 July 2020, p 2.
¹¹⁰ Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 11.
¹¹¹ *ibid.*, p 8.

Choice of care setting

'We know most Australians would like to die at home, but most do not'

(Dr David Joske)¹¹²

3.46 The 'End-of-life and palliative care snapshot' in the Department of Health's Implementation Plan One indicates that:

- 75 per cent of healthy people would prefer to die at home¹¹³
- preferences frequently change as death approaches
- for dying patients, freedom from distress and symptoms is more important than place of death.¹¹⁴

3.47 The Committee also notes the 2014 Grattan Institute report, *Dying Well*, which states that 'surveys consistently show that between 60 and 70 per cent of Australians would prefer to die at home'.¹¹⁵

3.48 However, the EMHS Implementation Plan notes that the choice to receive palliative care at home is a complex issue:

Community-based specialist palliative care services such as those provided by Silver Chain in WA, are enabling more people to die in their own home. However, in considering how we can continue to enhance provision of care that meets a person's end-of-life wishes, we have to be careful to not oversimplify a complex issue by only focusing on the setting in which death occurs ...

While most people state they would like to die at home, this question is not always raised as an illness progresses and people may change their mind as their circumstances change. We also know that people with a life-limiting condition often transition between community-based and hospital services.¹¹⁶

3.49 The Committee heard from a palliative care physician and representative of the Australian and New Zealand Society of Palliative Medicine (ANZSPM), Dr Derek Eng, citing data from the national Palliative Care Outcomes Collaboration (PCOC), that the risk of having uncontrolled symptoms is up to four times higher in community palliative care patients compared to those who die in inpatient facilities.¹¹⁷

¹¹² Dr David Joske, Clinical Haematologist and Medical Co-Director, Sir Charles Gairdner Hospital and founder, Solaris Cancer Care, transcript of evidence, 30 July 2020, p 2; see also Department of Health, WA Cancer and Palliative Care Network, *WA End-of-Life and Palliative Care Strategy 2018–2028 Implementation Plan One 2020–2022*, 2020, Appendix 1, note 4. See: <https://pch.health.wa.gov.au/-/media/Files/Corporate/Reports-and-publications/End-of-life/end-of-life-palliative-care-strategy-IP1.pdf>. Viewed 27 October 2020.

¹¹³ Note that the Department of Health, WA Cancer and Palliative Care Network, *WA End-of-Life and Palliative Care Strategy 2018–2028 Implementation Plan One 2020–2022*, 2020 references UK sources for this. See: <https://pch.health.wa.gov.au/-/media/Files/Corporate/Reports-and-publications/End-of-life/end-of-life-palliative-care-strategy-IP1.pdf>. Viewed 27 October 2020.

¹¹⁴ Department of Health, WA Cancer and Palliative Care Network, *WA End-of-Life and Palliative Care Strategy 2018–2028 Implementation Plan One 2020–2022*, 2020, p 5. See: <https://pch.health.wa.gov.au/-/media/Files/Corporate/Reports-and-publications/End-of-life/end-of-life-palliative-care-strategy-IP1.pdf>. Viewed 27 October 2020.

¹¹⁵ H Swerissen and S Duckett, *Dying well*, Sydney, New South Wales, Grattan Institute, 2014, p 4. See: <https://grattan.edu.au/wp-content/uploads/2014/09/815-dying-well.pdf>. Viewed 14 October 2020.

¹¹⁶ East Metropolitan Health Service, *End-of-Life and Palliative Care Strategy Implementation Plan 2019–2024*, September 2019, p 11 (Attachment to submission 8 from Dr Derek Eng, 8 July 2020).

¹¹⁷ Submission 8 from Dr Derek Eng, 8 July 2020, pp 2–3; Submission 37 from The Australian and New Zealand Society of Palliative Medicine, 10 July 2020, p 9.

- 3.50 The Department of Health noted the importance of realistic, informed choice as to the setting of care:

When we are thinking about real choice, although there is a big drive to meet people's desire to die at home, it needs to be informed choice. Some people may choose to die in an inpatient setting, so it is equally important, because we know that their symptom distress may be less in an inpatient setting, that we can meet that need as well if that is what they wish to do.¹¹⁸

Community palliative care in metropolitan Perth

Silver Chain

- 3.51 Community-based specialist palliative care in the Perth metropolitan area is provided by Silver Chain under contract with WA Health:

Care is provided by a multi-disciplinary team comprising specialist palliative care nurses, allied health, medical clinicians and trained volunteers. The nurse-led service is available 24/7 and uses an inter-disciplinary approach to meet each client's holistic needs. Individual care plans are needs-based and are responsive to changing needs with clients typically moving from periodic planned visiting to intensive daily support in the terminal phase.¹¹⁹

- 3.52 Silver Chain's community palliative care service operates within the Perth metropolitan region, including the Peel region,¹²⁰ and provides:

- symptom assessment and management
- psychosocial and spiritual care
- medication administration, wound care and personal care
- bereavement support
- planned home-based respite care.¹²¹

- 3.53 The Department of Health provided the Committee with a copy of its contract with Silver Chain as at 18 September 2020, in a redacted form.¹²²

- 3.54 Referrals to the Silver Chain's community-based specialist palliative care service are made by GPs, medical practitioners or nurse practitioners and must satisfy specified criteria.¹²³ Silver Chain advised the Committee that approximately:

¹¹⁸ Assoc Prof Alison Parr, Clinical Lead Palliative Care, WA Cancer and Palliative Care Network, transcript of evidence, 15 July 2020, p 4.

¹¹⁹ Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 11.

¹²⁰ Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 16, dated 18 September 2020, p 2; Dr DJ Russell-Weisz, Director General, Department of Health, letter, 16 October 2020, Attachment 2, p 9.

¹²¹ Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 11.

¹²² Dr DJ Russell-Weisz, Director General, Department of Health, Answers to question prior to hearing, dated 18 September 2020, Attachments A to L.

¹²³ Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 12.

- 46.6 per cent of referrals are from public hospitals
- 15 per cent are from private hospitals
- 37 per cent are from GPs.¹²⁴

Performance Indicators

3.55 Silver Chain is required to provide the Department of Health with information on 'the percentage of people accessing Silver Chain community-based palliative care whose wish to die at home was successfully supported'.¹²⁵ This information forms part of WA Health's and the Department of Health's outcomes reporting at budget time and in annual reports. Table 2 shows Silver Chain's performance against this indicator in 2017-18 and 2018-19.¹²⁶

Table 2. *Silver Chain actual results versus performance indicator targets*

Year	Target	Actual	Variation (actual minus target)
2017-18	≥68%	78%	10%
2018-19	≥85%	76%	-9%

[Source: Department of Health, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 22.]

3.56 Silver Chain records a patient's desired place of death at the time of the initial assessment.¹²⁷ The current system would not capture a change in the patient's views on place, which may occur closer to death.¹²⁸ The Department of Health's working paper, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings* (Current State Report) recommended further investigation into the use of key performance indicators to measure the effectiveness of palliative care services.¹²⁹

3.57 The Committee noted the large increase in the target percentage between 2017–18 and 2018–19. The Department of Health advised:

The methodology used to calculate this [performance indicator] was amended in 2018-19, which meant the previous target was no longer applicable. In the absence of national targets or relevant published literature on best practice, the updated target was selected based on recent historical performance. However due to an error in the historical recording of Place of Death by Silver Chain, this was significantly over-stated. An adjusted target based on accurate historical data is to be introduced from 2020-21 onwards.¹³⁰

3.58 In relation to performance indicators generally, the Department of Health advised:

Preliminary findings note that there are few effective indicators to measure the effectiveness of palliative care services. The National Palliative Care and End-of-Life Care Data Development Working Group, established by the Australian Institute of

¹²⁴ Tish Morrison, Director, Clinical Operations, Palliative and End-of-life Care, Silver Chain, transcript of evidence, 31 July 2020, p 3.

¹²⁵ Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 22.

¹²⁶ The performance indicator was introduced in 2017-18: *ibid.*

¹²⁷ *ibid.*

¹²⁸ *ibid.*, p 29.

¹²⁹ *ibid.*

¹³⁰ Amanda Bolleter, Project Director, End of Life Care, Department of Health, email, 2 November 2020, Attachment 1, Answer to question 10.

Health and Welfare (AIHW) and funded by the Commonwealth Department of Health, is collaborating to develop a set of national key performance indicators to drive improved palliative care practice. WA Health is an active member of the working group to develop these indicators.¹³¹

Community care in regional and remote areas

- 3.59 In regional and remote areas, community palliative care is provided by WACHS regional palliative care services, GPs and, in some regions, ACCHS.
- 3.60 The delivery of palliative care services in regional and remote areas is discussed in greater detail in Chapter 7.¹³²

Role of carers in relation to in-home palliative care

Importance of carers

- 3.61 Silver Chain's Director of Clinical Operations, Palliative and End-of-life Care, Tish Morrison, gave evidence that:
- for people who die at home, home is not an inpatient facility and an inpatient facility is not a home. That means that carers are actually managing the burden of care.¹³³
- 3.62 According to EMHS, the significance of carers is such that many people with a life-limiting illness would be unable to continue to live at home without the support of family and/or carers.¹³⁴
- 3.63 The issue of people living alone is noted in the EMHS Implementation Plan:
- By 2041, between 3.0 and 3.5 million people are projected to be living alone (up from 2.3 million in 2016), primarily due to the ageing population. More people living alone are expected to be doing so without the support of an informal carer given recent social trends such as smaller families and increased divorce rates. Older adults are also more likely to be living with chronic illness. Living alone is a significant predictor for hospital admissions for symptom control.¹³⁵
- 3.64 Silver Chain noted that while most clients of its community-based specialist palliative care service had a carer, 16 per cent had a carer but lived alone. A small number lived alone and did not have a carer.¹³⁶
- 3.65 The National Standards state:
- The needs and preferences of the family and carers, including their need for information, should be assessed independently from that of the person and aim to assist them to better fulfil their caring role and reduce associated stress. Support

¹³¹ Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 27, dated 18 September 2020, p 6.

¹³² Paragraphs 7.46–7.65.

¹³³ Tish Morrison, Director, Clinical Operations, Palliative and End-of-life Care, Silver Chain, transcript of evidence, 31 July 2020, p 5.

¹³⁴ East Metropolitan Health Service, *End-of-Life and Palliative Care Strategy Implementation Plan 2019–2024*, September 2019 (Attachment to submission 8 from Dr Derek Eng, 8 July 2020), p 33.

¹³⁵ East Metropolitan Health Service, *End-of-Life and Palliative Care Strategy Implementation Plan 2019–2024*, September 2019, p 11.

¹³⁶ Tish Morrison, Director, Clinical Operations, Palliative and End-of-life Care, Silver Chain, transcript of evidence, 31 July 2020, p 2.

may include facilitating access to equipment, nursing support, respite, counselling, information about financial support and any other services that may be required.

... It is important to recognise that carers are often but not always family members and that a person may have more than one carer, each one requiring assessment, information and support.¹³⁷

3.66 Progress in relation to support for informal carers is discussed further in Chapter 4.¹³⁸

Consultative specialist palliative care services

3.67 The Department of Health described consultative specialist palliative care services as follows:

Specialist palliative care consultancy services allow health professionals to seek expert advice from specialist palliative care physicians on the prognosis and management of people who are not under the fulltime care of specialist palliative care services.¹³⁹

3.68 There are currently four specialist palliative care consultancy services operating outside the hospital system in Western Australia:

- Metropolitan Palliative Care Consultancy Service (MPaCCS), operated by Bethesda
- WA Combined Palliative Outreach Service, managed by NMHS
- Silver Chain Palliative Care Specialist Nurse Consultation Service
- Residential Care Line Nurse Outreach Service, managed by NMHS.¹⁴⁰

Metropolitan Palliative Care Consultancy Service (MPaCCS)

3.69 Under a contract with the Department of Health, MPaCCS provides capacity-building palliative care consultancy services to residential care facilities including aged care, mental health, disability and correctional facilities.¹⁴¹ Bethesda advised that 95 per cent or more of all work done by MPaCCS is performed in aged-care facilities.¹⁴²

3.70 MPaCCS teams provide expert assessment and review, assistance to facility staff with care planning and technical advice on care.¹⁴³

3.71 Bethesda advised that each resident's GP retains clinical responsibility for the resident, and the objective of MPaCCS is to support the GP and other healthcare providers in the residential setting to provide quality care.¹⁴⁴

3.72 MPaCCS is funded under an activity-based funding structure which is limited by the Department of Health to the attendance of only one clinician per patient per day.

¹³⁷ Palliative Care Australia, *National Palliative Care Standards*, 5th edition, 2018, p 15. See: https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/11/PalliativeCare-National-Standards-2018_Nov-web.pdf. Viewed 23 October 2020.

¹³⁸ Paragraphs 4.79–4.92

¹³⁹ Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 10.

¹⁴⁰ *ibid.*

¹⁴¹ Submission 34 from Bethesda Health Care, 10 July 2020, p 1; Will Hallahan, Project Officer, Palliative Care, Bethesda Health Care, transcript of evidence, 30 July 2020, p 3.

¹⁴² Will Hallahan, Project Officer, Palliative Care, Bethesda Health Care, transcript of evidence, 30 July 2020, p 3.

¹⁴³ *ibid.*

¹⁴⁴ *ibid.*, p 4.

3.73 Issues relating to the funding of MPaCCS are discussed further in Chapter 4.¹⁴⁵

WA Combined Palliative Outreach Service

3.74 The WA Combined Palliative Outreach Service, also known as the Palliative Care Medical Advisory Service, is a telephone service that provides access to specialist palliative care advice for health professionals. The service is predominately used by rural and metropolitan health professionals and is managed by NMHS.¹⁴⁶

Silver Chain Palliative Care Specialist Nurse Consultation Service

3.75 The Department of Health contracts Silver Chain to provide the Palliative Care Specialist Nurse Consultation Service (also called the Residential Care Facility Palliative Nurse Consultancy or Metro Nurse Consultancy Service) to provide palliative care specialist nurse consultation in the Perth metropolitan area. It is a capacity-building service which works in partnership with MPaCCS¹⁴⁷ and provides consultancy to residential care facilities where there is no registered nurse available.¹⁴⁸

3.76 In addition, Silver Chain is contracted by the Department of Health to provide a 24-hour Telephone Advisory Service (the Palliative Care Rural Telephone Nurse Advisory Service) available to health professional staff providing palliative care in rural areas of Western Australia.¹⁴⁹ The Department of Health advised that this service receives an extremely small number of calls and is expected to be phased out once the WACHS telehealth hub (see paragraphs 4.58–4.63) is operational.¹⁵⁰

Residential Care Line Nurse Outreach Service

3.77 The Residential Care Line Nurse Outreach Service is a specialised aged care nursing service managed by NMHS. The service can be contacted directly by RACFs and hospital staff. Although the service does not solely provide palliative care services, it is sometimes used by residential aged care facilities along-side the service provided by MPaCCS. The service supports:

- direct care through clinical consultancy to staff
- care coordination facilitating timely access to hospital-based services, and assisting hospital staff with complex clinical discharges
- education for RACF staff.¹⁵¹

¹⁴⁵ Paragraph 4.162.

¹⁴⁶ Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 11.

¹⁴⁷ *ibid.*

¹⁴⁸ Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 19, dated 18 September 2020, p 3.

¹⁴⁹ Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 11.

¹⁵⁰ Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 24 and 26, dated 18 September 2020, p 5.

¹⁵¹ Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 11.

Hospital-based specialist palliative care services

3.78 Under the 'Hospital' model of care, the Department of Health indicated three sub-models— inpatient, consultancy and outpatient. These three sub-models are discussed in the following sections.

Hospital—inpatient

3.79 There are nine dedicated specialist palliative care inpatient units across WA:

Metropolitan

1. Bethesda Hospital Palliative Care Unit
2. Glengarry Hospital Palliative Care Unit
3. Hollywood Private Hospital
4. Kalamunda Hospital Palliative Care Service
5. St John of God Murdoch Community Hospice

Regional

6. Albany Community Hospice
7. Busselton Health Campus
8. St John of God Bunbury Hospital
9. St John of God Geraldton Hospital.¹⁵²

3.80 Inpatient palliative care services are provided in designated palliative care beds or in non-designated beds in either public or private hospitals:

Designated beds – hospitals may have dedicated beds that are used to provide palliative care via a specialist palliative care physician. An inpatient palliative care unit or hospice is a unit that provides patient care via an on-site specialist team in an inpatient setting.

Non-designated beds – palliative care may be provided to people receiving care in acute, subacute or other types of beds. The provision of palliative care in these settings may involve care by specialist or generalist palliative care providers and/or the involvement of specialist palliative care consultancy services.¹⁵³

Hospital—consultancy

3.81 Hospital-based specialist palliative care consultancy services are provided by interdisciplinary teams to inpatients and outpatients at Western Australian public hospitals.¹⁵⁴

3.82 Consultancy services provide specialist-level assessment and treatment for patients with a life-limiting diagnosis and end-of-life care either at the hospital site or by facilitating discharge to a patient's home, RACF or a palliative care unit.¹⁵⁵

3.83 Palliative care physician, Dr Derek Eng explained:

¹⁵² *ibid.*, p 9.

¹⁵³ *ibid.*, p 8.

¹⁵⁴ *ibid.*, p 9.

¹⁵⁵ *ibid.*

Within a hospital, we have what is called a consultative service ... We do not have palliative care beds and we do not have patients under our bed cards. We would see patients anywhere and everywhere within the hospitals, whether it is Royal Perth, Charles Gairdner, Fiona Stanley, but we do not necessarily take on ownership of them. So we would consult, very much like, say, a pain service would consult after an operation.¹⁵⁶

3.84 On-site inpatient palliative care consultancy services are provided by specialist teams at:

- Royal Perth Hospital
- Sir Charles Gairdner Hospital
- Joondalup Health Campus
- Fiona Stanley Hospital
- Rockingham General Hospital

and are also available to other hospitals within the relevant HSP that do not have a specialist palliative care service.¹⁵⁷

Hospital—outpatient

3.85 Under the Department of Health's five models of care outlined in paragraph 3.34, hospital outpatient palliative care services fall under the 'Hospital' model of care.

3.86 Outpatient palliative care services are provided to patients who do not undergo a formal admission process and do not occupy a hospital bed. For example, services provided in hospital outpatient clinics, community-based clinics or in patients' homes.¹⁵⁸

3.87 The Department advised that Symptom Assessment Clinics are available at a number of public hospitals for adult patients with progressive, life-limiting illnesses who require specialist consultation and symptom management, to which patients can be referred by their GPs or internally from specialists within a hospital.¹⁵⁹

Telehealth

3.88 According to the WHO, telehealth is:

the 'delivery of health care services, where patients and providers are separated by distance. Telehealth uses [information and communications technology] for the exchange of information for the diagnosis and treatment of diseases and injuries, research and evaluation, and for the continuing education of health professionals'.¹⁶⁰

3.89 The AMA(WA) noted the difference between telehealth consultations and more general telephone advice:

I think that telehealth, rather than an advice line—being able to actually contact a doctor or a nurse practitioner or an allied health care practitioner directly is

¹⁵⁶ Dr Derek Eng, Palliative Care Physician and Member, Australian and New Zealand Society of Palliative Medicine, transcript of evidence, 30 July 2020, p 2.

¹⁵⁷ Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 9.

¹⁵⁸ *ibid.*

¹⁵⁹ *ibid.*

¹⁶⁰ World Health Organization, 2020. See: <https://www.who.int/gho/goe/telehealth/en/>. Viewed 12 October 2020.

something that most people are capable of through an iPad or a mobile phone or even just a phone line these days.¹⁶¹

- 3.90 The Committee heard that telehealth plays an increasingly important role in the delivery of palliative care services, particularly in regional and remote areas.
- 3.91 Telehealth is used in all settings of care, and has particular application in community-based specialist palliative care, enabling patients to receive specialist care and advice at home, by telephone or video.
- 3.92 The use of telehealth in community palliative care, including the development of the WACHS telehealth hub, is discussed further in Chapter 4.¹⁶²

Palliative care and aged care

Role of aged care providers

- 3.93 Aged and Community Services Australia (ACSA) advised that:

Aged care providers typically provide palliative care in the course of service delivery to their residents, if they are a residential aged care provider, or to their clients if they provide in-home care services to people living in the community.¹⁶³

- 3.94 Palliative care services provided by aged and community care providers include, but are not limited to:

- Support for people to complete activities of daily living such as personal hygiene needs, taking meals and cleaning;
- Clinical care including medication management, pain management, wound care, nutrition management and other specialised nursing needs;
- Transport services including attending medical appointments or social activities;
- Carer or family support, including respite services; and
- Emotional and pastoral/spiritual support.¹⁶⁴

- 3.95 ACSA also advised that aged and community care providers are natural users of specialist palliative care services, particularly those that fall into the 'community care' section of the specialist palliative care services funded by WA Health.¹⁶⁵

- 3.96 Aged care providers also call upon the expertise of GPs, pharmacists, geriatricians and other medical condition specialists such as oncologists when creating and revising care plans and end-of-life treatment plans for clients living with life-limiting conditions.¹⁶⁶

- 3.97 The Department of Health's Current State Report advises:

The provision of palliative care in residential aged care facilities is regulated under the *Aged Care Act 1997*, within the Quality of Care Principles. Under the schedule of specified care and services, an Approved Provider is responsible for providing access to a qualified practitioner from a palliative care team, and the establishment

¹⁶¹ Dr Andrew Miller, President, Australian Medical Association (WA), transcript of evidence, 31 July 2020, p 11.

¹⁶² Paragraphs 4.45–4.66.

¹⁶³ Submission 17 from Aged and Community Services Australia, 10 July 2020, p 3.

¹⁶⁴ *ibid.*, pp 3–4.

¹⁶⁵ *ibid.*, p 4.

¹⁶⁶ *ibid.*

of a palliative care program including monitoring and managing any side effects for any resident that needs it.¹⁶⁷

Increasing demand for palliative care in residential aged care

3.98 The Current State Report advises:

As Australia's population ages and the number of people entering aged care increases, the demand for palliative and end-of-life care is also increasing. Availability of high quality palliative care services in aged care facilities enables older Australians to experience a good death and ensures families and carers are supported during the dying and bereavement process.¹⁶⁸

3.99 The Department of Health's Implementation Plan One reported that 32 per cent of deaths in Australia in 2014 'lived in residential aged care', citing the Grattan Institute report *Dying Well*.¹⁶⁹

3.100 The Palliative Care Australia and KPMG Report, *Investing to save: The economics of increased investment in palliative care in Australia*, cites data from AIHW indicating that, in 2017, 36 per cent of deaths occurred in RACFs.¹⁷⁰

Residential aged care facilities as palliative care 'settings'

3.101 Whilst ACSA submitted that 'it is important to recognise that [RACFs] are critically important providers of palliative care',¹⁷¹ the AMA(WA) submitted that RACFs are 'wrongly considered to be palliative care services'.¹⁷²

3.102 The Committee notes that the WA Strategy and the Current State Report refer to RACFs as 'settings' for palliative care.¹⁷³ The Committee agrees with that approach, but notes the evidence that increasing amounts of specialist palliative care services are provided in RACF settings by various providers.

FINDING 4

Residential aged care facilities are accurately characterised as settings for palliative care, not palliative care services.

¹⁶⁷ Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 13.

¹⁶⁸ *ibid.*

¹⁶⁹ Department of Health, WA Cancer and Palliative Care Network, *WA End-of-Life and Palliative Care Strategy 2018–2028 Implementation Plan One 2020–2022*, 2020, p 5. See: <https://pch.health.wa.gov.au/-/media/Files/Corporate/Reports-and-publications/End-of-life/end-of-life-palliative-care-strategy-IP1.pdf>. Viewed 27 October 2020. Citing Swerissen H, Duckett S. *Dying well*. Sydney, New South Wales: Grattan Institute; 2014, p 4. See: <https://grattan.edu.au/wp-content/uploads/2014/09/815-dying-well.pdf>. Viewed 27 October 2020.

¹⁷⁰ Submission 37 from The Australian and New Zealand Society of Palliative Medicine, 10 July 2020, p 10; citing Palliative Care Australia and KPMG, *Investing to Save: The economics of increased investment in palliative care in Australia*, May 2020, p 23. See: <https://palliativecare.org.au/kpmg-palliativecare-economic-report>. Viewed 23 October 2020.

¹⁷¹ Submission 36 from Palliative Care Western Australia, 10 July 2020, p 9.

¹⁷² Submission 41 from Australian Medical Association (WA), 17 July 2020, p 5.

¹⁷³ Department of Health, *WA End-of-Life and Palliative Care Strategy 2018–2028*, 2018, p iii. See: https://ww2.health.wa.gov.au/~/_/media/Files/Corporate/general%20documents/Health%20Networks/Palliative%20care/WA%20End-of-life%20and%20Palliative%20Care%20Strategy%202018-2028.pdf. Viewed 23 October 2020; Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 8.

Commonwealth palliative care funding through the Aged Care Funding Instrument

- 3.103 The Commonwealth government subsidises residential aged care through the Aged Care Funding Instrument (ACFI).¹⁷⁴ ACFI recognises and funds palliative care at the 'end of life' where the definition of end-of-life referenced is the last week or days of life.¹⁷⁵
- 3.104 The Current State Report advises that, according to the latest data, for the 20 048 permanent aged care residents in Western Australia in 2017–18, there were 337 (or 1.7 per cent) palliative care appraisals. This number appears to the Committee to be surprisingly low.
- 3.105 Similarly, the Department of Health estimates that as a result of the funding limitation referred to in paragraph 3.103:

the total number of aged care residents requiring and receiving palliative care is likely to be higher than what is indicated in the ACFI data.¹⁷⁶

FINDING 5

There is a paucity of data quantifying the number of aged care residents requiring and/or receiving palliative care in Western Australia.

WA government-funded palliative care services in residential aged care

- 3.106 In RACFs, WA Health funds consultative palliative care services provided by:

- MPaCCS
- Silver Chain Palliative Care Specialist Nurse Consultation Service
- Residential Care Line Nurse Outreach Service.¹⁷⁷

Details of the operation of these services are outlined in paragraphs 3.69–3.77.

- 3.107 ACSA noted in its submission:

Specialist palliative care outreach services that bring palliative care expertise into the aged care setting represent a positive and effective model for upskilling aged care workers and helping older people to achieve their end of life wishes in situ through direct care provision.¹⁷⁸

Metropolitan Palliative Care Consultancy Service (MPaCCS)

- 3.108 As a capacity-building service, MPaCCS does not directly provide palliative care services to RACF residents, but focuses on building the capacity of healthcare providers (GPs, nursing, allied health and other staff).¹⁷⁹

- 3.109 More specifically:

¹⁷⁴ Australian Department of Health, 23 April 2020. See: <https://www.health.gov.au/initiatives-and-programs/residential-aged-care/funding-for-residential-aged-care/the-aged-care-funding-instrument-acfi>. Viewed 14 October 2020.

¹⁷⁵ Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 29.

¹⁷⁶ *ibid.*

¹⁷⁷ *ibid.*, p 11.

¹⁷⁸ Submission 17 from Aged and Community Services Australia, 10 July 2020, p 6.

¹⁷⁹ Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 10.

MPaCCS provides organisations with a collaborative review of end-of-life care processes, protocols, policies and systems to help ensure they facilitate safe, efficient and evidence-based care. They provide education and mentoring of staff that is tailored to the specific needs of the facility. MPaCCS also provides support based on the unique needs of patients, carers and families including advice and advocacy.¹⁸⁰

- 3.110 MPaCCS is a highly regarded service, which the Committee heard achieves substantial capacity-building within RACFs for the provision of palliative care services.¹⁸¹

Silver Chain Palliative Care Specialist Nurse Consultation Service

- 3.111 The Silver Chain Palliative Care Specialist Nurse Consultation Service provides palliative care specialist nurse consultation to RACFs in the Perth metropolitan area, with the overarching aim of enhancing the capacity of non-specialist community services to provide a palliative approach to care. The service is expected to work in partnership with MPaCCS.¹⁸²
- 3.112 Bethesda advised that MPaCCS has ‘a very good working relationship’ with Silver Chain in the aged care setting.¹⁸³
- 3.113 Specific issues in relation to palliative care in residential aged care are discussed further in Chapter 4.¹⁸⁴

Primary care providers

- 3.114 As noted in Chapter 2, ‘primary care’ is defined by the Department of Health as:

The care the person receives at first contact with the healthcare system, usually involving coordination and continuity of care over time.¹⁸⁵

Role of general practitioners

- 3.115 The Committee heard that GPs play an important role in the delivery of specialist palliative care services, particularly in the community setting.
- 3.116 GPs provide a substantial proportion of the palliative care provision in WACHS regions.¹⁸⁶ In regional and remote communities, GPs play a central role in providing and coordinating multidisciplinary care for patients in palliative care across a range of settings.¹⁸⁷ The role of GPs in regional and remote areas is discussed further in Chapter 7.¹⁸⁸
- 3.117 The WA Primary Health Alliance (WAPHA) advised:

¹⁸⁰ *ibid.*

¹⁸¹ Amanda Bolleter, Project Director, End of Life Care, Department of Health, transcript of evidence, 18 September 2020, p 53.

¹⁸² Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 11.

¹⁸³ Will Hallahan, Project Officer, Palliative Care, Bethesda Health Care, transcript of evidence, 30 July 2020, p 4.

¹⁸⁴ Paragraphs 4.151–4.177.

¹⁸⁵ Department of Health, *WA End-of-Life and Palliative Care Strategy 2018–2028*, 2018, p 19. See https://ww2.health.wa.gov.au/~/_media/Files/Corporate/general%20documents/Health%20Networks/Palliative%20care/WA%20End-of-life%20and%20Palliative%20Care%20Strategy%202018-2028.pdf. Viewed 23 October 2020.

¹⁸⁶ Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 30.

¹⁸⁷ Submission 13 from Royal Australian College of General Practitioners, 9 July 2020, p 2.

¹⁸⁸ Paragraphs 7.30–7.36.

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.¹⁸⁹

3.118 The Royal Australian College of General Practitioners (RACGP) submitted:

When a GP is actively involved, patients may be less likely to visit emergency departments and enter intensive care units in the final months of life. Patients are up to four times more likely to die in their preferred setting when GPs are informed of their preference in the end-of-life phase.¹⁹⁰

Medicare Benefits Schedule issues—difficulties in measuring involvement

3.119 WAPHA advised that there are difficulties in ascertaining the level of involvement of GPs in palliative care:

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 [Medicare Benefits Schedule] items, for example, those for chronic disease management and home visit items, when providing patients with palliative care.¹⁹¹

3.120 In addition, the Project Director, End of Life Care with the Department of Health, Amanda Bolleter, advised that the Department of Health does not have access to GP or primary care data due to constraints in accessing Medicare Benefits Schedule (MBS) billing data:

This is a national challenge and needs to be addressed by states and territories on a national level.¹⁹²

FINDING 6

There is a paucity of data quantifying the level of involvement of general practitioners in palliative care.

General practitioner training in palliative care

3.121 WAPHA advised that knowledge about end-of-life care and specialist palliative care across the GP workforce is variable:

[T]here 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. Common reasons for this included patient complexity, inadequate training, insufficient resources, lack of experience or knowledge,

¹⁸⁹ Submission 40 from WA Primary Health Alliance, 17 July 2020, p 5.

¹⁹⁰ Submission 13 from Royal Australian College of General Practitioners, 9 July 2020, p 1.

¹⁹¹ Submission 40 from WA Primary Health Alliance, 17 July 2020, p 6.

¹⁹² Amanda Bolleter, Project Director, End of Life Care, Department of Health, transcript of evidence, 15 July 2020, p 10.

inability to provide 24-hour care, and lack of information or poor communication and links between healthcare providers and specialist palliative care services.¹⁹³

- 3.122 Dr Sean Stevens, Chair, RACGP Western Australia, outlined the College's rural generalist program as an example of training for GPs:

The RG program is designed to upskill rural practitioners, particularly in the formative years of their career, in areas more advanced than perhaps an urban GP would have—particularly things like obstetrics, anaesthetics, emergency medicine, but also palliative care. The idea is that those GPs would have similar sorts of levels of experience that [Silver Chain Hospice Doctor and General Practitioner, Dr Barry Fatovich] would have and would be able to apply that in a local context of their rural community.¹⁹⁴

Aboriginal community-controlled health services (ACCHS)

- 3.123 The Aboriginal Health Council of Western Australia (AHCWA) is the peak body for 23 ACCHS providing primary health services across diverse metropolitan, regional, remote and very remote locations in Western Australia.¹⁹⁵ The locations of these services are shown on the AHCWA map of member locations shown in Appendix 6.

- 3.124 AHCWA advised:

ACCHS currently support Aboriginal people with a life-limiting illness and their families in line with the holistic Model of Care. Palliative care interventions may involve: organising family meetings to plan palliative and end-of-life care; managing a roster of Aboriginal Health Worker staff who are trusted by the patient and their family to provide care; sourcing appropriate equipment and resources in a timely manner; and, engaging other services as required. As the care needs of a patient increase, many ACCHS are flexible and adaptable to the required changes in medical care and emotional support.

The capacity of ACCHS and clinics to deliver palliative care services varies across the state, however, all ACCHS have a variety of experience, expertise and diversifiable skills to provide culturally secure, primary health care to their communities.¹⁹⁶

- 3.125 The role of ACCHS in the delivery of palliative care, particularly in regional and remote areas, is discussed further in Chapter 7.¹⁹⁷

Palliative care nurses

- 3.126 The Department of Health advised:

In order to work in the field of palliative care nurses may complete a variety of professional development courses, including short courses or postgraduate qualification. Postgraduate qualifications are required for nurses who are employed in specialist palliative care services.¹⁹⁸

¹⁹³ Submission 40 from WA Primary Health Alliance, 17 July 2020, p 5.

¹⁹⁴ Dr Sean Stevens, Chair, Royal Australian College of General Practitioners, transcript of evidence, 31 July 2020, p 2.

¹⁹⁵ Submission 38 from the Aboriginal Health Council of Western Australia, 13 July 2020, p 1.

¹⁹⁶ Submission 38 from the Aboriginal Health Council of Western Australia, 13 July 2020, p 3.

¹⁹⁷ Paragraphs 7.37–7.45.

¹⁹⁸ Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 13.

3.127 The role and importance of specialist palliative care nurses and nurse practitioners is outlined in the Service Development Guidelines:

Palliative care nurses provide both direct care and consultative services. Ensuring an adequate supply of palliative care nurses is particularly important in expanding access to community-based palliative care including in people's homes and in residential aged care.

The value of nurses working in advanced practice roles, including as nurse practitioners, has gained increasing recognition and has allowed the development of more nurse-led models for the provision of specialist palliative care. In addition to providing direct care, nurse practitioners (and other advanced practice nurses) have an important role in providing consultative support to other health professionals (such as GPs) who provide palliative care to people living with a life-limiting illness.¹⁹⁹

Allied health providers

3.128 Allied health professionals are health professionals that are not part of the medical, dental or nursing professions,²⁰⁰ and in the context of specialist palliative care include psychologists, social workers, physiotherapists, occupational therapists, speech pathologists and dietitians.²⁰¹

3.129 The Service Development Guidelines state:

Allied health professionals play an essential role in meeting the palliative care needs of people living with a life-limiting illness, their families and carers. This includes:

- Providing support to manage physical symptoms including support related to medication, nutrition, communication and mobility;
- Assisting people with a life-limiting illness to maintain function and independence;
- Providing a wide range of psychological support, social support, pastoral care and bereavement support;
- Providing therapies that focus on improving the quality of life that support people, families and carers to achieve their goals; and
- Sharing information about disease progression and providing education for people living with a lifelimiting illness, their families and carers.²⁰²

3.130 The WA Strategy recognises the importance of:

- increased recognition of the value of allied health professionals in the provision of end-of-life and palliative care

¹⁹⁹ Palliative Care Australia, *Palliative Care Service Development Guidelines*, January 2018, p 22. See: https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/02/PalliativeCare-Service-Delivery-2018_web2.pdf. Viewed 23 October 2020.

²⁰⁰ Allied Health Professions Australia, 2020. See: <https://ahpa.com.au/what-is-allied-health/>. Viewed 26 October 2020.

²⁰¹ Palliative Care Australia, *Palliative Care Service Development Guidelines*, January 2018, p 23. See: https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/02/PalliativeCare-Service-Delivery-2018_web2.pdf. Viewed 23 October 2020.

²⁰² *ibid.*

- an increase in the number of allied health professionals providing quality, comprehensive, specialist palliative care, enabling people to maximise the quality of life and receive care in their place of choice.²⁰³

Community and volunteer involvement

Role of volunteers

- 3.131 The Committee received evidence from BHCI about its volunteer program, and conducted a site visit of BHCI's facility adjacent to the Busselton Health Campus.
- 3.132 BHCI advised the Committee that it:
- coordinates the work of over 100 trained volunteers in the palliative care unit at the Busselton Health Campus. The volunteers operate under the direction of the WACHS clinical team within the unit and enhance the clinical palliative care provision by providing emotional, social and spiritual support to patients and their families
 - provides furnishings and equipment to the palliative care unit to maintain an attractive and non-clinical atmosphere
 - provides a range of volunteer-based programs including 'a peer-based bereavement support service, carer education, community education, complementary therapies to support those dying in the community or hospital/hospice, home visiting palliative care volunteers, advance care plan workshops and professional education'
 - is developing a Community Outreach Program, in which trained volunteers will be available to support families caring for a loved one at home at the end of life, including carer education and respite.²⁰⁴
- 3.133 BHCI receives no funding from government and relies on private donations, which the Committee heard had slowed since the Busselton hospice was relocated into the WACHS-run Busselton Health Campus in 2015.²⁰⁵
- 3.134 Albany Community Hospice advised:
- ACH has up to 80 volunteers registered and trained to ACH induction standards. These volunteers fulfil various roles that add value to our guests and families experience...²⁰⁶
- 3.135 Other organisations such as Silver Chain also have volunteers involved in the provision of palliative care services.²⁰⁷
- 3.136 Training and supervision of volunteers is required by the National Standards.²⁰⁸

²⁰³ Department of Health, *WA End-of-Life and Palliative Care Strategy 2018–2028*, 2018, p 11. See: https://www2.health.wa.gov.au/~/_media/Files/Corporate/general%20documents/Health%20Networks/Palliative%20care/WA%20End-of-life%20and%20Palliative%20Care%20Strategy%202018-2028.pdf. Viewed 23 October 2020.

²⁰⁴ Submission 12 from Busselton Hospice Care Inc., 9 July 2020, p 1.

²⁰⁵ Rosie Brown, Chief Executive Officer and Jennifer Monson, Chair, Busselton Hospice Care Inc., transcript of evidence, 31 July 2020, pp 6–8.

²⁰⁶ Submission 4 from Albany Community Hospice, 5 July 2020, p 3.

²⁰⁷ Tish Morrison, Director, Clinical Operations, Palliative and End-of-life Care, Silver Chain, transcript of evidence, 31 July 2020, p 2.

²⁰⁸ Palliative Care Australia, *National Palliative Care Standards*, 5th edition, 2018, p 21. See: https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/11/PalliativeCare-National-Standards-2018_Nov-web.pdf. Viewed 23 October 2020.

- 3.137 The Committee has not received evidence as to the size of the volunteer workforce within palliative care services in Western Australia, but understands from anecdotal comments by witnesses that the contribution of volunteers is substantial. The Committee gained an appreciation of the valuable contribution made by volunteers to the delivery of palliative care services during its site visit to Busselton.

FINDING 7

Volunteers play a valuable but unquantified role in the provision of palliative care services in Western Australia.

Community involvement

- 3.138 The Committee heard evidence about the use of the ‘Compassionate Communities’ model in relation to palliative care, and some examples of Compassionate Communities projects in Western Australia. These are discussed further in Chapter 4.²⁰⁹

Data collection and outcomes assessment

Data collection systems

- 3.139 The Department of Health collects data on palliative care through two different systems—the web-based Patient Administration System (webPAS) and the Electronic Palliative Care Information System (ePalCIS)—which are described as follows:

WebPAS is the web-based Patient Administration System in use at all WA Health sites. It comprises a single application base and source of reference data and ensures common processes across the whole of WA Health. WebPAS provides clinicians and staff with up-to-date, integrated patient records which facilitate patient flow management; scheduling; admission, discharge, and transfer; ambulatory care; patient indexing and billing; clinical coding; and information management. It standardises business processes, produces consistent information and allows clinicians to access information on a patient from any site. webPAS enables the collection and management of standardised information relating to patients receiving palliative care and captures the minimum data required for Activity Based Funding (ABF).

ePalCIS is a specialised palliative care application used by palliative care clinicians to record patient consultations; patient assessments; management of referrals; transfer of patients between care providers; and team meetings and notes. It also enables the extraction of the more detailed data required for ABF and Palliative Care Outcomes Collaborative (PCOC) reporting. ePalCIS provides palliative care services with an extended data capture capability, and additional functionality supporting clinical and information management that webPAS does not offer.²¹⁰

- 3.140 The Department of Health advised that all public inpatient palliative episodes are required to be recorded in webPAS and ePalCIS.²¹¹
- 3.141 Data recorded in these systems are based on ‘episodes of care’ or ‘occasions of service’. The JSCEOLC noted:

²⁰⁹ Paragraphs 4.117–4.124.

²¹⁰ Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 42, dated 18 September 2020, p 10.

²¹¹ Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 24.

Palliative care services are focused around “episodes of care”, which are periods of contact between a patient and a palliative care service occurring in a single setting. An episode of care ends when the setting of care changes. Typically, a patient receiving palliative care is likely to have more than one episode of care. For example, a new episode of care commences on admission to hospital and would come to an end on discharge.²¹²

Electronic Palliative Care Information System (ePalCIS)

3.142 Dr Duncan James Williamson, Assistant Director General, Clinical Excellence Division, Department of Health, advised that ePalCIS:

was rolled out through the palliative care inpatient units in around 2016 so it includes all of the nine inpatient units at the moment. But it has also been extended to some other units, and so it probably captures data from overall about 19 sites—11 metro and eight regional. That has much more granular clinical information which we can then feed into ... PCOC.²¹³

3.143 The Department of Health advised that some elements of ePalCIS are used in all of the major public-funded metropolitan hospitals, along with Albany, Great Southern, Broome, Kalgoorlie, Bunbury and the South West. A full list of the specialist palliative care sites using ePalCIS as at June 2020 is provided in the Current State Report.²¹⁴

3.144 The Committee notes that the rollout of ePalCIS ceased in 2017 due to budget constraints.²¹⁵

3.145 ePalCIS does not collect data from the private sector. The Department of Health advised:

A good deal of our inpatient palliative care in both north metro and south metro is actually delivered within private hospital services, so that is an additional challenge in terms of understanding the picture and the usage of services as they are currently.²¹⁶

3.146 According to the Current State Report:

The End-of-Life and Palliative Care Project has undertaken an investigation into the current use of ePalCIS in WA. The review has:

- Improved knowledge of current use and barriers to using ePalCIS prior to commencing the next stage of roll-out
- Improved knowledge of level of support required prior to commencing the next stage of ePalCIS rollout.

²¹² Western Australia, Legislative Assembly and Legislative Council, Joint Select Committee on End of Life Choices, report 1, *My Life, My Choice*, 23 August 2018, p 64.

²¹³ Dr Duncan James Williamson, Assistant Director General, Clinical Excellence Division, Department of Health, transcript of evidence, 18 September 2020, p 27.

²¹⁴ Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, Appendix 5, Table 14, p 39.

²¹⁵ *ibid.*, p 25.

²¹⁶ Assoc Prof Alison Parr, Clinical Lead Palliative Care, WA Cancer and Palliative Care Network, transcript of evidence, 15 July 2020, p 18.

Recommendations from the review will inform the next phase of the ePalCIS rollout and improve usability and uptake.²¹⁷

- 3.147 The Current State Report recommends the increased roll-out and use of ePalCIS to enable all hospital sites to record and be appropriately funded for palliative care activity.²¹⁸

FINDING 8

- a) The Electronic Palliative Care Information System (ePalCIS) is a specialised palliative care data collection system in use in around 19 sites in Western Australia.
- b) The rollout of ePalCIS ceased in 2017 due to budget constraints.
- c) A subsequent investigation into the current use of ePalCIS has resulted in a recommendation for its increased rollout and use, to enable all hospital sites to accurately record palliative care activity and be funded accordingly.

Palliative Care Outcomes Collaboration (PCOC)

- 3.148 PCOC is the national evidence hub on patients' daily pain and symptom outcomes in Australia.²¹⁹
- 3.149 PCOC is a federally funded national palliative care and benchmarking program operated out of the University of Wollongong with the primary objective to systematically improve patient outcomes (eg pain and symptom control). PCOC provides information for patients, carers, families, the public, clinicians and researchers on palliative care.²²⁰
- 3.150 Participation by service providers in PCOC is voluntary.²²¹ The Current State Report advises:
- There are currently 19 participating specialist palliative care providers across WA, including 8 from regional areas. Data is collected using validated tools that include assessment of quality of life indicators such as distress, ability to perform activities of daily living, and functional dependence, alongside quantitative data such as episodes of care and clinically meaningful periods in a patients' condition, described as 'phases'.²²²
- 3.151 The Committee has not directly utilised PCOC data reports during its inquiry, but has been referred to PCOC data by various submitters and witnesses.

²¹⁷ Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 27.

²¹⁸ *ibid.*, p 28.

²¹⁹ CareSearch: palliative care knowledge network, 2008. See: <https://www.caresearch.com.au/caresearch/tabid/99/Default.aspx>. Viewed 5 October 2020.

²²⁰ Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 25.

²²¹ *ibid.*

²²² *ibid.*

CHAPTER 4

Term of reference (a) – ‘progress in relation to palliative care’

4.1 The Committee’s term of reference (a) is as follows:

To inquire into and report on ... the progress in relation to palliative care, in particular implementation of recommendations of the Joint Select Committee into End of Life Choices.²²³

4.2 The Committee noted a number of issues in the course of its inquiry which are not directly related to a recommendation of the JSCEOLC, but which are related more generally to the progress of palliative care in Western Australia. Those issues are discussed in this Chapter, while Chapter 5 deals specifically with the implementation of the recommendations of the JSCEOLC.

4.3 Issues relating to the progress of palliative care were identified in the following areas:

- coordination and navigation of care
- telehealth
- community palliative care including the role of carers and after-hours care
- community and volunteer involvement
- late referral to palliative care
- palliative care in residential aged care facilities
- workforce issues
- palliative care for Aboriginal people and other specific groups
- equity within the metropolitan and outer-metropolitan areas
- the impact of COVID-19.

4.4 In relation to the progress of palliative care in general, Bethesda submitted:

Palliative care in Western Australia has steadily progressed in the last decade.

While policy and planning improvements are evident, funding for Western Australian specialist palliative care services has been sub-optimal for many years. Some palliative care services are awarded indexation increases, but base funding has not grown across the system at a rate to match demographic and epidemiological changes over time.

The state’s expanding and ageing population, which has higher levels of chronic illness, has increased demand for specialist palliative care services. The nature of care and treatment provided by these services has changed substantially, becoming more intensive and medicalised, and thus more expensive.²²⁴

²²³ Western Australia, Legislative Assembly, *Parliamentary Debates (Hansard)*, 20 May 2020, p 2948.

²²⁴ Submission 34 from Bethesda Health Care, 10 July 2020, p 2.

Coordination and navigation of care

A complex and fragmented system

‘while the funding streams are siloed, people are not’

(Health Consumers’ Council (WA))²²⁵

- 4.5 The Committee heard evidence that the system of delivery of palliative care services is complex, fragmented and difficult to navigate.²²⁶
- 4.6 The Department of Health acknowledged this issue in the End-of-Life Framework document:
- The health system is currently organised by setting, including home, residential care, general practice and hospital, and this is challenging to continuity of care. Patients are required to navigate a fragmented system across a range of uncoordinated services that often do not match their needs. For patients who are already dealing with uncertainty regarding their declining health, a model that facilitates the continuity of care is paramount.²²⁷
- 4.7 The Liam James McLaughlin Memorial Hospice submitted that:
- we encourage the WA Government to do more to address the experience many people have of fragmented care that is difficult to access. At a critical time in a family’s life – when a member is approaching the end of their life – it should not be necessary for family members who are caring for their loved ones to have to try to navigate the labyrinth of services. While care navigation and coordination is a challenge in all areas of healthcare, it is particularly important at this time.²²⁸

FINDING 9

The palliative care system is fragmented and its navigation is a challenge for patients.

Person-centred care

- 4.8 As noted in Chapter 3,²²⁹ ‘person-centred care’ is a key concept in the WA Strategy and the Sustainable Health Review, as well as other documents provided to the Committee.
- 4.9 HCC noted in its submission:
- There needs to be direct referral options for consumers from their hospital palliative care team to home services, without the labyrinthine processes of having Regional Assessment Services. People’s needs always stretch well beyond clinical and while the funding streams are siloed, people are not.²³⁰

²²⁵ Submission 26 from Health Consumers’ Council (WA), 10 July 2020, p 5.

²²⁶ Submission 28 from Liam James McLaughlin Memorial Hospice, 10 July 2020, p 2; Submission 26 from Health Consumers’ Council (WA), 10 July 2020, p 2; Submission 36 from Palliative Care Western Australia, 10 July 2020, p 24.

²²⁷ Department of Health, *The End-of-Life Framework: A statewide model for the provision of comprehensive, coordinated care at end-of-life in Western Australia*, 2015, p 8. See: <https://ww2.health.wa.gov.au/-/media/Files/Corporate/general-documents/End-of-Life/PDF/The-End-of-Life-Framework.pdf>. Viewed 23 October 2020.

²²⁸ Submission 28 from Liam James McLaughlin Memorial Hospice, 10 July 2020, p 2.

²²⁹ Paragraphs 3.3–3.5.

²³⁰ Submission 26 from Health Consumers’ Council (WA), 10 July 2020, p 5.

Progress

4.10 The Department of Health advised:

People, families and carers are at the center of care. Work currently underway exploring service delivery models and the independent review into patient preferences will serve to merge the notion of care setting and patient centred delivery to bridge the gap between planning models and people's experience of palliative care.²³¹

Models of care

4.11 As noted in Chapter 3,²³² the Committee has heard some criticism of the Department of Health's models of care, and in particular that the models of care may not facilitate person-centred care.

4.12 AMA(WA) suggested that GPs 'should be integrated into the three palliative care delivery models'.²³³

Progress

4.13 In line with this concern, the Department of Health's Implementation Plan One recommended exploring alternative models of service, including funding requirements.²³⁴

4.14 The Committee expects that the interaction between the existing models of care and the concept of person-centred care will be a focus of the independent review resulting from recommendation 9 of the JSCEOLC, which is due to report in November 2020.²³⁵

FINDING 10

There is a need to assess the interaction between the existing models of care and the concept of person-centred care. It remains to be seen if this will be achieved by the independent review resulting from recommendation 9 of the Joint Select Committee on End of Life Choices.

Communication and coordination across settings

4.15 Many witnesses and submissions to the Committee noted the impact of poor coordination between palliative care service providers and across settings.²³⁶

4.16 The JSCEOLC noted that poor coordination and communication between treatment settings was recognised as a barrier to continuity of effective palliative care, and noted AMA(WA)'s view that:

²³¹ Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 31, dated 18 September 2020, p 7.

²³² Paragraphs 3.38–3.40.

²³³ Dr Andrew Miller, Australian Medical Association (WA), Answer to question on notice 6 asked at hearing held 31 July 2020, dated 26 August 2020, p 3.

²³⁴ Department of Health, WA Cancer and Palliative Care Network, *WA End-of-Life and Palliative Care Strategy 2018–2028 Implementation Plan One 2020–2022*, 2020, p 17. See: <https://pch.health.wa.gov.au/-/media/Files/Corporate/Reports-and-publications/End-of-life/end-of-life-palliative-care-strategy-IP1.pdf>. Viewed 27 October 2020.

²³⁵ Assoc Prof Alison Parr, Clinical Lead Palliative Care, WA Cancer and Palliative Care Network, transcript of evidence, 15 July 2020, p 18; See also Chapter 5, paragraphs 5.55–5.61.

²³⁶ For example, submission 6 from Child and Adolescent Health Service, 6 July 2020, p 2; Submission 41 from Australian Medical Association (WA), 17 July 2020, p 6; Submission 10 from Motor Neurone Disease Association of WA Inc, 8 July 2020, p 1.

better communication between care providers could not only improve continuity of care, but also 'prevent hospitalisations for patients at the end of life, and decrease inappropriate treatments through sharing of advance care plans.'²³⁷

4.17 The point of transfer between different settings, such as hospital to home, RACF to hospital or between hospitals, was recognised by the JSCEOLC as a point of risk for the failure of coordination of care.²³⁸

4.18 The Engagement Manager with HCC, Clare Mullen, advised the Committee:

I think across the board the challenge of the points at which somebody transitions from one bit of the system to the other is often the point at which they experience a dip in the care and support that is available to them.²³⁹

4.19 Similarly, RACGP advised:

Part of the issue we have is silos, so communication between the GP and the palliative care service, communication between the GP and the hospital service. You know, you can have your patient rolling up in hospital being treated, discharged on different medications and not finding out about it until they roll up at your door and say, "I've been to hospital and my medications were changed. I don't know why or what for or what to." So that is an issue.²⁴⁰

4.20 Albany Community Hospice submitted:

Please can the Government address the 'red tape' and other administrative barriers so that transition across each patient's services can be cooperatively planned and seamless in the patient's experience.

...

This requires health services to commit to trust and a willingness to share across services with the focus being on the patient at the centre.²⁴¹

4.21 SMHS submitted:

SMHS staff are keen to participate in any opportunities to work with the Department of Health and other stakeholders eg Palliative Care WA to explore and develop contemporary evidence-based community palliative and end of life models of care. This would include care coordination and integration across the continuum of care between community, hospital and hospice settings to meet the growing complexity and needs of all patients requiring care.²⁴²

4.22 The EMHS Implementation Plan noted that 'strengthening coordination across acute and primary care sectors is essential' and noted the important role of WAPHA in developing a network of general practice ACP champions and other initiatives such as HealthPathways.²⁴³

²³⁷ Western Australia, Legislative Assembly and Legislative Council, Joint Select Committee on End of Life Choices, report 1, *My Life, My Choice*, 23 August 2018, p 79.

²³⁸ *ibid.*

²³⁹ Clare Mullen, Engagement Manager, Health Consumers' Council (WA), transcript of evidence, 30 July 2020, pp 6–7.

²⁴⁰ Dr Sean Stevens, Chair, Royal Australian College of General Practitioners, transcript of evidence, 31 July 2020, p 6.

²⁴¹ Submission 4 from Albany Community Hospice, 5 July 2020, p 2.

²⁴² Submission 25 from South Metropolitan Health Service, 10 July 2020, p 5.

²⁴³ East Metropolitan Health Service, *End-of-Life and Palliative Care Strategy Implementation Plan 2019– 2024*, September 2019, p 31 (Attachment to submission 8 from Dr Derek Eng, 8 July 2020).

- 4.23 HealthPathways WA is a website which provides clinical pathways for assessing, managing and referring patients across Western Australia. WAPHA noted the importance of HealthPathways in ensuring coordination of care:

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.²⁴⁴

Progress—use of telehealth in coordination of care

- 4.24 In relation to improving communication and continuity of patient care, the Committee notes that the Department of Health's Implementation Plan One recommends the use of 'digital platforms and TelePalliative care'.²⁴⁵
- 4.25 The Committee received some evidence of this, including from AHCWA, which stated in its submission that telehealth is an effective option for facilitating a collaborative discharge from tertiary or secondary care, and ensuring early engagement with ACCHS.²⁴⁶

Progress—governance structures

- 4.26 In relation to Priority Three of the WA Strategy ('Care is coordinated'), the Department of Health's Implementation Plan One acknowledged in 2019 the need to:

Review and align networks and governance structures in end-of-life care and palliative care to promote statewide service integration and improvement.²⁴⁷

- 4.27 The Committee notes the recent changes to governance structure within WACHS in accordance with recommendation 12 of the JSCEOLC Report.²⁴⁸
- 4.28 In addition, the Department of Health advised that it has established an integrated End-of-Life Care Program team in WA Health to continue to progress the Department's end-of-life and palliative care agenda. The Department advised that the team would:
- ensure the coordination of interdependencies, stakeholder, community and clinician engagement to ensure an appropriate state-wide focus on end of life care going forward.²⁴⁹

FINDING 11

The cooperative planning and seamless transition (from a patient's perspective) between palliative care services remains a key aspiration amongst stakeholders.

²⁴⁴ Submission 40 from WA Primary Health Alliance, 17 July 2020, p 3.

²⁴⁵ Department of Health, WA Cancer and Palliative Care Network, *WA End-of-Life and Palliative Care Strategy 2018-2028 Implementation Plan One 2020-2022*, 2020, p 17. See: <https://pch.health.wa.gov.au/-/media/Files/Corporate/Reports-and-publications/End-of-life/end-of-life-palliative-care-strategy-IP1.pdf>. Viewed 27 October 2020.

²⁴⁶ Submission 38 from Aboriginal Health Council of Western Australia, 13 July 2020, p 2.

²⁴⁷ Department of Health, WA Cancer and Palliative Care Network, *WA End-of-Life and Palliative Care Strategy 2018-2028 Implementation Plan One 2020-2022*, 2020, p 19. See: <https://pch.health.wa.gov.au/-/media/Files/Corporate/Reports-and-publications/End-of-life/end-of-life-palliative-care-strategy-IP1.pdf>. Viewed 27 October 2020.

²⁴⁸ See paragraphs 8.15-8.21.

²⁴⁹ Submission 23 from Department of Health, 10 July 2020, p 7.

RECOMMENDATION 1

The Minister for Health facilitate the removal of administrative barriers to the smooth transition of patients between palliative care service providers.

Care coordination in regional and remote palliative care

- 4.29 The issue of care coordination in transfer to or from regional and remote palliative care settings was recognised as a particular issue.²⁵⁰
- 4.30 The RACGP, in its paper *GP-led Palliative Care in Rural Australia*, noted:
- The current fragmentation of care and poor communication between service providers is impacting on the ability of the GP to coordinate and continue care for rural palliative care patients.²⁵¹

Progress

- 4.31 The Department of Health advised that it 'is aware of these gaps and is working to develop a more integrated system through its engagement with HSPs and the service model development process'.²⁵²

FINDING 12

There are gaps in the care of regional and remote palliative care patients caused by fragmentation of care and poor communication between service providers.

- 4.32 Other evidence received by the Committee relating to coordination of care in regional and remote areas is discussed in Chapter 7.²⁵³

Improved communication protocol or pathway

- 4.33 A number of witnesses were asked whether they supported recommendation 4 (amongst others) of the Minority Report attached to the JSCEOLC Report (JSCEOLC Minority Report),²⁵⁴ and supported the Committee making a recommendation in the same terms.
- 4.34 Recommendation 4 of the Minority Report recommended that:
- The Minister for Health should facilitate and monitor an improved communication protocol, and if necessary an improved communication pathway, between medical practitioners and specialist palliative care services.²⁵⁵

²⁵⁰ Dr Lorraine Anderson, Medical Director and Jenny Bedford, Executive Manager, Kimberley Aboriginal Medical Services, transcript of evidence, 3 September 2020, p 6; Brett Hayes, Wheatbelt Palliative Care Manager, WA Country Health Service, transcript of evidence, 3 September 2020, p 14.

²⁵¹ Royal Australian College of General Practitioners, *GP-led Palliative Care in Rural Australia*, 2016, p 1. See: <https://www.racgp.org.au/FSDEDEV/media/documents/RACGP/Position%20statements/GP-led-Palliative-Care-in-RuralAustralia.pdf>. Viewed 26 October 2020.

²⁵² Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 70 and 71, dated 18 September 2020, p 13.

²⁵³ Paragraphs 7.43 and 7.44.

²⁵⁴ Parliament of Western Australia, Minority Report by Hon NP Goiran MLC for the Joint Select Committee on End of Life Choices submitted under Legislative Assembly Standing Order 274, *The safe approach to End of Life Choices: Licence to Care not Licence to Kill*, August 2018.

²⁵⁵ *ibid.*, p 34.

4.35 The following witnesses supported recommendation 4:

- Dr Derek Eng²⁵⁶
- Bethesda Health Care²⁵⁷
- PCWA.²⁵⁸

RECOMMENDATION 2

The Minister for Health facilitate and monitor an improved communication protocol, and if necessary an improved communication pathway, between medical practitioners and specialist palliative care services.

Palliative care ‘navigators’

4.36 PCWA submitted:

There needs to be an easier way for people with palliative care needs to access what they need. Currently eligibility criteria are complex and don't facilitate a straightforward response at all stages of the illness trajectory. A single point of contact would be very helpful i.e. a palliative care navigator model. This could operate similarly to what is being proposed as part of the [voluntary assisted dying] implementation plan in WA or the Motor Neurone Disease and cancer stream nurses employed by WA Health.²⁵⁹

4.37 The President of PCWA, Dr Elisa Campbell, added that within WA Health cancer streams ‘there is a specialist nurse who helps patients navigate between their different appointments with different specialities and the different services they can access’ and that:

Having that one-stop shop for palliative care would be very helpful ... I know that I, as a health professional with a high level of health literacy, find it very difficult to navigate all of these things. I can only imagine how difficult it is for someone who is very unwell or is caring for a loved one who is very unwell. I think a care navigator service would be really useful in helping to access palliative care services.²⁶⁰

4.38 A navigator concept for voluntary assisted dying under the *Voluntary Assisted Dying Act 2019* was discussed in the report of the Ministerial Expert Panel on Voluntary Assisted Dying, which recommended that:

The Government should develop a system of care navigators as part of any implementation of voluntary assisted dying in Western Australia.²⁶¹

4.39 The idea of a navigator or single point of contact for palliative care was also proposed by Silver Chain, which advised that it had identified an opportunity to develop a single point of

²⁵⁶ Dr Derek Eng, Answer to question on notice 2 asked at hearing held 30 July 2020, dated 11 August 2020, p 5.

²⁵⁷ Dr Neale Fong, Chief Executive Officer, Bethesda Health Care, Answer to question on notice 1 asked at hearing held 30 July 2020, dated 28 August 2020, p 9.

²⁵⁸ Lana Glogowski, Palliative Care Western Australia, Answer to question on notice 2 asked at hearing held 31 July 2020, dated 24 August 2020, p 2.

²⁵⁹ Submission 36 from Palliative Care Western Australia, 10 July 2020, p 24.

²⁶⁰ Dr Elissa Campbell, President, Palliative Care Western Australia, transcript of evidence, 31 July 2020, p 4.

²⁶¹ Department of Health, Ministerial Expert Panel on Voluntary Assisted Dying, *Final Report*, 2019, p 49. See: <https://ww2.health.wa.gov.au/-/media/Files/Corporate/general-documents/Voluntary-assisted-dying/PDF/voluntary-assisted-dying-final-report.pdf>. Viewed 26 October 2020.

contact system, and estimated that provision of the service would require \$0.5 million annually in additional funding.²⁶²

- 4.40 The Committee raised the issue of care navigators with other witnesses, who universally supported the proposal.²⁶³ The Committee also heard from a number of service providers who already provide a form of navigation service to their clients.²⁶⁴ This is likely to be the case in relation to all community palliative care service providers.

Progress

- 4.41 In 2019, the Department of Health's Implementation Plan One recommended exploring options:

including funding, for a Care Navigator role to connect and support people and their families/carers with service providers, including paediatric patients and their families/carers.²⁶⁵

- 4.42 In response to the Committee's question about palliative care navigators, the Department of Health advised that the recently commenced palliative care community hotline²⁶⁶ was expected to provide some navigation services:

Mr R.S. LOVE: in your presentation, along with Dr Williamson, at page 10, "Service models", you have "Navigator". I want to get some understanding of how that is progressing. That is something that has been raised with us numerous times. As part of that, is there a one-stop shop with a navigator for people to find a way to a service, but is there also a place they can go if they were not getting a service, like a sort of "Let's solve this problem"—a problem-solving service?

Ms BOLLETER: ... The care navigator function is one that will be addressed in part through the community hotline, which is currently out for tender. That phone service will be an option for people to call up to say, for example, "I've just been referred for palliative care. I have no idea what that means. Where do I go now? What services are available? What are the next steps for me and my family?" That phone line will be able to provide people with that information and advice, talk them through what the implications are for them, and then to provide them with contact details and link in with relevant services for them. That is part of the role of that community hotline...

²⁶² Tish Morrison, Silver Chain Group, Answer to question on notice 3 asked at hearing held 31 July 2020, dated 18 August 2020, p 5.

²⁶³ Dr Andrew Miller, President, Australian Medical Association (WA), transcript of evidence 31 July 2020, p 4; Rosie Brown, Chief Executive Officer and Jennifer Monson, Chair, Busselton Hospice Care Inc., transcript of evidence, 31 July 2020, pp 5 and 12; Pip Brennan, Executive Director, Health Consumers' Council (WA), transcript of evidence, 30 July 2020, p 7; Christine Kane, WA Primary Health Alliance, Answer to question on notice 1 asked at hearing on 30 July 2020, dated 13 August 2020, *Draft South West WA Palliative Care System Strategy*, 30 May 2019, p 1.

²⁶⁴ Vicki Kershaw, Chief Executive Officer, and Juan Andrade, Corporate Services Manager, East Pilbara Independence Support Inc, transcript of evidence, 10 August 2020, p 9; Alison Barnard, Chairperson, Chittering Health Advisory Group, transcript of evidence, 3 September 2020, p 2; Michele Harvey, Nurse Practitioner—Chronic Disease, Ord Valley Aboriginal Health Service, transcript of evidence, 3 September 2020, p 3; Jennifer Monson, Chair, Busselton Hospice Care Inc., transcript of evidence, 31 July 2020, p 5.

²⁶⁵ Department of Health, WA Cancer and Palliative Care Network, *WA End-of-Life and Palliative Care Strategy 2018–2028 Implementation Plan One 2020–2022*, 2020, p 17. See: <https://pch.health.wa.gov.au/-/media/Files/Corporate/Reports-and-publications/End-of-life/end-of-life-palliative-care-strategy-IP1.pdf>. Viewed 27 October 2020.

²⁶⁶ See paragraphs 5.102–5.108.

Dr PARR: In terms of sort of specific navigator roles—as in, a person in a role—in relation to the work that will be happening around voluntary assisted dying and supporting people through that process, we have been talking about the fact that one of the key things with that is that that person will need to know their links in terms of being able to discuss the alternative of specialist palliative care, and actually being able to direct a person to where they can get that support, so it will also link in with that stream of work.²⁶⁷

- 4.43 However, the witnesses from PCWA, which is delivering the interim community hotline, disagreed that the hotline fills a ‘navigator’ role:

The CHAIR: You touched on the issue of navigators and made the reference to the voluntary assisted dying navigators. The Department of Health’s report “WA End-of-Life and Palliative Care Strategy 2018–2028: Implementation Plan One 2020–2022” has this including some funding. Are you aware of progress of this navigator model at all?

The Witnesses: No.

Ms GLOGOWSKI: Could I comment that my understanding is they see the development of the hotline as in part providing some navigation support to people who were in that service.

Dr NICOLETTI: It is more general than what we were talking about which was more specific.

Dr CAMPBELL: We were discussing more of a case management–type model.²⁶⁸

- 4.44 The Department of Health advised that it is:

scoping a Navigator model that supports that patients’ journey through the clinical delivery of care in order to better support people with life limiting illnesses and their families/carers to navigate their clinical care provision. This will be further informed by the independent service review that is due for completion in November 2020.²⁶⁹

FINDING 13

- a) A system of palliative care navigators would be a welcome and valuable addition to Western Australia’s palliative care services.
- b) A palliative care community hotline does not fulfil the role of a palliative care navigator but could form a useful component of a palliative care navigation system if combined with a system of individual case-management.

RECOMMENDATION 3

The Minister for Health ensure that the scoping of a palliative care navigator model by the Department of Health is progressed.

²⁶⁷ Amanda Bolleter, Project Director, End of Life Care, Department of Health; Assoc Prof Alison Parr, Clinical Lead, Palliative Care, WA Cancer and Palliative Care Network, transcript of evidence, 18 September 2020, p 61.

²⁶⁸ Lana Glogowski, Chief Executive Officer, and Dr Elissa Campbell, President, Palliative Care Western Australia and Dr Margherita Nicoletti, Consultant in Palliative Care, Rockingham Hospital, transcript of evidence, 31 July 2020, p 17.

²⁶⁹ Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 119, dated 18 September 2020, p 24.

Telehealth

Definition

4.45 As noted in Chapter 3,²⁷⁰ telehealth refers to the delivery of health care services, where patients and providers are separated by distance, using information and communications technology.

Role of telehealth in palliative care

4.46 Many witnesses expressed the view that telehealth has a great role to play in the delivery of palliative care services.²⁷¹

4.47 In relation to health services generally, the Sustainable Health Review noted:

Telehealth and virtual services will become a regular part of service delivery in country and metropolitan areas, with much greater coordination and safer access for country patients to the services they need.²⁷²

4.48 Whilst its potential was recognised, AMA(WA) raised the concern that telehealth was not yet available to all people wanting to live at home for as long as possible.²⁷³

4.49 Witnesses recognised the limitations of telehealth.²⁷⁴ Silver Chain stated that:

Overall, we see telehealth or other technologies as an adjunct, but not a replacement of face-to-face visits in the provision of community-based palliative care service.²⁷⁵

²⁷⁰ Paragraph 3.88.

²⁷¹ Submission 36 from Palliative Care Western Australia, 10 July 2020, p 24; Christine Kane, General Manager, Strategy and Engagement, WA Primary Health Alliance, transcript of evidence 30 July 2020, pp 4–5; Dr Sean Stevens, Chair, Royal Australian College of General Practitioners, transcript of evidence, 31 July 2020, p 11; Vicki Kershaw, Chief Executive Officer, East Pilbara Independence Support Inc, transcript of evidence, 10 August 2020, p 8; Submission 41 from Australian Medical Association (WA), 17 July 2020, p 10; Shirley Newell, Executive Manager, Policy and Public Health, Aboriginal Health Council of Western Australia, transcript of evidence, 3 September 2020, pp 9 and 11; Dr Mark Monaghan, Emergency Physician, Director of Medical Services, South West Coastal, WA Country Health Service, Busselton Health Campus, transcript of evidence, 31 August 2020, p 6; Brett Hayes, Wheatbelt Palliative Care Manager, WA Country Health Service, transcript of evidence, 3 September 2020, pp 7–8; Michele Harvey, Nurse Practitioner – Chronic Disease, Ord Valley Aboriginal Health Service, transcript of evidence, 3 September 2020, p 9; Christine Waller, Senior Manager, Population Health Programs and Remote Areas, Derby Aboriginal Health Service, transcript of evidence, 3 September 2020, pp 6–7.

²⁷² Department of Health, *Sustainable Health Review: Final Report to the Western Australian Government*, 2019, p 7. See: <https://www2.health.wa.gov.au/-/media/Files/Corporate/general-documents/Sustainable-Health-Review/Final-report/sustainable-health-review-final-report.pdf>. Viewed 27 October 2020.

²⁷³ Submission 41 from Australian Medical Association (WA), 17 July 2020, p 4.

²⁷⁴ Christine Kane, General Manager, Strategy and Engagement, WA Primary Health Alliance, transcript of evidence 30 July 2020, p 5; Dr Sean Stevens, Chair, Royal Australian College of General Practitioners, transcript of evidence, 31 July 2020, pp 11–12; Tish Morrison, Silver Chain Group, Answer to question on notice 6 asked at hearing held 31 July 2020, dated 18 August 2020, p 13; Dr Mark Monaghan, Emergency Physician, Director of Medical Services, South West Coastal, WA Country Health Service, Busselton Health Campus, transcript of evidence, 31 August 2020, p 6; Michele Harvey, Nurse Practitioner – Chronic Disease, Ord Valley Aboriginal Health Service, transcript of evidence, 3 September 2020, p 9.

²⁷⁵ Tish Morrison, Silver Chain Group, Answer to question on notice 6 asked at hearing held 31 July 2020, dated 18 August 2020, p 13.

- 4.50 In relation to these limitations, the Service Development Guidelines note that:
- telehealth services must be supported by systems that ensure direct access to medical and/or nursing support, when required.²⁷⁶
- 4.51 WAPHA advised that the MBS funding made available for telehealth consultations by GPs because of COVID-19 had enabled a greater uptake of telehealth:
- [The funding] is still short term, but there is significant lobbying from GP peak organisations and consumer organisations to continue those telehealth MBS items, which has enabled a greater uptake of telehealth.²⁷⁷
- 4.52 AHCWA advised that this is also an issue for ACCHS:
- at the moment there is not an MBS item that says, "This particular person is spending sometimes two to three hours on a case conference." It could be one of the doctors in the ACCHS or an Aboriginal health worker sitting there doing that but there is no Medicare item for them to claim the time that they are actually doing that.²⁷⁸

Progress

- 4.53 The Department of Health advised that the use of telehealth had increased due to COVID-19:
- we saw an increased use of telehealth through COVID-19, which has been really beneficial, and I think again something we can learn from and think about how we use that better going forward. It has allowed us to have a really rapid route to enhancing our website to offer support to people who may want to look up advice and where they can access support as well.²⁷⁹
- 4.54 According to PCWA:
- The increased use of Telehealth in response to the COVID-19 pandemic has demonstrated significant opportunities that could be available with the increased use of technology. Telehealth will allow regional and rural patients much improved access to specialist palliative care but will also facilitate increased training and mentoring opportunities to primary and aged care staff practicing in the regions.²⁸⁰

FINDING 14

Telehealth is a welcome adjunct to direct access to palliative care and its use has increased in part as consequence of the COVID-19 pandemic.

²⁷⁶ Palliative Care Australia, *Palliative Care Service Development Guidelines*, January 2018, p 19. See: https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/02/PalliativeCare-Service-Delivery-2018_web2.pdf. Viewed 23 October 2020.

²⁷⁷ Christine Kane, General Manager, Strategy and Engagement, WA Primary Health Alliance, transcript of evidence 30 July 2020, p 5.

²⁷⁸ Shirley Newell, Executive Manager, Policy and Public Health, Aboriginal Health Council of Western Australia, transcript of evidence, 3 September 2020, p 12.

²⁷⁹ Assoc Prof Alison Parr, Clinical Lead, Palliative Care, WA Cancer and Palliative Care Network, transcript of evidence, 15 July 2020, p 5.

²⁸⁰ Submission 36 from Palliative Care Western Australia, 10 July 2020, p 22.

Telehealth in regional and remote areas

- 4.55 The Committee heard evidence from various sources of the expanding role of telehealth in the provision of palliative care services in regional and remote areas.
- 4.56 A number of regional service providers advised that they use telehealth frequently.
- Kimberley Aboriginal Medical Services advised:
We use telehealth very much on a daily basis, in and out of all of our clinics and for our on-call services.²⁸¹
 - Wheatbelt Palliative Care Service advised:
We currently provide a videoconferencing service within our team to patients' homes and we support them that way. It makes a huge difference to someone being able to stay in their home and feel supported.²⁸²
 - Derby Aboriginal Health Service advised:
Telehealth works very well. I love it. I think we should be doing more of it. My own personal view is that it is patient focused.²⁸³
 - Ord Valley Aboriginal Health Service advised:
We use telehealth. I love telehealth; I used it heaps in Queensland before coming here and really tried to ramp it up more here.²⁸⁴
- 4.57 In regional areas, the Department of Health acknowledges that telehealth 'provides an important role in supporting terminally ill patients and their families and carers, offering an option to remain at home with the aid of technology'.²⁸⁵

Progress

- 4.58 WACHS advised that it is developing a 'telehealth hub' to operate out of its command centre based at Royal Perth Hospital, which will operate as follows:
- in the first instance a phone number is called and then we have capacity through telepalliative care in the home and telehealth palliative care services through the command centre to provide either provisional or an additional layer of clinical support that will be enabled via face-to-face call through the iPads or Samsungs.²⁸⁶

²⁸¹ Dr Lorraine Anderson, Medical Director, Kimberley Aboriginal Medical Services, transcript of evidence, 3 September 2020, p 3.

²⁸² Brett Hayes, Wheatbelt Palliative Care Manager, WA Country Health Service, transcript of evidence, 3 September 2020, p 8.

²⁸³ Christine Waller, Senior Manager, Population Health Programs and Remote Areas, Derby Aboriginal Health Service, transcript of evidence, 3 September 2020, p 7.

²⁸⁴ Michele Harvey, Nurse Practitioner–Chronic Disease, Ord Valley Aboriginal Health Service, transcript of evidence, 3 September 2020, pp 1–2.

²⁸⁵ Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 12.

²⁸⁶ Marie Norris, Acting Executive Director, Nursing and Midwifery, WA Country Health Service, transcript of evidence, 18 September 2020, p 2.

- 4.59 The Department of Health advised that the WACHS telehealth hub will provide 24 hour support, including after-hours nursing support from 6pm to 8am.²⁸⁷
- 4.60 The 'Telepalliative Care in the Home' program using iPads has been piloted in the Wheatbelt WACHS region, and has been expanded to all of the other WACHS regions except the Kimberley and Pilbara, where it is expected to be rolled out by March 2021.²⁸⁸ According to the Department of Health, the program has 'enabled patients and carers to stay connected with palliative care staff through existing telehealth services'.²⁸⁹
- 4.61 The Acting Chief Executive of WACHS told the Committee:
- We have a long and strong history in telehealth service provision in country WA and, more recently, our really successful WACHS command centre, which you may well know as the emergency telehealth service recently expanded to inpatient telehealth service and mental health emergency telehealth service, and now we will have specialty streams attached to it, one of which will be palliative care support out to the regions.²⁹⁰
- 4.62 WACHS explained the operation of Telepalliative Care in the Home as follows:
- The TelePalliative Care in the Home service provides patients and their family/carer the opportunity to choose to access palliative care and support at home, to help patients remain at home longer. iPads and Samsung devices have been procured and are distributed to patients opting to receive care at home, so that they can connect with palliative care staff through video conference.²⁹¹
- 4.63 These measures have been funded through the funding of \$2.98 million announced in May 2019²⁹² for the expansion of telehealth services in regional Western Australia to 24 hour support.

FINDING 15

Following a pilot in the Wheatbelt region, the Telepalliative Care in the Home program has been expanded to all of the other regions of the WA Country Health Service, except the Kimberley and Pilbara where it is expected to be rolled out by March 2021.

Telehealth in metropolitan and outer-metropolitan areas

- 4.64 Some stakeholders noted that the WACHS telehealth model has potential to benefit patients in the metropolitan and outer-metropolitan areas. For example:
- PCWA noted in its submission:

²⁸⁷ Department of Health, *Palliative Care in WA*, PowerPoint presentation, tabled by Angela Kelly, Acting Director General, Department of Health, during hearing held 15 July 2020, p 14.

²⁸⁸ Jeffrey Moffet, Chief Executive, WA Country Health Service, Answer to question prior to hearing no 74, dated 18 September 2020, p 10.

²⁸⁹ Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 12.

²⁹⁰ Margaret Denton, Acting Chief Executive, WA Country Health Service, transcript of evidence, 15 July 2020, p 14.

²⁹¹ Jeffrey Moffet, Chief Executive, WA Country Health Service, Answer to question prior to hearing no 73, dated 18 September 2020, p 10.

²⁹² See Chapter 6, paragraphs 6.15 and 6.29–6.33.

Models being rolled out in WA Country Health Service (WACHS) could be replicated in Perth particularly for people in outer metro areas and for people whose illness makes it difficult to attend face-to-face appointments.²⁹³

- The AMA(WA) expressed the view that:

As WACHS enhances its telehealth structures and starts to provide palliative care via telehealth to rural and regional Western Australians, it's possible that patients in metropolitan Perth will not have the same level of support. It is important to try and avoid unnecessary duplication of services but there needs to be consistent access to support throughout WA, regardless of geographic location. Services should ideally be available 24/7 to all Western Australians and details of how to access this service must be clear to patients and health professionals.²⁹⁴

4.65 Silver Chain noted the following lessons from the COVID-19 pandemic in relation to its use of telehealth:

- Telehealth is useful for enabling continued interaction with our clients and their carers whilst alleviating their concerns about having visitors in their home at a time when physical distancing is necessary.
- Telehealth can be used to maintain support that is not related to hands-on nursing care. For example, our social workers have been able to provide financial assessments via telehealth. Telehealth could possibly be used to support discussion around advanced care planning and development of AHDs but we routinely encourage people [to] develop their AHD with their GP so that they remain connected with their primary health care provider.²⁹⁵

Progress

4.66 The Department of Health advised that a review of the current contract with Silver Chain is currently underway by WA Health,²⁹⁶ and that future service delivery models 'may include a telehealth component to palliative care service delivery and consideration of Siler Chain delivery of such a service'.²⁹⁷

RECOMMENDATION 4

The Minister for Health commission an independent evaluation of whether telepalliative care services would be of benefit to patients in the metropolitan area.

Issues in community palliative care

4.67 Issues concerning funding of community palliative care are discussed under recommendation 8 of the JSCEOLC in Chapter 5.²⁹⁸

²⁹³ Submission 36 from Palliative Care Western Australia, 10 July 2020, p 7.

²⁹⁴ Submission 41 from Australian Medical Association (WA), 17 July 2020, p 10.

²⁹⁵ Tish Morrison, Silver Chain Group, Answer to question on notice 7 asked at hearing held 31 July 2020, dated 18 August 2020, p 14.

²⁹⁶ Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 12, dated 18 September 2020, p 2.

²⁹⁷ Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question on notice 1 asked at hearing held 18 September 2020, dated 20 October 2020, p 2.

²⁹⁸ Paragraphs 5.34–5.53.

- 4.68 The Committee has identified a number of other issues relating to the progress of delivery of community palliative care services. These are:
- diversity and accountability of providers
 - the role of carers
 - access to domiciliary homecare services
 - after-hours care.

Diversity and accountability of providers

- 4.69 There is currently only one contracted service providing community palliative care services in the metropolitan area, which is the Silver Chain Community-Based Specialist Palliative Care Service.²⁹⁹
- 4.70 Amana Living submitted:
- There should be more options available to consumers to support and facilitate choice and ease of access to palliative care services.³⁰⁰
- 4.71 TPG Aged Care submitted that funding should be allocated to:
- a wider range of service providers to ensure that care is provided by support teams who are familiar to clients over a longer time frame to achieve improved social, clinical and financials (*sic*) outcomes for people at the end of life.³⁰¹
- 4.72 Bethesda also noted the opportunity to broaden the scope of community palliative care providers:
- Silver Chain is not the only possible provider of specialist palliative care services in the community, and all services operating in this setting need to be appropriately resourced.³⁰²
- 4.73 The AMA(WA) acknowledged that Silver Chain provides a vital service but raised concerns about the transparency, accountability and delivery model of publicly-funded, privately-operated providers.³⁰³
- 4.74 Silver Chain noted its support for the appointment of an independent review and an audit process pursuant to recommendation 14 of the JSCEOLC, to create transparency and equity across all aspects of palliative care service provision'.³⁰⁴

Progress

- 4.75 As noted in paragraph 4.66, a review of the current contract with Silver Chain is currently underway by WA Health.³⁰⁵ The Department of Health advised that the current contract

²⁹⁹ Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 11.

³⁰⁰ Submission 15 from Amana Living Incorporated, 9 July 2020, p 2.

³⁰¹ Submission 24 from TPG Aged Care, 10 July 2020, p 4.

³⁰² Dr Neale Fong, Chief Executive Officer, Bethesda Health Care, Answer to question on notice 1 asked at hearing held 30 July 2020, dated 28 August 2020, p 6.

³⁰³ Submission 41 from Australian Medical Association (WA), 17 July 2020, p 8.

³⁰⁴ Submission 42 from Silver Chain Group Limited, 14 July 2020, p 7.

³⁰⁵ Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 12, dated 18 September 2020, p 2.

expires on 30 June 2021, but that the finalisation date of the contract review is yet to be determined.³⁰⁶

4.76 In addition, the Department of Health advised:

the current suite of Silver Chain palliative care services is being considered in collaboration as part of the service model review and planning process to ensure that the most effective use of resources is undertaken, and identify opportunities to re-align or improve services in order to meet the needs and preferences of patients and their families accessing palliative care.³⁰⁷

4.77 The Department of Health advised that 'the newly introduced patient level reporting requirements for contracted entities will increase transparency and provide a detailed level of information regarding funding and service provision'.³⁰⁸

4.78 The Department also referred to the work underway to identify performance indicators to support improved accountability.³⁰⁹

FINDING 16

The outcome of the current contract review with the sole metropolitan provider of community specialist palliative care will be instrumental in any goal of increased market contestability of specialist community palliative care providers.

Role of carers

4.79 The important role of carers in relation to community-based specialist palliative care is discussed in Chapter 3.³¹⁰

4.80 A number of witnesses remarked on the need for increased assistance and respite services for carers.³¹¹

4.81 Although some progress is being made through carer education and support programs,³¹² which could be made available in a number of formats,³¹³ the availability of respite for carers was consistently raised as an area requiring attention.

4.82 Due to the critically important role of carers in the provision of in-home community palliative care services, the Committee noted that an increasing need for carer support and assistance

³⁰⁶ Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question on notice 1 asked at hearing held 18 September 2020, dated 20 October 2020, p 2.

³⁰⁷ Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 12, dated 18 September 2020, p 2.

³⁰⁸ Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 81, dated 18 September 2020, p 14.

³⁰⁹ *ibid.*

³¹⁰ Paragraphs 3.61–3.65.

³¹¹ Submission 4 from Albany Community Hospice, 5 July 2020, p 3; Submission 14 from Catholic Homes Incorporated, 9 July 2020, p 2; Submission 26 from Health Consumers' Council (WA), 10 July 2020, p 5; Submission 36 from Palliative Care Western Australia, 10 July 2020, pp 6 and 10; Dr Margherita Nicoletti, Consultant in Palliative Care, Rockingham Hospital, Dr Elissa Campbell, President, and Lana Glogowski, Chief Executive Officer, Palliative Care Western Australia, transcript of evidence, 31 July 2020, p 12; Rosie Brown, Chief Executive Officer and Jennifer Monson, Chair, Busselton Hospice Care Inc., transcript of evidence, 31 July 2020, p 11; Irene Mooney, Chief Executive Officer, MYVISTA, transcript of evidence, 10 August 2020, p 9.

³¹² For example, submission 12 from Busselton Hospice Care Inc., 9 July 2020, p 1.

³¹³ Submission 36 from Palliative Care Western Australia, 10 July 2020, p 10.

is an inevitable consequence of a policy to deliver more in-home palliative care services to patients wishing to remain at home.

4.83 In this context the Committee notes the comment of the JSCEOLC that:

The committee is concerned that the emphasis on community care is coming at the expense of optimal symptom relief and may also be placing carers and family under significant pressure in dealing with very distressing and unmanageable situations.³¹⁴

Communication with carers

4.84 The National Standards state:

It is important that the family and carers are provided with a clear plan for the management of out-of-hours concerns or unexpected events in relation to the care of the person.

...

a person may want specific family members or friends who are not their identified carers to be involved in and informed about their care. Clear identification of these individuals is necessary to enable effective communication and avoid distress caused by inadequate communication.³¹⁵

Carer support and respite

4.85 The Committee heard that the contribution of carers in the provision of in-home specialist palliative care services is significant.³¹⁶

4.86 EMHS noted in its Implementation Plan:

caring for a person with palliative care needs can be very challenging and many experience substantial physical, psychological, social and financial challenges. In addition, self-perceived burden is often reported by people living with a life-limiting condition as a significant issue.³¹⁷

4.87 Respite care is intended to reduce carer burden and maintain carer capacity.³¹⁸ It is defined as:

The provision of care for a person with a disability, severe medical condition or who is frail aged, by an organisation or another person other than the carer for a temporary period so the carer can have a break from caring.³¹⁹

³¹⁴ Western Australia, Legislative Assembly and Legislative Council, Joint Select Committee on End of Life Choices, report 1, *My Life, My Choice*, 23 August 2018, para 3.80, p 74.

³¹⁵ Palliative Care Australia, *National Palliative Care Standards*, 5th edition, 2018, p 15. See https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/11/PalliativeCare-National-Standards-2018_Nov-web.pdf. Viewed 23 October 2020.

³¹⁶ See paragraphs 3.61–3.65.

³¹⁷ East Metropolitan Health Service, *End-of-Life and Palliative Care Strategy Implementation Plan 2019– 2024*, September 2019, p 33 (Attachment to submission 8 from Dr Derek Eng, 8 July 2020).

³¹⁸ Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 11.

³¹⁹ Australian Government, Department of Health, *National Palliative Care Strategy 2018*, December 2018, p 30. See: <https://www.health.gov.au/resources/publications/the-national-palliative-care-strategy-2018>. Viewed 23 October 2020.

- 4.88 Silver Chain advised the Committee that they currently provide respite during the day, but that carers may also sometimes need overnight respite, which is currently not available.³²⁰
- 4.89 The Committee heard that the availability of respite services for carers in regional and remote areas is limited, but may now be available in some areas through the homecare packages made available by WACHS,³²¹ the details of which are outlined in Chapter 6.³²²
- 4.90 Albany Community Hospice advised that it provides respite care for community palliative care patients,³²³ and recommended that funding be made available for paid respite care in homes and hospice facilities.³²⁴

Progress

- 4.91 The Committee notes Priority Four of the WA Strategy, which is that ‘families and carers are supported’,³²⁵ and the recommended actions under this priority in Implementation Plan One, including to:

Develop care pathways to facilitate access to psychosocial, respite and bereavement support for carers, including support from volunteers.³²⁶

- 4.92 Apart from the development of the Implementation Plan and its recommended actions for increased support for families and carers, together with respite care under the WACHS domiciliary homecare packages discussed in Chapter 6, the Committee has seen little evidence of progress in addressing the needs of carers, including respite care.

FINDING 17

In some areas, respite care is limited or non-existent and is an important component in fulfilling the priority that Western Australian families and carers are supported and have access to such care.

Access to domiciliary homecare services

- 4.93 Another concern in relation to in-home palliative care service delivery is the availability of domiciliary homecare services for patients wishing to remain at home.³²⁷

³²⁰ Tish Morrison, Silver Chain Group, Answer to question on notice 3 asked at hearing held 31 July 2020, dated 18 August 2020, pp 4–5.

³²¹ Submission 33 from WA Country Health Service, 13 July 2020, p 10; Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 13; Department of Health, *Palliative Care in WA*, PowerPoint presentation, tabled by Angela Kelly, Acting Director General, Department of Health, during hearing held 15 July 2020, p 14.

³²² Paragraphs 6.58–6.61.

³²³ Submission 4 from Albany Community Hospice, 5 July 2020, p 1.

³²⁴ *ibid.*, p 3.

³²⁵ Department of Health, *WA End-of-Life and Palliative Care Strategy 2018–2028*, 2018, p 6. See: https://www2.health.wa.gov.au/~/_media/Files/Corporate/general%20documents/Health%20Networks/Palliative%20care/WA%20End-of-life%20and%20Palliative%20Care%20Strategy%202018-2028.pdf. Viewed 23 October 2020.

³²⁶ Department of Health, WA Cancer and Palliative Care Network, *WA End-of-Life and Palliative Care Strategy 2018–2028 Implementation Plan One 2020–2022*, 2020, p 22. See: https://pch.health.wa.gov.au/~/_media/Files/Corporate/Reports-and-publications/End-of-life/end-of-life-palliative-care-strategy-IP1.pdf. Viewed 27 October 2020.

³²⁷ Submission 36 from Palliative Care Western Australia, 10 July 2020, p 24.

4.94 WACHS advised in its submission that palliative care as an approach to care:

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.³²⁸

4.95 The following lengthy passage from the Department of Health's evidence to the Committee illustrates the complexities in access to domiciliary homecare packages for palliative care patients:

For many people, access to home care services occurs prior to the development of the person's palliative care needs and therefore those services are able to continue throughout the palliative phase. For these people access to home care continues via either through the National Disability Insurance Scheme, Commonwealth Home Support Programme (CHSP) or residual Home and Community Care Program services, Home Care Packages (HCP) or the Transition Care Program (TCP), while the palliative care service concurrently meets the person's palliative needs.

Programs such as Interim Hospital Packages (IHP), TCP and Silver Chain's Hospital Discharge Support (HDS) service are short-term, time-limited, post-discharge programs, aimed at improving clients' functioning (or also awaiting permanent residential aged care for TCP) to enable a return to greater independence and decreased service usage. Given this, these types of home care services are not always suitable for people with newly diagnosed palliative care needs. Referral to these services therefore needs to be made on a case-by-case basis.

For those palliative patients without existing home care services at the commencement of a palliative phase of care, the aged care guidelines for HCP and CHSP are relatively silent on whether palliative care patients meet the criteria for ongoing home care services and it is the responsibility of the assessment service – currently Regional Assessment Services (RAS) or Aged Care Assessment Teams (ACAT) - to determine eligibility based on individual circumstances.

Protracted delays and priority of access to limited services are also critical issues for palliative care patients (and families) with rapidly deteriorating clinical conditions. For example, protracted delays in accessing HCP were well documented in the Interim Report of the ongoing Royal Commission into Aged Care Quality and Safety. Consequently, some patients and families may need to privately fund home care assistance and others without financial capacity rely on ad hoc access to unpaid carers and volunteer services.³²⁹

4.96 ACSA advised:

Under a home care package unless the client has unspent funds, additional family support or willing to pay for additional care services the current funding levels make it difficult to fully support good palliative care – end of life care at home. Awareness of the need to plan for palliative care / end of life care is often lacking not only with older people and their loved ones, but also the GP's and hospital

³²⁸ Submission 33 from WA Country Health Service, 13 July 2020, p 10.

³²⁹ Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 29, dated 18 September 2020, p 6.

discharge teams. There are waiting periods for home care packages, finding the right provider and working through what individual choices and needs are.³³⁰

- 4.97 In regional areas, WACHS advised that some palliative care patients are at risk of hospital or residential aged care admission because of a lack of domiciliary homecare services.³³¹
- 4.98 In the metropolitan area, Silver Chain advised that it provides some home help services to its community palliative care clients.³³²
- 4.99 In all areas, the availability of homecare services was noted to be a particular issue in relation to patients under the age of 65.³³³ The Committee received evidence that following the transition from the Home and Community Care Program to the Commonwealth Home Support Program in July 2018, access to domiciliary homecare services for patients aged under 65 had become limited, and that waiting times for homecare packages can be up to 12 months.³³⁴
- 4.100 BHCI stated in its submission:

People under 65 with a palliative care diagnosis are not entitled to access any home care support as they do not meet the criteria for HACC or the disability scheme. There are no options for people under 65 and their families to access professional personal care or domestic support to enable them to exercise their choice to die at home. Any support provided to them is capped at limited time frames for only domestic help through Cancer Council and Red Cross. This is capped up to 6 visits. This is inconsistent and limited to certain geographical locations. People under 65 rely on their own informal networks to provide physical care and support a death at home.³³⁵

- 4.101 The Department of Health confirmed:

Protracted delays and priority of access to limited services are also critical issues for palliative care patients (and families) with rapidly deteriorating clinical conditions. For example, protracted delays in accessing HCP were well documented in the Interim Report of the ongoing Royal Commission into Aged Care Quality and Safety. Consequently, some patients and families may need to privately fund home care assistance and others without financial capacity rely on ad hoc access to unpaid carers and volunteer services.³³⁶

Progress

- 4.102 In the WACHS regions, as a result of recent funding discussed in Chapter 6 of this report,³³⁷ the Palliative Care Program now provides interim home care packages for palliative care patients in exceptional circumstances who do not qualify for the National Disability Insurance

³³⁰ Irene Mooney, Aged and Community Services Australia, Answer to question on notice 1 asked at hearing held 10 August 2020, dated 24 August 2020, p 2.

³³¹ Submission 33 from WA Country Health Service, 13 July 2020, p 10.

³³² Tish Morrison, Director, Clinical Operations, Palliative and End-of-life Care, Silver Chain, transcript of evidence, 31 July 2020, p 4.

³³³ Assoc Prof Alison Parr, Clinical Lead Palliative Care, WA Cancer and Palliative Care Network, transcript of evidence, 15 July 2020, p 5.

³³⁴ Submission 33 from WA Country Health Service, 13 July 2020, p 10.

³³⁵ Submission 12 from Busselton Hospice Care Inc., 9 July 2020, p 3.

³³⁶ Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 29, dated 18 September 2020, p 6.

³³⁷ Paragraphs 6.58–6.61.

Scheme or Commonwealth Home Support Program. As noted in Chapter 6,³³⁸ WACHS advised that as at 18 September 2020, 15 of these packages had been approved.

- 4.103 WACHS noted that in some areas there have been issues with the availability of local providers to provide services under those packages, and in some instances the services were being provided directly by WACHS.³³⁹
- 4.104 In the metropolitan area, the Committee has not seen evidence of progress in relation to the acknowledged problem of substantial delays in access to homecare packages by people under 65.

FINDING 18

Regional palliative care patients in exceptional circumstances who do not qualify for the National Disability Insurance Scheme or the Commonwealth Home Support Program now have access to interim domiciliary homecare packages through the WA Country Health Service.

RECOMMENDATION 5

The Minister for Health ensure that metropolitan palliative care patients who do not qualify for the National Disability Insurance Scheme or the Commonwealth Home Support Program have timely access to domiciliary homecare assistance.

After-hours care

'Death, like birth, is no respecter of time'

(AMA(WA))³⁴⁰

- 4.105 Many witnesses and submitters stressed the importance of a 24/7 model for the delivery of community palliative care.³⁴¹ Despite this, the Committee heard that the availability of after-hours palliative care across the state is variable.³⁴²
- 4.106 In metropolitan Perth, Silver Chain provides palliative care nursing services to its clients 24 hours per day, 7 days per week.³⁴³ Outside of the metropolitan area, GPs, some WACHS palliative care services and some ACCHS also provide after-hours care on what appeared to the Committee to be an ad hoc basis.³⁴⁴

³³⁸ Paragraph 6.60.

³³⁹ Nathalie Pass, Acting Coordinator of Nursing, Surgical Services, Ambulatory Care, WA Country Health Service Midwest, transcript of evidence, 14 September 2020, p 5; Marie Norris, Acting Executive Director, Nursing and Midwifery, WA Country Health Service, transcript of evidence, 15 July 2020, p 33.

³⁴⁰ Dr Andrew Miller, Australian Medical Association (WA), Answer to question on notice 4 asked at hearing held 31 July 2020, dated 26 August 2020, p 2.

³⁴¹ Dr Andrew Miller, Australian Medical Association (WA), Answer to question on notice 4 asked at hearing held 31 July 2020, dated 26 August 2020, p 2; Christine Kane, WA Primary Health Alliance, *Draft South West WA Palliative Care System Strategy*, 30 May 2019, Answer to question on notice 1 asked at hearing on 30 July 2020, 13 August 2020 p 1; Irene Mooney, Aged and Community Services Australia, Answer to question on notice 1 asked at hearing held 10 August 2020, dated 24 August 2020, p 2; Submission 31 from Hall & Prior Health & Aged Care Group, 10 July 2020, p 9; Dr Mark Monaghan, Emergency Physician, Director of Medical Services, South West Coastal, WA Country Health Service, Busselton Health Campus, transcript of evidence, 31 August 2020, p 8.

³⁴² See paragraphs 7.59–7.63.

³⁴³ Tish Morrison, Director, Clinical Operations, Palliative and End-of-life Care, Silver Chain, transcript of evidence, 31 July 2020, pp 3–4.

³⁴⁴ See paragraph 7.25.

- 4.107 The AMA(WA) noted that ‘GPs must be adequately remunerated to be on call and provide their patients with palliative care at any time of the day’.³⁴⁵
- 4.108 The availability of after-hours care in regional and remote areas is a significant issue in the delivery of community specialist palliative care and is discussed further in Chapter 7.³⁴⁶ The Committee found that access to after-hours palliative care is variable in regional and remote Western Australia in contrast to the metropolitan area.³⁴⁷

Progress

- 4.109 The Committee heard some evidence of progress in relation to after-hours palliative care services in regional and remote areas, which is outlined in Chapters 6 and 8.³⁴⁸

Community and volunteer involvement

Volunteers

- 4.110 The role of volunteers in the delivery of palliative care services is discussed in Chapter 3.³⁴⁹

- 4.111 BHCI advised the Committee:

any model of care that involves the use of volunteers adds an incredible amount to people at the end of life. It is enshrined in the services around the world and in the eastern states, but in WA there is no inclusion of volunteer services in the funded programs. We have been going for 30 years and we have never had any government funding. We are funded by the generosity of the local community.³⁵⁰

- 4.112 During the Committee’s visit to Busselton, representatives from BHCI advised that they found it increasingly difficult to obtain funding from donations from the local community, following the transfer of its volunteer workforce from the original hospice site to the WACHS-operated palliative care unit within the Busselton Health Campus in 2015.

- 4.113 Albany Community Hospice submitted:

Whilst our volunteers are willing and generous and capable, there are aspects of listening, assessing, empathising that need particular skills that would be invaluable in improving their care role with patients.

They especially need guidance in how to understand the specific needs of each dying person.

and recommended that funds and resources be provided to support volunteer training in palliative care.³⁵¹

- 4.114 In response to Committee questions about the impact of the volunteer workforce on numbers of paid staff, the Department of Health advised:

If, for example, there were less volunteers, it would be likely we would have to respond in some way. The volunteers provide essential community connection, and obviously a very personalised service to the clients that are in there. In the

³⁴⁵ Dr Andrew Miller, Australian Medical Association (WA), Answer to question on notice 4 asked at hearing held 31 July 2020, dated 26 August 2020, p 2.

³⁴⁶ Paragraphs 7.59–7.63.

³⁴⁷ Page 166 (finding 52).

³⁴⁸ Paragraphs 6.23 and 8.37.

³⁴⁹ Paragraphs 3.131–3.136.

³⁵⁰ Submission 12 from Busselton Hospice Care Inc., 9 July 2020, p 3.

³⁵¹ Submission 4 from Albany Community Hospice, 5 July 2020, p 3.

broadest terms, if we did not have the volunteers, would we need to increase our staffing? Probably, but I do not think it is a one-on-one increase, if you bring it back to basics.³⁵²

Progress

- 4.115 The Committee witnessed the important contribution of volunteers to the palliative care unit at the Busselton Health Campus.
- 4.116 The Committee has not seen evidence of progress in relation to the funding of volunteer services to provide the necessary support, training and infrastructure to guarantee the continued involvement of volunteers in the delivery of palliative care services.

FINDING 19

The funding of volunteer services to support, train and guarantee the sustainable involvement of volunteers in the delivery of palliative care in Western Australia remains under-prioritised.

Compassionate Communities model

- 4.117 The 'Compassionate Communities' model and its potential benefits in the delivery of community palliative care services were raised by a number of witnesses and submitters.
- 4.118 Palliative Care Australia describes Compassionate Communities as:
- a way of thinking about how care is provided to people who are dying. It relies on the identification and development of caring networks, around the person and their carer, extending the concept of person-centred care to network-focused care.³⁵³
- 4.119 WAPHA, which is undertaking a Compassionate Communities project in the Great Southern region, explained:
- Compassionate communities is an international public health palliative approach. The aim is to engage broad community support for people approaching the end of their lives. The model provides a more equitable level of palliative care for all people, irrespective of diagnosis and increases the quality of nonmedical nursing care in the context of diminishing resources.³⁵⁴
- 4.120 The Great Southern project is funded by the Commonwealth government under the 'Choice for At Home Palliative Care' Commonwealth budget measure.³⁵⁵ The project:
- aims to improve care coordination and clinical pathways across primary, secondary, tertiary and community health services to support at home palliative care. It also focuses on building community capacity, social capital and empowerment to create supportive environments for individuals around death, dying and loss.³⁵⁶

³⁵² Jeffrey Moffet, Chief Executive, WA Country Health Service, transcript of evidence, 18 September 2020, p 23.

³⁵³ Palliative Care Australia, *Compassionate Communities Communique*, p 3. Tabled by Jennifer Monson, Chair, Busselton Hospice Care Inc., during hearing held 31 July 2020.

³⁵⁴ Christine Kane, General Manager, Strategy and Engagement, WA Primary Health Alliance, transcript of evidence 30 July 2020, p 9.

³⁵⁵ *ibid.*

³⁵⁶ East Metropolitan Health Service, *End-of-Life and Palliative Care Strategy Implementation Plan 2019–2024*, September 2019, p 16 (Attachment to submission 8 from Dr Derek Eng, 8 July 2020).

4.121 A similar model has been operated in Busselton by BHCI since 2000.³⁵⁷

Progress

4.122 Compassionate Communities models are recognised as a priority in implementation in the final report of the Sustainable Health Review³⁵⁸ and are recommended in the Department of Health's Implementation Plan One.³⁵⁹

4.123 A number of witnesses expressed the view that the Compassionate Communities model should be implemented in other locations following the pilot program in the Great Southern.³⁶⁰ WAPHA advised that it plans to take the model into other regions, but will not have dedicated funding.³⁶¹

4.124 Assoc Prof Alison Parr advised that the Department of Health is:

also looking at models such as compassionate communities' models where actually you build capacity within the community and you enable them to be able to support each other in a different way. Those sorts of models do not rely on state funding other than to facilitate the set-up of the models. Once they are up and running, they are self-sufficient, potentially.³⁶²

RECOMMENDATION 6

The funding of volunteer services in palliative care be prioritised through models such as the Compassionate Communities model.

Late referral to palliative care

Method of referral and admission criteria

4.125 Referral to community specialist palliative care services can be made by GPs, medical specialists or nurse practitioners.³⁶³ Referral to hospital consultancy services can be made by

³⁵⁷ Jennifer Monson, Chair, Busselton Hospice Care Inc., transcript of evidence, 31 July 2020, p 2.

³⁵⁸ Department of Health, *Sustainable Health Review: Final Report to the Western Australian Government*, 2019, p 71. See: <https://ww2.health.wa.gov.au/-/media/Files/Corporate/general-documents/Sustainable-Health-Review/Final-report/sustainable-health-review-final-report.pdf>. Viewed 27 October 2020; East Metropolitan Health Service, *End-of-Life and Palliative Care Strategy Implementation Plan 2019–2024*, September 2019, p 16 (Attachment to submission 8 from Dr Derek Eng, 8 July 2020).

³⁵⁹ Department of Health, WA Cancer and Palliative Care Network, *WA End-of-Life and Palliative Care Strategy 2018–2028 Implementation Plan One 2020–2022*, 2020, p 28.

³⁶⁰ Submission 28 from Liam James McLaughlin Memorial Hospice, 10 July 2020, p 8; Submission 26 from Health Consumers' Council (WA), 10 July 2020, p 3; Christine Kane, General Manager, Strategy and Engagement, WA Primary Health Alliance, transcript of evidence, 30 July 2020, p 10; Lana Glogowski, Chief Executive Officer, Palliative Care Western Australia, transcript of evidence, 31 July 2020, pp 15–6; Clare Mullen, Engagement Manager, Health Consumers' Council (WA), transcript of evidence, 30 July 2020, pp 5–6.

³⁶¹ Christine Kane, General Manager, Strategy and Engagement, WA Primary Health Alliance, transcript of evidence 30 July 2020, p 10.

³⁶² Assoc Prof Alison Parr, Clinical Lead, Palliative Care, WA Cancer and Palliative Care Network, transcript of evidence, 18 September 2020, p 51.

³⁶³ Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 12.

medical, nursing or allied health staff.³⁶⁴ The Department of Health advised that self-referral is available for some services.³⁶⁵

- 4.126 The Department of Health's *Guide to Specialist Palliative Care Services* sets out the admission criteria for each of the five models of specialist palliative care shown in Figure 4. The *Guide to Specialist Palliative Care Services* is reproduced in Appendix 7.

Time of referral

- 4.127 Many witnesses and submitters commented that referral to specialist palliative care commonly occurs too late,³⁶⁶ one submitting that late referral to specialist palliative care 'remains a serious problem'.³⁶⁷

- 4.128 Dr Derek Eng submitted:

A large proportion of non-cancer patients do not receive timely palliative care. Statistics show that about 20-30% of dying patients will ever see a palliative care team and most of this occurs within days to weeks of death. We need earlier referrals (ideally 1 month or more before death) and 50 to 75% of patients accessing palliative care advice. Identification of these patients who need palliative care advice and management is an enormous challenge and requires financial and human resources.³⁶⁸

- 4.129 The EMHS Implementation Plan advised:

Many people are dying in hospital as it is too short notice to move them or hospice beds are [not] available at the time.³⁶⁹

- 4.130 There was also evidence of a large variation in when (that is, at what point in the patient's illness) individual specialists would refer to palliative care. This evidence was provided by a clinical haematologist, Dr David Joske, who tabled a paper he had published with Dr Kirsten Auret,³⁷⁰ asking Australian haematologists to respond to a number of hypothetical situations involving referral to specialist palliative care.³⁷¹

³⁶⁴ *ibid.*, p 9.

³⁶⁵ Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 7, dated 18 September 2020, p 2.

³⁶⁶ Submission 16 from Dr David Joske, 9 July 2020, p 1; East Metropolitan Health Service, *End-of-Life and Palliative Care Strategy Implementation Plan 2019–2024*, September 2019, p 24 (Attachment to submission 8 from Dr Derek Eng, 8 July 2020); Submission 10 from Motor Neurone Disease Association of WA Inc, 8 July 2020, p 1; Submission 24 from TPG Aged Care, 10 July 2020, p 1; Dr Paula Moffat, Medical Director, Palliative Care, Bethesda Health Care, transcript of evidence, 30 July 2020, p 7; Tish Morrison, Director, Clinical Operations, Palliative and End-of-life Care, Silver Chain, transcript of evidence, 31 July 2020, p 3; Shirley Newell, Executive Manager, Policy and Public Health, Aboriginal Health Council of Western Australia, transcript of evidence, 3 September 2020, pp 2–3.

³⁶⁷ Submission 34 from Bethesda Health Care, 10 July 2020, p 11.

³⁶⁸ Submission 8 from Dr Derek Eng, 8 July 2020, p 3.

³⁶⁹ East Metropolitan Health Service, *End-of-Life and Palliative Care Strategy Implementation Plan 2019–2024*, September 2019, p 24 (Attachment to submission 8 from Dr Derek Eng, 8 July 2020).

³⁷⁰ Now the Clinical Director, Palliative Care, WA Country Health Service.

³⁷¹ Submission 16 from Dr David Joske, 9 July 2020, p 1; Dr David Joske, Clinical Haematologist and Medical Co-Director, Sir Charles Gairdner Hospital; Founder, Solaris Cancer Care, transcript of evidence, 30 July 2020, p 2, citing K. Auret, C. Bulsara and D. Joske, *Australasian Haematologist referral patterns to palliative care: lack of consensus on when and why*, *Internal Medicine Journal* 2003; 33: 566–571, tabled by Dr David Joske during hearing held 30 July 2020.

4.131 The EMHS Implementation Plan noted that in some areas there is a lack of guidance about when to refer to specialist palliative care, specific tools and pathways.³⁷²

4.132 Dr Paula Moffat, Medical Director, Palliative Care with Bethesda advised:

I would surmise that it is not the palliative care colleagues in the tertiary hospitals that are identifying them too late. I think they are being referred to them too late, so they can only deal with what they are getting. We can understand from the community that people come in late from the community from Silver Chain because they have tried as long as they can at home. That is not an issue for us to take them really late because they have done all they can, but it is the ones from the hospitals that we do not quite understand why they are coming in so late.³⁷³

4.133 Silver Chain provided the following examples of late referrals to its community specialist palliative care service:

- We may receive a referral for a client to receive palliative care at home, and we commence the admission process, but the client is too unwell to get home. The client may deteriorate and die either in the hospital, hospice or on their way home. The Silver Chain palliative care nurse may have planned to visit them at home but may never have been able to see the client.
- We come across instances when clients have disclosed that they had requested referral to palliative care earlier, but that their doctor had suggested it was too early.
- We can receive referrals for clients already in their last days of life and they may die shortly within days or hours from the time of referral. Depending on their disease trajectory, some of these clients could have been provided optimal palliative care at home, had they been referred earlier. More timely referrals can enable better symptom management and quality of life for those with terminal illnesses.³⁷⁴

4.134 The JSCEOLC noted that for patients and their families, the decision to commence palliative care can be difficult as it 'involves an acknowledgment that the patient cannot be cured of the illness or disease that is afflicting them'.³⁷⁵ As noted in Chapter 2, Bethesda advised:

We observe that some associate palliative care with lesser levels of care, choice and hope.³⁷⁶

4.135 Silver Chain advised that clients sometimes decline referral to its palliative care service because they hold the belief that:

- they do not need palliative care
- it is too early

³⁷² East Metropolitan Health Service, *End-of-Life and Palliative Care Strategy Implementation Plan 2019– 2024*, September 2019, p 26 (Attachment to submission 8 from Dr Derek Eng, 8 July 2020).

³⁷³ Dr Paula Moffat, Medical Director, Palliative Care, Bethesda Health Care, transcript of evidence, 30 July 2020, p 10.

³⁷⁴ Tish Morrison, Silver Chain Group, Answer to question on notice 5 asked at hearing held 31 July 2020, dated 18 August 2020, p 12.

³⁷⁵ Western Australia, Legislative Assembly and Legislative Council, Joint Select Committee on End of Life Choices, report 1, *My Life, My Choice*, 23 August 2018, p 63 para 3.31.

³⁷⁶ Dr Neale Fong, Chief Executive Officer, Bethesda Health Care, Answer to question on notice asked at hearing held 30 July 2020, dated 28 August 2020, p 2.

- referral to specialist palliative care means that ‘there is no hope’
 - their death will be hastened.³⁷⁷
- 4.136 The Committee heard that a change in the referral culture involves, in part, addressing the misperceptions about palliative care discussed in Chapter 2.³⁷⁸
- 4.137 The Committee received evidence that early referrals to palliative care must be managed with sensitivity, having regard to the perception in the community that palliative care is for the ‘imminently dying’:³⁷⁹

Integration of palliative care is an individual, patient-centred process that starts with honesty and sensitivity at the point of diagnosis. There is heartening evidence that some haematology departments in Australia are providing leadership through their respect for the expertise of palliative specialists and their willingness to integrate such specialists (usually for psychosocial support, pain and symptom management) from the point of diagnosis. This is usually achieved by making an early referral under the guise of assistance with symptom control, which allows an introduction to be made between patients, carers and the palliative care team.³⁸⁰

- 4.138 The point was raised that early referral may not be appropriate in regional and remote areas if the specialist palliative care services available to the patient are based a significant distance from the patient’s home.³⁸¹

Benefits of early and proactive referrals

- 4.139 The value of early access to specialist palliative care was recognised by all witnesses to the inquiry,³⁸² and as noted by Bethesda, is supported by robust scientific evidence.³⁸³

- 4.140 Dr Derek Eng said of the importance of timely referrals:

We are saying, “How can we help you to live life the way you want to, even though you have a life-limiting disease?” ... if we say, “This could well be the last 12 months, and I’m hoping it won’t be, but we need to start thinking, if this is the last 12 months, how do we make the best of it?” That, in essence, is good palliative care.³⁸⁴

- 4.141 PCWA submitted:

Early and proactive intervention keeps people out of hospital, ensures a better quality of life, results in improved prognosis in some cases and better outcomes in bereavement. Services need to be able to respond earlier but currently there is

³⁷⁷ Tish Morrison, Silver Chain Group, Answer to question on notice 14 asked at hearing held 31 July 2020, dated 18 August 2020, p 18.

³⁷⁸ Paragraph 2.13.

³⁷⁹ Submission 41 from Australian Medical Association (WA), 17 July 2020, p 7.

³⁸⁰ D Joske and P McGrath, *Editorial: Palliative care in haematology*, *Internal Medicine Journal* 37 (2007) 589–590, p 590, tabled by Dr David Joske during hearing held 30 July 2020.

³⁸¹ Michele Harvey, Nurse Practitioner–Chronic Disease, Ord Valley Aboriginal Health Service, transcript of evidence, 3 September 2020, p 10.

³⁸² See for example, submission 36 from Palliative Care Western Australia, 10 July 2020, p 25; Submission 41 from Australian Medical Association (WA), 17 July 2020, p 8.

³⁸³ Submission 34 from Bethesda Health Care, 10 July 2020, p 11.

³⁸⁴ Dr Derek Eng, Palliative Care Physician and Member, Australian and New Zealand Society of Palliative Medicine, transcript of evidence, 30 July 2020, p 11.

very limited capacity to do so. Unfortunately we are still focussed on the very end of life, by which time people are distressed and carers are burnt out.³⁸⁵

4.142 The End-of-Life Framework states:

Evidence indicates that early referral is linked to improved quality of life and mood, survival and reduced depression and stress burden for family caregivers.³⁸⁶

Referral issues for non-cancer patients

4.143 The Committee heard that the issue of late referrals has particular impact on patients whose disease trajectory is long, including diseases other than cancer. The Motor Neurone Disease Association of WA Inc (MND Association) noted in its submission:

It is important that palliative care services are involved early after diagnosis for a rapidly progressive disease like MND to:

1. Enable adequate time to build a relationship
2. Manage symptoms throughout the course of the disease
3. Have conversations with the patient and family early enough about goals of care, advance care plans etc.³⁸⁷

4.144 It was noted that 'engagement of palliative care services with MND patients is often not long enough to establish a rapport before death, as the referral is accepted too late in the disease journey'.³⁸⁸

4.145 The MND Association advised:

- GP referral is often declined by palliative care services. No home visit for assessment takes place by the palliative team. Clarity on criteria needs to be improved.
- There is regular discharge from palliative care services that then requires a new referral for re-engagement.
- Palliative care services only accept referrals of 'dying' patients, or when they are distressed with symptoms, then discharge them.³⁸⁹

Progress in relation to change in referral culture

4.146 The Department of Health acknowledged a need to 'change the referral culture within palliative care away from us dealing with people in the very last days of life to the benefits that we can offer with early intervention and very proactive intervention as well'.³⁹⁰

³⁸⁵ Submission 36 from Palliative Care Western Australia, 10 July 2020, p 25. See also Submission 41 from Australian Medical Association (WA), 17 July 2020, p 8.

³⁸⁶ Department of Health, *The End-of-Life Framework: A statewide model for the provision of comprehensive, coordinated care at end-of-life in Western Australia*, 2015, p 11. See <https://ww2.health.wa.gov.au/-/media/Files/Corporate/general-documents/End-of-Life/PDF/The-End-of-Life-Framework.pdf>. Viewed 23 October 2020.

³⁸⁷ Submission 10 from Motor Neurone Disease Association of WA Inc, 8 July 2020, p 1.

³⁸⁸ *ibid.*

³⁸⁹ *ibid.*, p 2.

³⁹⁰ Assoc Prof Alison Parr, Clinical Lead Palliative Care, WA Cancer and Palliative Care Network, transcript of evidence, 15 July 2020, p 4.

- 4.147 In line with this, the Department's Implementation Plan One recommends improved timeliness and appropriateness of referrals from treating teams to specialist palliative care teams.³⁹¹
- 4.148 The Department of Health also acknowledged the importance of having services available to meet increased demand 'if the culture switched tomorrow'.³⁹²
- 4.149 The Committee notes that the measures implemented pursuant to JSCEOLC recommendation 11 (measures to improve understanding of palliative care)³⁹³ may improve understanding about palliative care by health professionals and may result in changes in the referral culture.
- 4.150 However, the Committee also notes that changes in workforce capacity³⁹⁴ are necessary to enable any changes in the referral culture to facilitate greater and earlier access to specialist palliative care.

FINDING 20

Despite the well-evidenced benefits of early and proactive referral to specialist palliative care, the change in referral culture necessary to achieve those benefits is yet to occur.

Issues in residential aged care

- 4.151 As discussed in Chapter 3,³⁹⁵ RACFs are increasingly a setting for palliative care services.
- 4.152 The National Standards state:
- It is important that older people are supported to receive high quality palliative care in the setting of their choice, whether that be in their own home, in residential aged care, in hospital or in a dedicated hospice service. For many people a residential aged care facility is their home and it is important they have access to the same range of community and inpatient based services available to people residing in their own homes. This includes access to appropriate and adequate levels of support from general practitioners and access to consultative support and/or direct care from specialist palliative care services on a needs basis.³⁹⁶
- 4.153 The General Manager, Care Services, Coolibah Care, Amanda Crook, advised in her evidence:
- I have worked now in aged care for only three years, so a short period in comparison to lots of people. I have not yet known one of our residents say that they did not want to die at our facility. They all want to die at the facility. They want to die at home. It is their home. They do not want to be going to a

³⁹¹ Department of Health, WA Cancer and Palliative Care Network, *WA End-of-Life and Palliative Care Strategy 2018–2028 Implementation Plan One 2020–2022*, 2020, p 18. See: <https://pch.health.wa.gov.au/-/media/Files/Corporate/Reports-and-publications/End-of-life/end-of-life-palliative-care-strategy-IP1.pdf>. Viewed 27 October 2020.

³⁹² Assoc Prof Alison Parr, Clinical Lead Palliative Care, WA Cancer and Palliative Care Network, transcript of evidence, 15 July 2020, p 5.

³⁹³ See paragraphs 5.85–5.108.

³⁹⁴ See paragraphs 4.186–4.197

³⁹⁵ Paragraphs 3.93 to 3.102.

³⁹⁶ Palliative Care Australia, *National Palliative Care Standards*, 5th edition, 2018, p 11. See: https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/11/PalliativeCare-National-Standards-2018_Nov-web.pdf. Viewed 23 October 2020.

hospice. They do not want to be going into hospital. They actually want to be dying at home.³⁹⁷

Barriers in relation to palliative care in residential aged care

4.154 The End-of-Life Framework document identifies the following barriers in relation to the provision of palliative care in RACFs:

- adequate staffing
- access to allied health providers
- limited access to general practitioners with skills and knowledge in end-of-life care.³⁹⁸

4.155 The Committee heard evidence that palliative care services provided in RACFs are limited. Dr Derek Eng advised:

Quite often I hear from residential facilities that they can look after “palliative care”. They certainly can, but what we are seeing is very basic palliative care. They can give morphine if there is a little bit of pain. They can give a little bit of sedative if there is some restlessness and they can certainly manage agitation if there is some agitation. But we know they are stretched from a staffing perspective. We know that, by and large, there are more carers than there are registered nurses.³⁹⁹

4.156 AMA(WA) submitted that RACFs:

have been referred to as “the new palliative care service” because a lot of people die in RACFs. However, RACF staff generally have limited palliative care training. Medical cover for RACFs is often not adequate, and very often is not 24/7. There is a need to develop better models for medical cover in RACFs to provide palliative care and/or solutions so staff can have palliative care support, for example, via telehealth after hours.⁴⁰⁰

4.157 St John of God Healthcare submitted that:

existing inpatient palliative care services across Perth are regularly at capacity with many patients being inappropriately managed in the community or aged care settings that are unable to care for deteriorating patients.⁴⁰¹

Funding issues

4.158 ACSA summarised the limitations of palliative care funding for RACFs as follows:

ACSA recognises that funding for aged care is largely a Commonwealth responsibility. However, it is impossible to consider the challenges of palliative care delivery to older people devoid of the context of the funding constraints within which aged care providers operate.

Aged care providers need to be funded through a mechanism that recognises the importance of palliative care and adequately funds providers to embed it within

³⁹⁷ Amanda Crook, General Manager, Care Services, Coolibah Care, transcript of evidence, 10 August 2020, p 5.

³⁹⁸ Department of Health, *The End-of-Life Framework: A statewide model for the provision of comprehensive, coordinated care at end-of-life in Western Australia*, 2015, p 8. See: <https://ww2.health.wa.gov.au/-/media/Files/Corporate/general-documents/End-of-Life/PDF/The-End-of-Life-Framework.pdf>. Viewed 23 October 2020.

³⁹⁹ Dr Derek Eng, Palliative Care Physician and Member, Australian and New Zealand Society of Palliative Medicine, transcript of evidence, 30 July 2020, p 6.

⁴⁰⁰ Submission 41 from Australian Medical Association (WA), 17 July 2020, p 10.

⁴⁰¹ Submission 11 from St John of God Health Care, 10 July 2020, p 1.

their service delivery models, including through ear-marked training to upskill staff where required.

The efficacy of state-run and state-funded specialist care services that intersect with the aged care system relies on the ability of aged care providers to be able to deliver the clinical care required during a person's end-of-life phase.

Thus without a stable and sustainable funding base, aged care providers will not be able to consistently act as the skilled, responsive partner to state-run palliative care services in delivering best practice end-of-life care to West Australians.⁴⁰²

- 4.159 In their submissions, Catholic Homes Incorporated, the Steering Committee, Western Australian Catholic Sector Response to Voluntary Assisted Dying and the LJ Goody Bioethics Centre expressed the concern that:

government funding for palliative care accessed in aged care facilities and home care does not match funding for the same services accessed in hospital acute care settings. For example, patients at the Community Hospice in Murdoch are funded under an acute care model, while just down the road patients at the Catholic Homes Comfort Care Centre receive much less funding under an aged care model.⁴⁰³

- 4.160 ACSA submitted that 'aged care providers are not consistently funded or supported to deliver a holistic approach to palliative care that responds to their clients' clinical needs as well as their personal preferences when it comes to end of life choices', and that in this constrained funding environment:

delivering a comprehensive suite of best practice palliative care choices can be a challenge for many aged care providers.⁴⁰⁴

- 4.161 ACSA noted that this issue could be addressed by the provision of a palliative care/end of life supplement, which could be offered to RACFs to enable appropriate remuneration for the additional care required during this time and to enable additional staffing.⁴⁰⁵
- 4.162 Funding issues affecting consultative palliative care services in aged care were raised by Bethesda, the operator of MPaCCS:

Mr HALLAHAN: We can charge for a visit to a facility to see a patient or a resident, but we can only charge one visit per patient per day. If we take along half a dozen people on our interdisciplinary team, we can still only make that one charge, whereas true interdisciplinary practice would be facilitated if we could, you know, take along the nurse and then charge perhaps not a complete visit but an additional sum if we took along a doctor, as clinically indicated, and a social worker, as clinically indicated. So this is about putting the clinical resources that the patient's or resident's situation requires in at the right time, in the one go.

Hon NICK GOIRAN: Is it the same charge irrespective of who attends?

Mr HALLAHAN: It is the same charge.

⁴⁰² Submission 17 from Aged and Community Services Australia, 10 July 2020, p 7.

⁴⁰³ Submission 14 from Catholic Homes Incorporated, 9 July 2020, p 2; Submission 7 from The Steering Committee, WA Catholic Sector Response to Voluntary Assisted Dying, 7 July 2020, p 2. See also Submission 3 from LJ Goody Bioethics Centre, 23 June 2020, p 4.

⁴⁰⁴ Submission 17 from Aged and Community Services Australia, 10 July 2020, p 5.

⁴⁰⁵ Irene Mooney, Aged and Community Services Australia, Answer to question on notice 5 asked at hearing held 10 August 2020, dated 24 August 2020, p 6.

Hon NICK GOIRAN: So, presumably, you still send out a team?

Dr MOFFAT: Yes, we do.

Mr HALLAHAN: We are seeing about 15 per cent of all MPaCCS visits require more than one healthcare professional, one clinician in attendance from different disciplines, but we can only charge the once.⁴⁰⁶

4.163 Bethesda also noted that MPaCCS is subject to a funding cap, which was exceeded in the year ending 30 June 2020.⁴⁰⁷

Unnecessary hospitalisations from residential aged care

4.164 The Committee heard evidence that the limitations in palliative care service delivery within RACFs often leads to unnecessary hospital admissions.

4.165 Dementia Australia submitted:

Once in their 'end of life' stage, people with dementia face frequent hospitalisations and may be given unnecessary procedures and treatment.

...

people with dementia can end up being caught in a cycle of transfers from home to hospital to residential aged care and back to hospital.⁴⁰⁸

4.166 Similarly, Dr Derek Eng submitted:

As MPaCCS is poorly resourced, patients in RACF are returning to Emergency Departments and subsequently dying in tertiary hospitals. Improvements in resourcing of specialist palliative care to RACF to enable hands-on, direct patient care at all hours of the day/night will improve end of life care in these facilities.⁴⁰⁹

4.167 The President of PCWA, Dr Campbell, advised:

I do agree that a lot of aged-care residents with palliative care needs do end up in emergency departments, because it is all well and good to say, "We've done an advance care plan and this person doesn't want to come into hospital", but you cannot also leave them suffering, extremely short of breath or in pain in the middle of the night and wait for a doctor to come in the next morning. I have worked for MPaCCS previously. The consultative nature means that the clinical governance or care of the patient remains under the general practitioner, not the doctors who work for MPaCCS, so we can ask the GP if they are happy for us to prescribe medications, but you cannot just go in there and write up medications, change the med charts and things like that. Most GPs are happy for the palliative care specialists to do that for them, but some do not want it to happen.⁴¹⁰

4.168 Mr Will Hallahan, Project Officer, Palliative Care with Bethesda Health Care, advised that Bethesda:

asked to use some of the money under the proposed [National Partnership Agreement on Comprehensive Palliative Care in Aged Care] to employ a liaison

⁴⁰⁶ Dr Paula Moffat, Medical Director, Palliative Care, and Will Hallahan, Project Officer, Palliative Care, Bethesda Health Care, transcript of evidence, 30 July 2020, p 6.

⁴⁰⁷ Dr Neale Fong, Chief Executive Officer, Bethesda Health Care, Answer to question on notice 1 asked at hearing held 30 July 2020, dated 28 August 2020, p 5.

⁴⁰⁸ Submission 5 from Dementia Australia, 9 July 2020, p 1.

⁴⁰⁹ Submission 8 from Dr Derek Eng, 8 July 2020, p 3.

⁴¹⁰ Dr Elissa Campbell, President, Palliative Care Western Australia, transcript of evidence, 31 July 2020, p 20.

nurse who would have a program of visitation around Perth hospitals looking at appropriate transfers, discharges back to residential aged-care facilities.⁴¹¹

- 4.169 Dr Kristi Holloway, Executive Manager of Clarence Estate, a RACF operated in Albany by Hall & Prior Health & Aged Care, noted that unnecessary hospital admissions could be avoided by greater availability of GPs after hours:

Access to GPs and also registered nurses was sometimes limited and I think there is still an element of access to GPs across the community in Western Australia that is limited after hours for residential care facilities. That is certainly something that we have addressed in recent times in Albany with a GP after-hours model which has been based on a collaborative model of GPs across the community, which has been absolutely amazing. That now means that residents and obviously their supporting staff have got access to GPs around the clock, which prevents unnecessary hospital presentations.⁴¹²

- 4.170 Family Voice Australia cited estimates of significant costs savings across Australia through funding more palliative care hospice beds, upskilling residential aged care staff to coordinate with palliative care specialists, and increasing appropriate palliative home care services:

If, we actually did [improve palliative care in nursing homes], the resulting net benefits from inappropriate hospital admissions would be about \$27m per annum. More importantly, it enables people to die safely and well in familiar environments...⁴¹³

Proposals to improve palliative care in residential aged care facilities

- 4.171 ACSA recommended in its submission to the inquiry:

While aged care providers are not and never will be a substitute for higher level acute care settings that some people will require during the terminal phase, there are several key ways through which providers could be better supported to cater to the end of life wishes of their residents and clients:

1. Adequate funding provision through the Aged Care Funding Instrument or other mechanism to ensure aged care providers are resourced and equipped to embed best practice palliative care principles within their day-to-day service delivery;
2. Improving access to external specialist palliative care services through a more consistent and seamless aged care/health system interface; and
3. Improving awareness and understanding of the practice of palliative care within the aged care and health systems, as well as the general population more broadly.⁴¹⁴

⁴¹¹ Will Hallahan, Project Officer, Palliative Care, Bethesda Health Care, transcript of evidence, 30 July 2020, p 10. See paragraph 4.175 as to the National Partnership Agreement on Comprehensive Palliative Care in Aged Care.

⁴¹² Dr Kristi Holloway, Executive Manager, Clarence Estate, Hall & Prior Health and Aged Care Group, transcript of evidence, 10 August 2020, p 10.

⁴¹³ Submission 6 from FamilyVoice Australia, 6 July 2020, p 3, citing Stephen Judd, *We can't build more hospitals*, Palliative Care Australia - Palliative Matters. See: <https://palliativecare.org.au/palliative-matters/we-cant-build-more-hospitals>. Viewed 27 October 2020.

⁴¹⁴ Submission 17 from Aged and Community Services Australia, 10 July 2020, pp 7–8.

4.172 In its submission, ANZSPM recommended that the Committee support:

improvements in the resourcing of specialist palliative care to RACFs, enabling hands-on, direct patient care at all hours of the day/night that will improve end of life care in these facilities and prevent unnecessary hospital admissions.⁴¹⁵

4.173 In the Current State Report, the 'Comprehensive Aged Residents Emergency and Partners in Assessment Care and Treatment' (CARE-PACT) model used in Queensland was raised as an exemplar model used in residential aged care facilities as a hospital substitution service that may be modified to include palliative care provision, and have applicability in Western Australia:⁴¹⁶

The four main components of the CARE-PACT model are:

- 1) Telephone triage and clinical care planning
- 2) Inpatient resource and early discharge service
- 3) Urgent assessment, care and treatment service provided by mobile teams
- 4) Consultation with a GP to ensure health concerns are resolved.⁴¹⁷

4.174 The Department of Health advised that the requirements for establishing a CARE-PACT type model in Western Australia had yet to be scoped, but that:

It may be possible to fund an initiative like this through the [National Partnership Agreement on Comprehensive Palliative Care in Aged Care]...⁴¹⁸

Progress in relation to palliative care in residential aged care

4.175 The Committee noted the National Partnership Agreement on Comprehensive Palliative Care in Aged Care (National Partnership Agreement), under which the Commonwealth and State governments will contribute \$5.7 million each to:

Support the delivery of projects that expand existing models of care or new approaches to the way care is delivered or commissioned, to improve palliative and end-of-life coordination for older Australians living in residential aged care facilities.⁴¹⁹

4.176 The scope of and delivery of services under the National Partnership Agreement is discussed in Chapter 6.⁴²⁰

4.177 The Department of Health advised:

As part of the immediate introduction of initiatives as part of the national partnership agreement, the department is in discussion with a number of service providers, including the Metropolitan Palliative Care Consultancy Service, commonly known as MPaCCS, and the Palliative and Supportive Care Education

⁴¹⁵ Submission 37 from The Australian and New Zealand Society of Palliative Medicine, 10 July 2020, p 10.

⁴¹⁶ Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 13.

⁴¹⁷ *ibid.*

⁴¹⁸ Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 111, dated 18 September 2020, p 21.

⁴¹⁹ Commonwealth of Australia & Government of Western Australia, *Project Agreement for Comprehensive Palliative Care in Aged Care*, October 2019, p 1.

⁴²⁰ Paragraphs 6.72–6.75.

service, PaSCE, to provide additional service and education that will improve residential aged-care facility capacity to deliver care in the initial phase of the program...

A longer term planning process is underway that will include close collaboration and engagement with a broader range of key stakeholders, such as health service providers, GPs, the WA Primary Health association, St John Ambulance, and, very importantly, consumers and peak bodies, to provide long-term solutions that will provide more integrated service delivery and care for people who are living in aged care and are at end of life.⁴²¹

FINDING 21

Progressing improved palliative care in residential aged care remains under-prioritised.

Psycho-social care

Importance of psycho-social care in palliative care

4.178 RANZCP submitted:

In designing palliative care it is helpful to consider Saunders' concept of 'total pain' – the suffering that encompasses all of a person's physical, psychological, social, spiritual and practical struggles. Responding to the physical pain and challenges of life-threatening illness is but one element of the provision of palliative care. Good mental health care in the palliative setting requires an integrated approach that is able to balance biological, psychological and social factors.⁴²²

Availability of consultant psychiatry services

4.179 RANZCP advised in its submission:

Adequate support for consultation–liaison services is essential in ensuring people with chronic and terminal illnesses are able to alleviate or manage psychological suffering. It is arguable that patients are currently able to fully exercise choice regarding end of life care where such services are unavailable or poorly understood.⁴²³

4.180 Due to the underfunding of consultant-liaison psychiatry in hospitals, and its inaccessibility in other settings, RANZCP submitted that:

palliative care patients in regional or remote areas, and those cared for at home or in a hospice setting do not have access to care that includes consultation-liaison psychiatry. This is significant as a large portion of these patients have either untreated mental health comorbidities or psychiatric side effects of their terminal illness or the treatments provided for these illnesses.⁴²⁴

4.181 RACGP expanded in its evidence to the Committee:

The current consultation–liaison services are inadequate, which is leading to poor quality care, increased length of stay, preventable behavioural disturbances in healthcare settings and unsafe discharge planning. We are also concerned that the

⁴²¹ Amanda Bolleter, Project Director, End of Life Care, Department of Health, transcript of evidence, 15 July 2020, p 8.

⁴²² Submission 21 from The Royal Australian and New Zealand College of Psychiatrists, 10 July 2020, p 1.

⁴²³ *ibid.*, p 2.

⁴²⁴ *ibid.*, p 2.

end-of-life care needs of those living in residential mental health and disability accommodation is not being adequately met.⁴²⁵

4.182 Similarly, Bethesda advised:

Critical gaps in the ability of services to provide comprehensive evidence-based psycho-social-spiritual support to patients and their family carers affects outcomes at different levels (individual, family, community and health system). Palliative care providers need more funding to provide comprehensive psycho-social-spiritual care for their patients and family carers.⁴²⁶

4.183 In response to a Committee question, RANZCP and Bethesda gave evidence that they supported the Committee making a recommendation in the same terms as recommendation 7 of the JSCEOLC Minority Report,⁴²⁷ which recommended:

The Minister for Health should develop a plan to increase the number of consultation-liaison psychiatrists in Western Australia.⁴²⁸

Progress in relation to psycho-social care

4.184 In 2020, the Department of Health's Implementation Plan One recommended that psychosocial care be promoted through strengthened funding, governance and quality measures.⁴²⁹

4.185 The Committee has not received any evidence of progress in relation to psycho-social care.

RECOMMENDATION 7

The Minister for Health develop a plan to increase the number of consultation liaison psychiatrists available to palliative care patients.

Workforce issues

Workforce benchmarks

Specialist palliative medicine physicians

4.186 A number of witnesses noted that the number of palliative care specialist physicians in Western Australia (and in all other states) is well below the benchmark number of 2.0 FTE

⁴²⁵ Dr Michael Verheggen, Psychiatrist, Western Australian Branch Committee Representative of the Royal Australian and New Zealand College of Psychiatrists, transcript of evidence, 30 July 2020, p 2.

⁴²⁶ Submission 34 from Bethesda Health Care, 10 July 2020, p 6.

⁴²⁷ Dr Michael Verheggen, Psychiatrist, Western Australian Branch Committee Representative of the Royal Australian and New Zealand College of Psychiatrists, transcript of evidence, 30 July 2020, p 5; Dr Paula Moffat, Medical Director, Palliative Care, Bethesda Health Care, transcript of evidence, 30 July 2020, p 8.

⁴²⁸ Parliament of Western Australia, Minority Report by Hon NP Goiran MLC for the Joint Select Committee on End of Life Choices submitted under Legislative Assembly Standing Order 274, *The safe approach to End of Life Choices: Licence to Care not Licence to Kill*, August 2018, p 55.

⁴²⁹ Department of Health, WA Cancer and Palliative Care Network, *WA End-of-Life and Palliative Care Strategy 2018-2028 Implementation Plan One 2020-2022*, 2020, p 17. See: <https://pch.health.wa.gov.au/-/media/Files/Corporate/Reports-and-publications/End-of-life/end-of-life-palliative-care-strategy-IP1.pdf>. Viewed 27 October 2020.

specialist palliative medicine physicians per 100 000 population recommended in the Service Development Guidelines.⁴³⁰

4.187 The Department of Health acknowledged this in the Current State Report, and advised:

HSPs have reported that this shortage impacts on their ability to meet demand for palliative care services. Additionally, with only 25 specialist palliative medicine physicians in WA, workforce shortages are felt by all clinicians when specialists retire or move outside of WA.⁴³¹

4.188 The latest data published by AIHW indicates that in 2018, this equated to a population ratio of specialist palliative medicine physicians per 100 000 population in Western Australia of 1.1 FTE (0.9 clinical FTE). Other states and territories varied from 0.7 to 1.8 FTE. Nationally, the ratio was 1.0 FTE (0.8 clinical FTE).⁴³²

4.189 In relation to inpatient hospital consultancy services, Dr Derek Eng explained:

We have one full-time equivalent of palliative care specialists in Royal Perth Hospital; there is about 1.7 in Sir Charles Gairdner and there is approximately about 1.2 in Fiona Stanley Hospital, so we talk about the biggest hospitals. That is essentially a little bit more than that full-time palliative care specialist for an entire hospital. If we were to take over a patient, we would not have any capacity to look after them properly.⁴³³

4.190 Dr Eng noted that addressing the ratio of specialist palliative care physicians will take time as well as financial investment:

Just because \$6 million is put into a service does not mean that will translate into care, partly because we just do not have the doctors. We cannot grow a doctor in nine months.⁴³⁴

Palliative care nurses

4.191 Palliative Care Australia's *Background Report to the Service Development Guidelines* states:

Palliative Care Nurses Australia does not publish ratios on what constitutes a minimum or desirable level of access to palliative care nurses, nor are there commonly accepted international benchmarks. There is not a sufficiently robust basis on which to set national workforce ratios for planning the requirements for palliative care nurses that form part of the specialist palliative care workforce.⁴³⁵

4.192 The latest data published by AIHW indicates that, in 2018, the population ratio of palliative care nurses per 100 000 population in Western Australia was 11.7 FTE (11.0 clinical FTE).

⁴³⁰ Palliative Care Australia, *Palliative Care Service Development Guidelines*, January 2018, p 22. See: https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/02/PalliativeCare-Service-Delivery-2018_web2.pdf. Viewed 23 October 2020.

⁴³¹ Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 30.

⁴³² Australian Institute of Health and Welfare, September 2020. See: <https://www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/contents/palliative-care-workforce>. Viewed 4 October 2020.

⁴³³ Dr Derek Eng, Palliative Care Physician and Member, Australian and New Zealand Society of Palliative Medicine, transcript of evidence, 30 July 2020, p 4.

⁴³⁴ *ibid.*, pp 8–9.

⁴³⁵ Palliative Care Australia, *Background Report to the Palliative Care Service Development Guidelines*, January 2018, p 31. See: https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/02/PalliativeCare-Background-to-Service-Delivery-2018_v3.pdf. Viewed 23 October 2020.

Nationally, the ratio was 12.0 FTE (11.2 clinical FTE) and other states and territories varied from 11.3 to 15.1 FTE.⁴³⁶

4.193 The Current State Report noted:

HSPs have reported shortages in specialist palliative care nurse positions and allied health.⁴³⁷

4.194 To meet the Service Development Guidelines for medical specialist palliative medicine physicians, the number of FTE would need to increase to 53.1 and to meet the Australian average of palliative care nurses, the number of FTE would need to increase to 324.1.⁴³⁸

4.195 Dr Derek Eng and the ANZSPM expressed the view that the palliative care workforce (including specialist palliative care medical, nursing and allied health) needs to double.⁴³⁹

Progress

4.196 In relation to palliative care specialist physicians, the Current State Report advised of the following planned actions:

- Additional funding to increase the number of specialist palliative care physicians in WA was not allocated in the January [Expenditure Review Committee] submission to Department of Treasury. Funding will be sought via future [Expenditure Review Committee] submissions.
- To achieve this, an increase in the number of positions available as well as training pathways would be required.⁴⁴⁰

4.197 In relation to the nursing and allied health workforce, the Current State Report advised that additional funding to increase the number of specialist palliative care nurses and allied health professionals in Western Australia was not allocated in the January Expenditure Review Committee submission to Department of Treasury, and that funding would be sought via future submissions.⁴⁴¹

Education and training issues

Palliative care specialist training

4.198 Dr Andrew Miller, President, AMA(WA) noted:

As I highlighted in our submission, the training pipeline has not been corrected at this point. There is no funding for a supervisor of training positions within the state, and those who are interested in going into this area are likely to travel over east... I think there is a brain drain in relation to people who are very interested in

⁴³⁶ Australian Institute of Health and Welfare, September 2020. See: <https://www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/contents/palliative-care-workforce>. Viewed 4 October 2020.

⁴³⁷ Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 30.

⁴³⁸ Staff calculations. Western Australia had a population of 2.7 million as at 31 March 2020 (Commonwealth of Australia, Australian Bureau of Statistics. See: www.abs.gov.au/statistics/people/population/national-state-and-territory-population/latest-release#states-and-territories. Viewed 15 October 2020).

⁴³⁹ Dr Derek Eng, Palliative Care Physician and Member, Australian and New Zealand Society of Palliative Medicine, transcript of evidence, 30 July 2020, p 5.

⁴⁴⁰ Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 30.

⁴⁴¹ *ibid.*

practising in this area. They want to go to a good environment—a healthy reef where there are lots of practitioners around and there is lots going on.⁴⁴²

- 4.199 ANZSPM submitted that ‘tertiary education also requires attention, to improve the baseline palliative care knowledge of healthcare professionals as they enter the workplace’.⁴⁴³

Training pathways that incorporate palliative care placements and rotations should begin in undergraduate healthcare professional education and extend into postgraduate training positions. Innovative funding, educational opportunities and supervision may provide the ability to develop services in rural areas. Collaborations with the Royal Flying Doctor Service, rural training pathways and Aboriginal Medical Services not only allow for greater integration of palliative care across the State, but also create a network of support and potential sustainability in terms of workforce development.⁴⁴⁴

- 4.200 The University of Notre Dame Australia advised in its submission:

The Schools of Medicine and Nursing & Midwifery currently address palliative care in an integrated fashion across the course, including lectures, interactive case based learning, and small group tutorials. Medical students have a 2 week clinical attachment with a palliative care service in 4th year, with close mentorship from palliative medicine specialists.⁴⁴⁵

GP training in palliative care

- 4.201 WAPHA noted that:

Knowledge about end-of-life care and specialist palliative care across the GP workforce is variable and there is significant scope to improve capability.⁴⁴⁶

- 4.202 It was noted that some GPs have concerns about the medico-legal implications of palliative care, which WAPHA noted may potentially be limiting their engagement with education and training.⁴⁴⁷

- 4.203 Albany Community Hospice advised that it:

has 56 accredited GPs, who have met our palliative care admission parameters, as approved by our Medical Advisory Committee. This ensures they gain increased exposure to new treatment trends and specialised experience in palliative care when they have patients in the Hospice.⁴⁴⁸

- 4.204 RACGP noted that a key issue in increasing GP knowledge and capacity in palliative care was the creation of GP registrar positions in palliative care.⁴⁴⁹ GP registrar positions do currently exist, but in the RACGP’s view there are not enough.⁴⁵⁰

⁴⁴² Dr Andrew Miller, President, Australian Medical Association (WA), transcript of evidence 31 July 2020, p 6.

⁴⁴³ Submission 37 from The Australian and New Zealand Society of Palliative Medicine, 10 July 2020, p 5.

⁴⁴⁴ *ibid.*

⁴⁴⁵ Submission 19 from the University of Notre Dame Australia, 10 July 2020, p 2.

⁴⁴⁶ Submission 40 from WA Primary Health Alliance, 17 July 2020, p 5.

⁴⁴⁷ *ibid.*

⁴⁴⁸ Submission 4 from Albany Community Hospice, 5 July 2020, p 2.

⁴⁴⁹ Submission 13 from Royal Australian College of General Practitioners, 9 July 2020, p 2; Dr Sean Stevens, Chair, Royal Australian College of General Practitioners, transcript of evidence, 31 July 2020, p 7.

⁴⁵⁰ Dr Sean Stevens, Chair, Royal Australian College of General Practitioners, transcript of evidence, 31 July 2020, p 11.

4.205 AMA(WA) submitted that an '8-12 weeks course should be made available to GPs seeking further education in palliative care'.⁴⁵¹

Workforce well-being

4.206 RANZCP gave evidence that:

members of our palliative care workforce ... have expressed distress and demoralisation about their inability to provide the level of care they believe should be available to the Western Australian community.

We note this to be particularly true when the palliative care workforce is supporting patients with complex comorbidity, such as mental illness or substance abuse disorders. Palliative care workers can face difficulties when accessing the appropriate specialist services to assist in managing patients with complex comorbidities who require more time spent caring for them. Tasks can end up being left uncompleted due to insufficient resourcing and workforce capacity. This can of course be demoralising.⁴⁵²

4.207 In relation to this issue, the Committee notes the comments of RANZCP that:

- an indirect role of consultation-liaison psychiatry services is the support of the healthcare workforce⁴⁵³
- consultation-liaison psychiatry is underfunded in major metropolitan public hospitals and 'practically inaccessible' in other service settings.⁴⁵⁴

Progress

4.208 The Department of Health advised that it is developing:

- an Education and Training for Health Professionals Framework, which is currently in draft and is being remodelled following input from key stakeholders
- a Training and Education Resource Hub which is due for completion by November 2020.⁴⁵⁵

4.209 The Committee has not heard evidence of progress in relation to the creation of more GP registrar positions in palliative care.

FINDING 22

In Western Australia, the:

- a) national benchmark number of specialist palliative care physicians specified in the *Palliative Care Service Delivery Guidelines* of 2.0 full time equivalent per 100 000 population has not been met
- b) number of palliative care nurses does not meet the national average of 12 full time equivalent nurses per 100 000 population according to the Australian Institute of Health and Welfare.

⁴⁵¹ Dr Andrew Miller, Australian Medical Association (WA), Answer to question on notice 4 asked at hearing held 31 July 2020, dated 26 August 2020, p 1.

⁴⁵² Prof Megan Galbally, Chair, WA Branch Committee, Royal Australian and New Zealand College of Psychiatrists, Answer to question on notice 3 asked at hearing held 30 July 2020, dated 13 August 2020, p 2.

⁴⁵³ *ibid.*

⁴⁵⁴ Submission 21 from The Royal Australian and New Zealand College of Psychiatrists, 10 July 2020, p 2.

⁴⁵⁵ Submission 23 from the Department of Health, 10 July 2020, p 14.

FINDING 23

Knowledge about end-of-life care and specialist palliative care across the general practitioner workforce is variable and there is significant scope to improve capability.

FINDING 24

The establishment of a training and education resource hub by the Department of Health will be a step towards addressing education and training issues impacting palliative care in Western Australia.

RECOMMENDATION 8

The Minister for Health explain why additional funding to increase the palliative care workforce was not allocated in the January 2020 Expenditure Review Committee submission.

RECOMMENDATION 9

A majority of the Committee, comprising Hon Nick Goiran MLC, Mr Zak Kirkup MLA, Mr Shane Love MLA and Hon Alison Xamon MLC, recommends that the Minister for Health prioritise additional funding to increase the palliative care workforce as noted in the Department of Health's *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, page 30.

RECOMMENDATION 10

The Minister for Health prepare a plan to:

- a) increase the palliative care workforce
- b) increase the availability of further education in palliative care and general practitioner registrar positions in palliative care.

Palliative care for Aboriginal people

4.210 The Committee adopted the Department of Health's use of the term 'Aboriginal' as follows:

Within Western Australia, the term Aboriginal is used in preference to Aboriginal and Torres Strait Islander, in recognition that Aboriginal people are the original inhabitant of Western Australia. Aboriginal and Torres Strait Islander may be referred to in the national context and Indigenous may be referred to in the international context. No disrespect is intended to our Torres Strait Islander colleagues and community.⁴⁵⁶

4.211 The Committee heard evidence that Aboriginal people are generally underrepresented in the palliative and end-of-life care patient population,⁴⁵⁷ and often have difficulty accessing palliative care services.⁴⁵⁸

⁴⁵⁶ *ibid.*, p 2.

⁴⁵⁷ Submission 40 from WA Primary Health Alliance, 17 July 2020, p 7, citing Palliative Care Outcomes Collaboration, 2018, *Patient outcomes in palliative care: national report July-December 2017*.

⁴⁵⁸ Submission 11 from St John of God Health Care, 10 July 2020, p 1.

- 4.212 The Current State Report identified that the JSCEOLC Report and the Consumer Workshop referred to in paragraph 5.59 had highlighted a number of barriers for Aboriginal Australians accessing palliative care services in Western Australia, including:
- a general distrust in mainstream healthcare services felt by many Aboriginal Australians
 - a lack of knowledge and understanding about palliative care
 - mainstream palliative care practices conflicting with cultural practices and beliefs concerning death.⁴⁵⁹
- 4.213 An area of particular concern to the Committee, which is discussed in more detail in Chapter 7,⁴⁶⁰ is the limited resources and infrastructure for community palliative care in rural and remote communities to support Aboriginal patients who wish to die at home or close to home.⁴⁶¹

Importance of beliefs and practices about death and dying

- 4.214 It is recognised that health care will be more effective if it is responsive to cultural needs. For example, the 2003 *National Indigenous Palliative Care Needs Study* concluded:

Facilitation of access to traditional medicine where requested and ensuring that protocols are in place to discover and accommodate end-of-life cultural practices should be an integral part of palliative care service delivery.⁴⁶²

- 4.215 It has been noted that beliefs about life and death will influence the extent to which Aboriginal people access health and palliative care, and that those beliefs and associated customs and ceremonies about death vary widely among Aboriginal groups and communities.⁴⁶³
- 4.216 Aboriginal culture is not singular, but rather consists of a number of diverse cultural groups who share some common values and beliefs.⁴⁶⁴
- 4.217 The needs and cultural preferences of each individual should be assessed. While there are some common themes or principles, a generalised view of 'Aboriginal culture' is unlikely to be relevant in all cases.⁴⁶⁵

⁴⁵⁹ Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 31.

⁴⁶⁰ Paragraphs 7.67–7.70.

⁴⁶¹ See Western Australia, Legislative Assembly and Legislative Council, Joint Select Committee on End of Life Choices, report 1, *My Life, My Choice*, 23 August 2018, para 3.60 p 71.

⁴⁶² Australian Government Department of Health and Aging, *National Indigenous Palliative Care Needs Study, Final Report*, report prepared by K Sullivan, L Johnston, C Colyer, J Beale, J Willis, J Harrison and K Welsh, Kate Sullivan and Associates Pty Ltd, Canberra, April 2003, p 82. See: <http://ksaco.com.au/files/PC%20Needs%20Study.pdf>. Viewed 17 September 2020.

⁴⁶³ AP O'Brien, MJ Bloomer, P McGrath, K Clarke, T Martin, M Lock, T Pidcock, P van der Riet, 'Considering Aboriginal palliative care models: the challenges for mainstream services', *Rural and Remote Health*, 2013, vol. 13, No 2, p 5. See: <https://www.rrh.org.au/journal/download/pdf/2339/>. Viewed 18 September 2020.

⁴⁶⁴ *ibid.*, p 3.

⁴⁶⁵ Program of Experience in the Palliative Approach (PEPA), *Cultural Considerations: Providing end of life care for Aboriginal peoples and Torres Strait Islander peoples*, Commonwealth of Australia, ACT, 2017, p 5. See: <https://pepaeducation.com/wp-content/uploads/2019/07/2651-Pepa-Indigenous-FlipChart-F4-LR.pdf>. Viewed 17 September 2020; Australian Government Department of Health and Aging, *National Indigenous Palliative Care Needs Study, Final Report*, report prepared by K Sullivan, L Johnston, C Colyer, J Beale, J Willis, J Harrison and K Welsh, Kate Sullivan and Associates Pty Ltd, Canberra, April 2003, p 38. See: <http://ksaco.com.au/files/PC%20Needs%20Study.pdf>. Viewed 17 September 2020; Australian Government Department of Health, *Exploratory Analysis of Barriers to Palliative Care*, report prepared by Australian Healthcare

Need for holistic approach to care

4.218 The *Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer* notes that because the well-being of Aboriginal people encompasses more than just medical imperatives, a holistic approach to health and well-being is important.⁴⁶⁶

For Aboriginal and Torres Strait Islander people, optimal patient-centred care includes acknowledging the philosophies of holistic health and wellbeing, and the role of Aboriginal and Torres Strait Islander knowledge, values, beliefs, cultural needs and health history in decision making about treatment and ongoing care. Patient-centred care also considers the impact of family structures and responsibilities including kinship (Council of Australian Governments 2016). It is also important to recognise that for Aboriginal and Torres Strait Islander people health means not just the physical wellbeing of an individual but refers to the social, emotional and cultural wellbeing of the whole community in which each individual is able to achieve their full potential as a human being, thereby bringing about the total wellbeing of their community. It is a whole-of-life view and includes the cyclical concept of life–death–life (National Aboriginal Community Controlled Health Organisation 2017).⁴⁶⁷

4.219 AHCWA advised in its submission:

Common to all ACCHS is a commitment to delivering health and wellbeing services under a holistic Model of Care designed by Aboriginal people, for Aboriginal people. The Model of Care necessarily locates Aboriginal people within the context of eight determinants of health; family; community; culture; language; country; physical wellbeing; spiritual wellbeing; and, emotional wellbeing. Each of these elements is fundamental to the health and well-being of Aboriginal people, their families and communities and must be the foundation for any palliative care services for Aboriginal people in WA.⁴⁶⁸

4.220 As an example of the need for a holistic approach to care, witnesses raised with the Committee a cultural requirement in some communities for a house in which a person had died to be vacated for a number of months after the death.⁴⁶⁹

4.221 The 2003 *National Indigenous Palliative Care Needs Study* advised:

In many parts of South Australia, the Northern Territory and Western Australia there are strong cultural requirements regarding ritual cleansing and/or vacating places where people have passed away and this can cause people to have to leave home. Sometimes houses are abandoned for months or years; sometimes they can be cleansed and re-occupied; sometimes they are cleansed and the family will swap with another family. Sometimes people have beliefs about spirits which may not be traditional but which will still require them to leave home.⁴⁷⁰

Associates, Melbourne, September 2019, p 7. See: <https://www.health.gov.au/resources/publications/exploratory-analysis-of-barriers-to-palliative-care-issues-report-on-aboriginal-and-torres-strait-islander-peoples>. Viewed 18 September 2020.

⁴⁶⁶ Cancer Australia, *Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer*, Australian Government, Canberra, p 8. See: <https://www.cancer.org.au/assets/pdf/optimal-care-pathway-for-aboriginal-and-torres-strait-islander-people-report> Viewed 11 September 2020.

⁴⁶⁷ *ibid.*, p 9.

⁴⁶⁸ Submission 38 from the Aboriginal Health Council of Western Australia, 13 July 2020, pp 1–2.

⁴⁶⁹ Shirley Newell, Executive Manager, Policy and Public Health, Aboriginal Health Council of Western Australia, transcript of evidence, 3 September 2020, p 6.

⁴⁷⁰ Australian Government Department of Health and Aging, *National Indigenous Palliative Care Needs Study, Final Report*, report prepared by K Sullivan, L Johnston, C Colyer, J Beale, J Willis, J Harrison and K Welsh, Kate Sullivan

- 4.222 Michele Harvey, Nurse Practitioner Chronic Disease, Ord Valley Aboriginal Health Service, recounted a conversation about this issue:

One lady said, “We have only got 14 houses in this community, and when someone dies, that house gets emptied, and those people have got nowhere to live, so can you build a spare house just for the person to die in and then it can always be empty until someone else needs to die so that that is the house the family move into?” This was a 70-odd-year-old lady who has just been through it so many times and seen that whole disruption: “My whole family of 20 people, usually kids and the works, having to move out of a house because someone died in that house.”⁴⁷¹

- 4.223 The Goldfields Regional Palliative Care Manager, Kalgoorlie Health Campus, Gayle Paterson, advised:

Some people do like to die in country and some do not. It is usually to do with the sorry camp. If somebody dies out in country—if they die in their house, family cannot live in that house for the next six months. Sometimes the patients will opt to come down to us to die in hospital because they do understand that their family cannot remain in that house...⁴⁷²

- 4.224 WACHS advised that because of this issue:

where it is appropriate, we would provide that service in a facility, and if that is not required by the family or the patient, then we support them to have their care provided in the home.⁴⁷³

- 4.225 It was clear to the Committee that unless issues of this nature are taken into account, palliative care services available to Aboriginal people may not offer a realistic choice of care setting.

Importance of person-centred care and a flexible approach

- 4.226 Palliative care for Aboriginal people requires a flexible approach to the delivery of services:⁴⁷⁴

‘Mainstream’ palliative care services are often not suited to care for Aboriginal and Torres Strait Islander people either culturally, geographically or logistically.⁴⁷⁵

- 4.227 The *Exploratory Analysis of Barriers to Palliative Care*, prepared for the Commonwealth Department of Health, advised:

Greater flexibility within services, including an ability and willingness to adapt ‘conventional’ processes to support cultural needs, was recognised as a key enabler of appropriate palliative care for Aboriginal and Torres Strait Islander

and Associates Pty Ltd, Canberra, April 2003, p 115. See: <http://ksaco.com.au/files/PC%20Needs%20Study.pdf>. Viewed 17 September 2020.

⁴⁷¹ Michele Harvey, Nurse Practitioner—Chronic Disease, Ord Valley Aboriginal Health Service, transcript of evidence, 3 September 2020, pp 11–12.

⁴⁷² Gayle Paterson, Goldfields Regional Palliative Care Manager, Kalgoorlie Health Campus, transcript of evidence, 14 September 2020, p 7.

⁴⁷³ Marie Norris, Acting Executive Director, Nursing and Midwifery, WA Country Health Service, transcript of evidence, 18 September 2020, p 24.

⁴⁷⁴ Australian Government Department of Health, *Exploratory Analysis of Barriers to Palliative Care: Literature Review* prepared by Australian Healthcare Associates, Melbourne, September 2019, p 15. See: <https://www.health.gov.au/resources/publications/exploratory-analysis-of-barriers-to-palliative-care-literature-review>. Viewed 21 September 2020.

⁴⁷⁵ *ibid.*, p 13.

peoples. For 'mainstream' services, this may include, for example, more appropriate accommodation (e.g. to cater for larger family groups, furnished/decorated in a culturally sensitive manner), relevant support for families, and openness to facilitating cultural requests relevant to end of life (eg smoking ceremonies).⁴⁷⁶

- 4.228 The Committee noted, during its visit to Busselton Health Campus, that the palliative care unit, whilst accommodating and 'non-clinical' in some respects, is located on the first floor of the building, and rooms have no direct access to outdoor areas, other than on a small private balcony.⁴⁷⁷ Building design of this kind raises issues in relation to its suitability and flexibility in the provision of specialist palliative care services for Aboriginal people.

RECOMMENDATION 11

Palliative care units be designed in consultation with local Aboriginal community members and elders.

Culturally secure palliative care

- 4.229 In this context, the Committee heard from a number of witnesses and submitters about the importance of culturally secure palliative care for Aboriginal people.⁴⁷⁸
- 4.230 Shirley Newell, Executive Manager, Policy and Public Health, AHCWA, advised that cultural safety involves 'an individual cultural perspective':

Just even having Aboriginal people present, especially one who is a local and understands the family and community, that goes way beyond a lot of things that are happening at the moment. It means a lot for them to have somebody there who understands what they are going through, who knows their family and can support their family.⁴⁷⁹

- 4.231 The following evidence from Christine Waller, Senior Manager, Population Health Programs and Remote Areas, Derby Aboriginal Health Service, illustrates culturally secure palliative care in practice:

The CHAIR: Just to tease out a little bit more, Christine, being culturally sensitive to Aboriginal people in the palliative care phase—how do you go about being sure that you are respecting the cultural traditions?

Ms WALLER: We ask the people to tell us what those needs are, and if we are making errors there, to tell us. We are all well-trained in culturally sensitive care. Ninety-eight per cent of our patients are Aboriginal. Our staff are long-term Derby

⁴⁷⁶ Australian Government Department of Health, *Exploratory Analysis of Barriers to Palliative Care*, report prepared by Australian Healthcare Associates, Melbourne, September 2019, p 15. See: <https://www.health.gov.au/resources/publications/exploratory-analysis-of-barriers-to-palliative-care-issues-report-on-aboriginal-and-torres-strait-islander-peoples>. Viewed 18 September 2020.

⁴⁷⁷ See Dr Mark Monaghan, Emergency Physician, Director of Medical Services, South West Coastal, WA Country Health Service, Busselton Health Campus, transcript of evidence, 31 August 2020, p 13.

⁴⁷⁸ Submission 38 from the Aboriginal Health Council of Western Australia, 13 July 2020, p 2; Submission 39 from East Pilbara Independence Support Inc, 15 July 2020, p 2; Jenny Bedford, Executive Manager, Kimberley Aboriginal Medical Services, transcript of evidence, 3 September 2020, pp 3 and 8; Submission 33 from WA Country Health Service, 13 July 2020, p 11; Submission 40 from WA Primary Health Alliance, 17 July 2020, p 8; Submission 19 from the University of Notre Dame Australia, 10 July 2020, p 2; Submission 37 from The Australian and New Zealand Society of Palliative Medicine, 10 July 2020, p 12.

⁴⁷⁹ Shirley Newell, Executive Manager, Policy and Public Health, Aboriginal Health Council of Western Australia, transcript of evidence, 3 September 2020, pp 6–7.

residents. We have many Aboriginal staff. We have senior Aboriginal elders on staff and on our board, and we will check with the right elder group, with the family, with the individual themselves and with our own built-up knowledge, the longstanding relationships between the families ... Every time we see them, we check: "Are we doing okay culturally? Is there someone else you might need to see? Can you tell us if we're going all right?" That is at every visit and we take note of that.

Then we have our cultural advisers and elders—a number of people. If it is for men, we would go to men, for women, to the women. As I said, some of them are part of DAHS. In my programs, I have many Aboriginal people—health professionals and others—who I can check with and bounce some cultural ideas off. It can be getting down to: "Would you like us to come in and have the elders smoke the house now or after?" Some have an affiliation with the church: "Do you want us to bring the church in now; or, you say when, if at all."⁴⁸⁰

- 4.232 The Committee received a submission entitled 'A positive view on Palliative Care Service Delivery in a remote indigenous community'.⁴⁸¹ The name of the service making the submission was redacted for cultural reasons at the request of the submitter. The submission stated 'palliative care from a cultural perspective delivered in a remote area has its challenges from both a medical and cultural point of view':

Clients have access to Medicine man when needed, families are also encouraged to visit during the evening without time restrictions and can stay the night in the dayroom with [the] client if they want to. Clients, if able are encouraged to be taken out in the community (by wheelchair or car) by staff to continue to be a part of the community. Aboriginal health workers from the families are encouraged to help out at the Centre to help with the traditional side of end of life. Non indigenous staff all have cultural awareness training and have lived in community for 10-15 years.

Traditional Bush medicine is used by the elders in the end of life process.⁴⁸²

- 4.233 The submission noted that the service is not a funded service for palliative care but delivers the service as part of the community need. Some services are brokered from a palliative care service provider.⁴⁸³
- 4.234 The Committee also received evidence from East Pilbara Independence Support Incorporated (EPIS) of palliative care 'from a Martu perspective', outlining some cultural beliefs relevant to the delivery of culturally secure palliative care in parts of the Pilbara.⁴⁸⁴
- 4.235 Numerous submissions and witnesses noted the need for training amongst health professionals in culturally secure palliative care.⁴⁸⁵

⁴⁸⁰ Christine Waller, Senior Manager, Population Health Programs and Remote Areas, Derby Aboriginal Health Service, transcript of evidence, 3 September 2020, p 5.

⁴⁸¹ Submission 18 from a private citizen, 10 July 2020.

⁴⁸² *ibid.*, p 1.

⁴⁸³ *ibid.*

⁴⁸⁴ *Palliative Care from a Martu Perspective*, tabled by Vicki Kershaw, Chief Executive Officer, East Pilbara Independence Support Inc., during hearing held 10 August 2020.

⁴⁸⁵ Submission 38 from the Aboriginal Health Council of Western Australia, 13 July 2020, p 4; Marie Norris, Acting Executive Director, Nursing and Midwifery, WA Country Health Service, transcript of evidence, 15 July 2020, p 15; Submission 33 from WA Country Health Service, 13 July 2020, p 11; Submission 25 from South Metropolitan Health Service, 10 July 2020, p 8; Submission 19 from the University of Notre Dame Australia, 10 July 2020, p 2.

4.236 AHCWA noted in its submission:

True access to palliative care services for Aboriginal people ... requires that those services are culturally appropriate. While there continues to be lack of access to comprehensive, culturally secure palliative care services in rural and remote areas, AHCWA welcomes the IP1's culturally sensitive approach for the future.⁴⁸⁶

4.237 AHCWA submitted:

Many health professionals continue to demonstrate a lack of awareness of cultural considerations and protocols related to death and dying. Therefore, the importance of ACCHS in palliative care for Aboriginal people is reinforced, as some of these customary traditions may be sacred and not shared with people outside the community.

Disappointingly, there are very few references to the need for culturally secure palliative care services in the Joint Select Committee into End of Life Choices report. AHCWA strongly recommends that all health professionals providing health care to Aboriginal people, whether it is palliative care or not, be required to undertake cultural safety training.⁴⁸⁷

4.238 SMHS submitted:

There is an opportunity to build on the expertise and knowledge within the SMHS Aboriginal Health Strategy Team to develop End of Life and Palliative care cultural care guidelines for implementation across for all Health Service Providers. This would be undertaken in consultation with community providers and community members. SMHS would require one-off seeding funding to undertake the development of this resource.⁴⁸⁸

Communication about death and dying

4.239 The Committee heard evidence of cultural beliefs which may impact on the ability of an Aboriginal patient or their family to discuss their palliative care needs with care providers, and to access palliative care services.

4.240 AHCWA advised in its submission:

There continues to be a lack of culturally appropriate resources for Aboriginal people to explain palliative care. Given the deep-seeded cultural perceptions of death and dying held by many Aboriginal people and their communities, it is very important that the benefits of engaging in palliative care in the early stages of a life-limiting illness are clearly defined.

Resources and educational material must also be developed with culturally appropriate language and images to support community understanding of palliative care.⁴⁸⁹

⁴⁸⁶ Submission 38 from the Aboriginal Health Council of Western Australia, 13 July 2020, p 2.

⁴⁸⁷ *ibid.*, p 4.

⁴⁸⁸ Submission 25 from South Metropolitan Health Service, 10 July 2020, p 6.

⁴⁸⁹ Submission 38 from the Aboriginal Health Council of Western Australia, 13 July 2020, p 3.

4.241 The Derby Aboriginal Health Service advised that it utilises a simplified form specially adapted for its clients in conjunction with local doctors in order to facilitate conversations about palliative care and ACP.⁴⁹⁰

4.242 AHCWA advised that ACCHS have a valuable communication role to play on these issues:

it has to be done in a culturally appropriate way. Like I said, we have got seven regions in WA. There are over 90 language groups and dialects within the Aboriginal population. A lot of the time people think we have developed an Aboriginal resource, but unless it is really significant to that local area, and that is what the ACCHS can actually help you do, because they are in those regions and they know what the languages are of the people who they are coming to be with, so they can actually advise on that.⁴⁹¹

4.243 The Department of Health advised that it is developing an Aboriginal End-of-Life and Palliative Care Framework, which:

outlines service considerations for the planning and provision of culturally respectful and appropriate end of life and palliative care. The Framework highlights the importance of developing culturally appropriate resources, in collaboration with local communities and service providers to meet the unique needs of those communities. There is also a brochure on ACP for Aboriginal people. The brochure outlines in simple, easy to understand and Aboriginal-oriented language about what ACP is and explains how people can go through the process. Aboriginal artwork is used throughout the document and there is also a vignette from an Aboriginal individual explaining how advance care planning may occur in community.⁴⁹²

RECOMMENDATION 12

The Minister for Health ensure that culturally appropriate resources are available for Aboriginal people to explain palliative care.

Progress in relation to palliative care for Aboriginal people

Additional WACHS Aboriginal health workers

4.244 The Committee notes the evidence from WACHS that, as at 18 September 2020, it had increased the number of Aboriginal health workers in its regional palliative care teams from one FTE to five FTE as part of the expansion of regional and remote community palliative care pursuant to recommendation 13 of the JSCEOLC.⁴⁹³

⁴⁹⁰ Christine Waller, Senior Manager, Population Health Programs and Remote Areas, Derby Aboriginal Health Service, transcript of evidence, 3 September 2020, pp 2–4 and Answer to question on notice 1 asked at hearing held 3 September 2020, dated 4 September 2020.

⁴⁹¹ Shirley Newell, Executive Manager, Policy and Public Health, Aboriginal Health Council of Western Australia, transcript of evidence, 3 September 2020, p 3.

⁴⁹² Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 91, dated 18 September 2020, pp 16–7.

⁴⁹³ Marie Norris, Acting Executive Director, Nursing and Midwifery, WA Country Health Service, transcript of evidence, 18 September 2020, p 12.

Aboriginal End-of-Life and Palliative Care Framework

- 4.245 As noted in paragraph 4.243, the Department of Health advised that it is developing an Aboriginal End-of-Life and Palliative Care Framework, to support and improve equity of access to palliative care by Aboriginal people throughout WA.⁴⁹⁴
- 4.246 As at September 2020, the Department of Health advised that the draft framework document and targeted stakeholder consultation had been completed. Following integration of feedback, the draft framework will be circulated to a wider stakeholder group for input.⁴⁹⁵
- 4.247 The Department advised that the framework will support health service providers in the planning and implementation of end-of-life and palliative care services for Aboriginal people by providing insight into relevant Aboriginal cultural knowledge and practices and outlining service considerations for the planning and provision of culturally respectful and appropriate end of life and palliative care.⁴⁹⁶

FINDING 25

The development of an Aboriginal End-of-Life and Palliative Care Framework will be an important first step to support and improve equity of access to palliative care by Aboriginal people throughout Western Australia.

Equity within Perth metropolitan and outer metropolitan areas

- 4.248 The JSCEOLC found that apart from a small number of private beds at Glengarry Hospital, there is no inpatient specialist palliative care hospice in the northern suburbs of Perth.⁴⁹⁷ Consequently, the JSCEOLC recommended that an inpatient specialist palliative care hospice providing publicly funded beds be established in the northern suburbs of Perth.⁴⁹⁸ The progress of this recommendation is discussed in Chapter 5.⁴⁹⁹
- 4.249 The Committee heard evidence from a number of sources that there is also a need for increased inpatient services in the southern suburbs of Perth.⁵⁰⁰
- 4.250 Dr Nicoletti and Dr Campbell from PCWA stated in their evidence:
- Dr NICOLETTI:** people from the Rockingham region in the south do not go to a hospice bed because it is too far to travel, so they stay in acute hospitals if it is inappropriate to be at home...
- Mr Z.R.F. KIRKUP:** I think Peel Health Campus has five palliative care beds.
- Dr NICOLETTI:** There is no palliative care service. They have nominal palliative care beds, but there is no palliative care service.

⁴⁹⁴ Submission 23 from Department of Health, 10 July 2020, p 5.

⁴⁹⁵ Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 89, dated 18 September 2020, p 16.

⁴⁹⁶ Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 90, dated 18 September 2020, p 16.

⁴⁹⁷ Western Australia, Legislative Assembly and Legislative Council, Joint Select Committee on End of Life Choices, report 1, *My Life, My Choice*, 23 August 2018, finding 10, p 67.

⁴⁹⁸ *ibid.*, recommendation 7, p 67.

⁴⁹⁹ Paragraphs 5.21–5.33.

⁵⁰⁰ Submission 25 from South Metropolitan Health Service, 10 July 2020, pp 2–5; Submission 34 from Bethesda Health Care, 10 July 2020, p 4; Submission 36 from Palliative Care Western Australia, 10 July 2020, p 24; Assoc Prof Alison Parr, Clinical Lead Palliative Care, WA Cancer and Palliative Care Network, transcript of evidence, 15 July 2020, p 5.

Mr Z.R.F. KIRKUP: What does that mean, sorry? ...

Dr CAMPBELL: It is a bed that is labelled “palliative care”, usually for people who are dying, but there is no palliative care specialist doctor and there is no palliative care multidisciplinary team of nurses and allied health professionals to care for that person.

Mr Z.R.F. KIRKUP: So effectively it is just a nicer room?

Dr NICOLETTI: Correct ... The generalist staff will look after that patient.⁵⁰¹

4.251 In relation to outer-metropolitan areas, AMA(WA) submitted:

For people who live in outer metropolitan areas of Perth, travelling into the city for palliative care is often daunting, inconvenient and expensive. It is also inappropriate to keep palliative care patients in their local acute hospital (especially when acute hospitals in outer metropolitan Perth are under resourced). Outer metropolitan areas of Perth desperately need more inpatient palliative care beds and access to the telehealth services implemented in WACHS.⁵⁰²

4.252 PCWA noted:

We have been very pleased to see the work done with the WA Country Health Service and the new models that are being set up there to improve access for people in rural and remote WA and we wonder if some of those models could also be helpful for people in the outer metropolitan areas like Waroona, Two Rocks or Gidgegannup.⁵⁰³

4.253 In contrast, the Chittering Health Advisory Group advised the Committee that community specialist palliative care services in the outer metropolitan part of the Shire of Chittering are more comprehensive than those available to residents of the northern part of Chittering which falls within the WACHS Wheatbelt region.⁵⁰⁴ The Committee notes that this may change as a result of the expansion of regional palliative care services discussed in Chapter 6.⁵⁰⁵

Progress

4.254 The Department of Health advised:

There was a recognition within the “My Life, My Choice” report that actually access to inpatient beds in the northern suburbs needed enhancing. That is certainly something that the Department of Health has moved with, but there was not a recognition that there is actually a gap south of the river as well. If we look at Mandurah and Rockingham areas and access to specialist palliative care inpatient beds, there is equally a need there potentially.⁵⁰⁶

⁵⁰¹ Dr Margherita Nicoletti, Consultant in Palliative Care, Rockingham Hospital and Dr Elissa Campbell, President, Palliative Care Western Australia, transcript of evidence, 31 July 2020, pp 5–6.

⁵⁰² Submission 41 from Australian Medical Association (WA), 17 July 2020, p 12.

⁵⁰³ Dr Elissa Campbell, President, Palliative Care Western Australia, transcript of evidence, 31 July 2020, p 4.

⁵⁰⁴ Submission 29 from Chittering Health Advisory Group, 10 July 2020, p 1.

⁵⁰⁵ Paragraphs 6.13–6.33.

⁵⁰⁶ Assoc Prof Alison Parr, Clinical Lead Palliative Care, WA Cancer and Palliative Care Network, transcript of evidence, 15 July 2020, p 5.

4.255 SMHS submitted that the additional funding made available in 2019–20:

does not address the identified significant gaps that exist in the current service provision at all SMHS hospital sites to provide equity of access to patients requiring palliative care. Further funding and investment is required.⁵⁰⁷

4.256 SMHS proposed the following actions:

- Build the capacity to provide appropriate and timely access to palliative and end of life care services to all patients who would benefit at Rockingham and Murray Districts hospitals.
- Advocate for the establishment of an inpatient specialist palliative care hospice in the southern corridor of SMHS catchment to overcome the barriers to access for the residents of Rockingham and Mandurah.⁵⁰⁸

4.257 The Committee has not heard evidence of progress in relation to the issues of equity of access in outer metropolitan areas.

FINDING 26

There is an inequity of access to appropriate and timely specialist palliative care in parts of the Perth metropolitan area, including the south metropolitan region which particularly impacts residents in and around the Rockingham and Mandurah corridor.

Palliative care for specific groups

4.258 Dr Margherita Nicoletti, Consultant in Palliative Care, Rockingham Hospital and board member of PCWA, advised:

We are a diverse community and in palliative care, one size does not fit all. We have heard from that diverse community. We have done workshops with Aboriginal people, local culturally and ethnically diverse people, people with disabilities and people with diseases that do not often fit into the mainstream palliative care model here in WA like motor neurone disease. What we have heard loud and clear is that one size does not fit all, that the palliative care sector needs to be made more aware, maybe trained in or certainly informed about cultural differences, about becoming more culturally competent in providing care at end of life for these vulnerable groups of people, and vulnerable groups of people that have a high mortality. I guess what I am saying is that in palliative care more training needs to be done to cover the care providers in cultural safety.⁵⁰⁹

4.259 PCWA submitted that the palliative care needs of the following specific groups were not addressed in the report of the JSCEOLC:

- paediatric palliative care
- culturally and linguistically diverse communities
- people experiencing cognitive decline and dementia
- people with disabilities
- people living with mental illness

⁵⁰⁷ Submission 25 from South Metropolitan Health Service, 10 July 2020, p 2.

⁵⁰⁸ *ibid.*

⁵⁰⁹ Dr Margherita Nicoletti, Consultant in Palliative Care, Rockingham Hospital, transcript of evidence, 31 July 2020, p 3.

- people with degenerative neurological conditions
- people experiencing homelessness
- the LGBTIQ community
- asylum seekers
- prisoners.⁵¹⁰

FINDING 27

The report by the Joint Select Committee on End of Life Choices did not address the palliative care needs of several specific groups, namely paediatric patients, culturally and linguistically diverse communities, people experiencing cognitive decline and dementia, people with disabilities, people living with mental illness, people with degenerative neurological conditions, people experiencing homelessness, the LGBTIQ community, asylum seekers and prisoners.

Paediatric palliative care

Differences between paediatric and adult palliative care

4.260 In its submission to the inquiry, CAHS detailed the many distinct differences between paediatric and adult palliative care and advised:

There are unique characteristics of paediatric palliative care that differentiate it from adult palliative care that warrant special consideration for service planning and resource allocation.⁵¹¹

Need for a children's hospice

4.261 Currently, the WA Paediatric Palliative Care Service, a consultative service hosted by CAHS, is the only specialist palliative care service for children in Western Australia.⁵¹²

4.262 The Current State Report noted that a comparative analysis of existing national and international palliative care models against current Western Australian palliative care models had highlighted a lack of 'hospice care' for children in Western Australia:

This limits choice for place of care at end of life, choices of respite care, restricts access to coordinated psychosocial support and limits comprehensive bereavement support. Bear Cottage (New South Wales), Very Special Kids (Victoria) and Hummingbird House (Queensland) are the only hospices available for children and their families in Australia, with only 24 beds available nationwide. The hospices provide 24 hour specialist care from palliative care consultants, nurses, social workers and therapists trained in complex needs, family support, creative therapies and end-of-life care.⁵¹³

4.263 CAHS submitted that:

the current lack of a children's hospice in WA has an adverse effect on choice, and quality of care offered to children and families in WA. This is not merely about a bed in any hospice; it reflects the need for a place of care which can address the

⁵¹⁰ Submission 36 from Palliative Care Western Australia, 10 July 2020, p 7.

⁵¹¹ Submission 6 from Child and Adolescent Health Service, 6 July 2020, p 2.

⁵¹² *ibid.*, p 3.

⁵¹³ Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 13.

specialist, holistic needs of palliative care children and their families, during illness, at end of life and for the family who live on.⁵¹⁴

Regional and remote paediatric palliative care

- 4.264 WACHS advised that, as at July 2020, approximately 10–15 paediatric palliative care patients are supported by the Perth Children’s Hospital state-wide service in rural and remote Western Australia.⁵¹⁵

Progress in relation to paediatric palliative care

- 4.265 CAHS advised that it has commenced a project to develop a paediatric addendum to the WA Strategy, and an Optimal Care Pathway for Paediatric Palliative Care, in collaboration with the WA Cancer and Palliative Care Network and Curtin University:

The project included state-wide consultation with consumers and service providers in rural and metropolitan areas. Consumers included bereaved parents and parents of current palliative care patients. Over 160 people contributed to the project.⁵¹⁶

- 4.266 In August 2020, the Government announced the construction of a new children’s hospice in Perth. Details of this announcement and the ongoing operation of the proposed hospice are set out in Chapter 6.⁵¹⁷
- 4.267 The Committee notes the progress generally in regional and remote community palliative care by WACHS.⁵¹⁸ However CAHS submitted that:

The Management of children and their families with palliative care needs in regional and remote WA requires paediatric clinical collaboration and oversight by specialist Paediatric palliative care service to support the adult paediatric work services. This is necessary due to the small numbers of children in each area, rare conditions and hence the ability for local teams to develop appropriate skills to manage such children is challenging (*sic*). Despite funding increases into regional services investment in developing stronger process for paediatric patients has not occurred.⁵¹⁹

FINDING 28

The construction of a new Children’s Hospice will be a welcome addition to Western Australia’s palliative care infrastructure.

FINDING 29

Despite funding increases in regional services, investment in developing a stronger process for paediatric palliative care patients in regional and remote areas has yet to occur.

Culturally and linguistically diverse groups

- 4.268 The National Standards state:

Differences in beliefs, values, and traditional health care practices may be of particular relevance for people at the end of their life. Quality, appropriate and

⁵¹⁴ Submission 6 from Child and Adolescent Health Service, 6 July 2020, p 3.

⁵¹⁵ Submission 33 from WA Country Health Service, 13 July 2020, p 5.

⁵¹⁶ Submission 6 from Child and Adolescent Health Service, 6 July 2020, p 4.

⁵¹⁷ Paragraphs 6.86–6.90.

⁵¹⁸ See paragraphs 6.13–6.33.

⁵¹⁹ Submission 6 from Child and Adolescent Health Service, 6 July 2020, p 7.

comprehensive care is culturally sensitive and requires health professionals to understand each person's view of the situation and their expectations regarding decision making and type of care.⁵²⁰

4.269 In its submission to the inquiry, the Office of Multicultural Interests emphasised the necessity of sharing information on palliative care to people from culturally and linguistically diverse backgrounds.

Without appropriate and relevant information available in multiple languages (including plain English) and through diverse channels of communication, people from [culturally and linguistically diverse] backgrounds find it increasingly difficult to make informed decisions.⁵²¹

4.270 Specifically, the Office of Multicultural Interests noted the importance of:

- culturally competent staff who demonstrate empathy and openness, cultural awareness and understanding of different client groups and communities
- the provision of language resources to ensure equitable access by clients who are not proficient in spoken or written English
- collection of cultural and linguistic data that identifies the demographic profile of clients to contribute to evidence-based policy and program development
- the engagement of diverse communities in policy and program design, development, implementation and review.⁵²²

4.271 The National Standards note the importance of flexible models of care, which:

may assist in considering how to best support local communities, as well as to support people to access care that not only considers their culture and language but also recognises their individualised needs as well.⁵²³

4.272 The Committee noted that it is a building block to priority one of the WA Strategy ('Care is accessible to everyone, everywhere') in the Department of Health's Implementation Plan One to:

Improve access to care for Culturally and Linguistically Diverse communities.⁵²⁴

4.273 Recommended actions under this building block include:

- identifying access gaps
- building on existing relationships with under-served population groups and organisations to develop culturally respectful and appropriate training and resources.⁵²⁵

⁵²⁰ Palliative Care Australia, *National Palliative Care Standards*, 5th edition, 2018, p 12. See: https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/11/PalliativeCare-National-Standards-2018_Nov-web.pdf. Viewed 23 October 2020.

⁵²¹ Submission 32 from The Office of Multicultural Interests, 13 July 2020, p 2.

⁵²² *ibid.*, pp 3–4.

⁵²³ Palliative Care Australia, *National Palliative Care Standards*, 5th edition, 2018, p 12. See: https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/11/PalliativeCare-National-Standards-2018_Nov-web.pdf. Viewed 23 October 2020.

⁵²⁴ Department of Health, WA Cancer and Palliative Care Network, *WA End-of-Life and Palliative Care Strategy 2018–2028 Implementation Plan One 2020–2022*, 2020, p 8. See: <https://pch.health.wa.gov.au/-/media/Files/Corporate/Reports-and-publications/End-of-life/end-of-life-palliative-care-strategy-IP1.pdf>. Viewed 27 October 2020.

⁵²⁵ *ibid.*, p 9.

People experiencing cognitive decline and dementia

4.274 In its discussion paper *Dying Well: improving palliative and end of life care for people with dementia*, Dementia Australia noted:

[In] Australia, palliative care services for dementia are inconsistent in the way they are delivered, they lack equitable service provision, and services lack unified standards and accepted definitions. Improving palliative care for people with dementia therefore must be a policy priority, Australia-wide, across the different states and territories.⁵²⁶

4.275 In the discussion paper, Dementia Australia called on the Australian government in collaboration with State and Territory governments:

to systematise and customise palliative care for people with dementia, acknowledging the contextual complexities of dementia care within the different health care and community settings.⁵²⁷

4.276 In its submission, Dementia Australia highlighted the need 'to upskill the workforce, particularly those within [WA Health], to ensure that all staff, including medical practitioners and decision makers receive specific dementia training'.⁵²⁸

4.277 The Department of Health advised that the need for specific training in providing palliative care for people with dementia has been identified in the Education and Training for Health Professionals Framework referred to in paragraph 4.208.⁵²⁹

4.278 In addition to training:

Dementia Australia supports a collaborative approach, whereby medical professionals ... utilise the expertise of neuropsychologists, geriatricians, palliative care professionals and dementia experts to ensure the best possible advice is being given to people living with dementia, their families and carers.⁵³⁰

4.279 The Department of Health advised:

The complexity of the disease trajectory and implications for clinical, social and psychological care needs highlight the need for a carefully considered model that would best meet the needs of this cohort, consistent with the [Dementia Australia's *Dying Well* Report]. Negotiation is currently underway with Silver Chain to bolster an existing model that provides care for those with dementia. The additional funding will allow improved wrap around services that will facilitate dying in their own home for those who wish to. It is considered a pilot program to allow for evaluation and modification to ensure effective service delivery and efficient funding utilisation.⁵³¹

⁵²⁶ Dementia Australia, *Dying Well*, November 2019, p 1. See: <https://www.dementia.org.au/sites/default/files/documents/19013-DA-Dying-Well-Discussion-Paper.pdf>. Viewed 27 October 2020.

⁵²⁷ *ibid.*

⁵²⁸ Submission 5 from Dementia Australia, 9 July 2020, p 2.

⁵²⁹ Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 98, dated 18 September 2020, p 18.

⁵³⁰ Submission 5 from Dementia Australia, 9 July 2020, p 2.

⁵³¹ Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 28, dated 18 September 2020, p 6.

- 4.280 PCWA also noted the importance of ACP and supported decision-making for people experiencing cognitive decline or dementia.⁵³²

Progress specific to people experiencing cognitive decline and dementia

- 4.281 The Department of Health advised that it is developing a Palliative Care Dementia Framework, 'to support and improve equity of access to palliative care'.⁵³³
- 4.282 As at September 2020, the Department advised that an initial draft of the framework document had been undertaken and targeted consultation was underway to ensure scope and purpose of the framework meets with the needs of the community and service providers:

The framework aims to support local health services in the planning and delivery of care to meet the needs of people with dementia and their carers. In doing this, it aims to expand awareness and understanding of the specialist needs associated with caring for people with dementia and other forms of cognitive decline so that health services are better equipped to address these unique needs, ultimately, improving access to appropriate end-of-life care for people with dementia.

The Framework will align with the WA End of Life and Palliative Care Strategy's six Priorities and will assist health systems and services to operationalise the Priorities in local implementation plans as they relate to the needs of these people.⁵³⁴

People with intellectual disabilities

- 4.283 Developmental Disability (WA) submitted that:

In our experience people with intellectual disability are usually not told they are terminally ill or that one of their family members may be terminally ill. We are not aware of any resources that are WA based that address this issue.⁵³⁵

- 4.284 In support of that submission, copies of information resources developed in New South Wales addressing palliative care for people with intellectual disabilities were provided, for the purposes of development of similar resources in Western Australia.⁵³⁶

People living with mental illness

- 4.285 RANZCP advised:

It is rare for people requiring palliative care to be accepted and treated if referred to mainstream mental health services as they are often deemed to fall outside the core business of the services or the services feel that they lack the required expertise. People who usually reside in residential care have limited options for palliative care once their psychiatric hostels or mental health services are unable to meet their physical health care requirements. This leads to people going untreated, or alternatively transferred to tertiary hospitals to wait in acute beds until eligible for palliative care hostels.

⁵³² Submission 36 from Palliative Care Western Australia, 13 July 2020, p 14.

⁵³³ Submission 23 from Department of Health, 10 July 2020, p 5.

⁵³⁴ Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 97, dated 18 September 2020, p 18.

⁵³⁵ Submission 35 from Developmental Disability WA, 13 July 2020, p 1.

⁵³⁶ *ibid.*, Attachments.

Likewise, people who are unable to be managed in palliative care settings due to psychiatric symptoms such as agitation, aggression, mood lability, psychotic symptoms, are transferred to tertiary hospitals to access palliative care.⁵³⁷

LGBTQIA+ community

4.286 PCWA submitted that in its consultation process, members of the LGBTQIA+ community:

reported a significant interest in engaging with advance care planning and palliative care service providers but registered many concerns regarding cultural safety and legal issues.

Critical issues identified included:

- Challenges with advance care planning where the person has not publicly declared their sexual orientation; where family members are hostile; when same sex partners are not recognised; and when health professionals have faith perspectives that interfere with their engagement.
- LGBTQIA+ specific resources. PCWA indicated its interest in partnering with the LGBTQIA+ community to develop specific resources and training in advance care planning and palliative care that addresses some of the issues identified above.
- Register of culturally safe services. It was recognised that a number of age care service providers were promoting themselves as sensitive to the needs of the LGBTQIA+ community. While that was a positive development it was suggested that a register of culturally safe services would be very helpful and that funding would be required to establish and maintain such a register.⁵³⁸

Progress in relation to meeting the palliative care needs of diverse groups

4.287 The Department of Health advised:

WA Health recognises that equity of access encompasses a diverse number of people with differing needs, which must be considered. WA Health is working with stakeholders to improve equity of access to palliative care services, including specific attention and consideration to geographical access, culturally and linguistically diverse population groups, Aboriginal and Torres Strait Islander people, people with a disability, people with dementia or those experiencing mental health issues...⁵³⁹

4.288 The Committee notes that it is a building block to priority one of the WA Strategy ('Care is accessible to everyone, everywhere') in the Department of Health's Implementation Plan One to:

- Improve access to care for condition-specific groups (e.g. people with dementia or those experiencing mental health issues).
- Improve access to care for marginalised groups.⁵⁴⁰

⁵³⁷ Submission 21 from The Royal Australian and New Zealand College of Psychiatrists, 10 July 2020, p 3.

⁵³⁸ Submission 36 from Palliative Care Western Australia, 10 July 2020, p 11.

⁵³⁹ Amanda Bolleter, Project Director, End of Life Care, Department of Health, transcript of evidence, 15 July 2020, p 13.

⁵⁴⁰ Department of Health, WA Cancer and Palliative Care Network, *WA End-of-Life and Palliative Care Strategy 2018–2028 Implementation Plan One 2020–2022*, 2020, p 8. See: <https://pch.health.wa.gov.au/>

- 4.289 Recommended actions under this building block include:
- identifying access gaps for marginalised groups
 - building on existing relationships with under-served population groups and organisations to develop appropriate training and resources for marginalised groups.

- 4.290 The Department of Health advised that a service agreement in development with PCWA, detailed in paragraphs 5.95 and 5.96:

will include community awareness development and provides for both general and special population cohorts to be provided for across the state (such as cultural and linguistically diverse populations, Aboriginal people, people with a disability, and people with a mental illness and/or dementia).⁵⁴¹

FINDING 30

Improving access to palliative care for condition-specific and other diverse groups requires the identification of access gaps and co-design of appropriate training and resources.

Impact of COVID-19

- 4.291 A number of witnesses and submitters advised that COVID-19 had highlighted gaps in the current health system and opportunities for learning and improvement. ANZSPM stated:

ANZSPM believes that the Western Australian Government, as with other State Governments, should act on the gaps highlighted by the COVID-19 pandemic in order to maintain access to services and continue care for the vulnerable palliative care population. For example, telehealth has enabled palliative care and general practice services to maintain their support for community patients, especially [in] rural and regional areas, and this should be continued.⁵⁴²

- 4.292 The Department of Health acknowledged:

Because we are working across different models within the WA health system and with the commonwealth, some of those processes to access appropriate care at home can be really lengthy. We have people whose conditions may be changing rapidly, so we need a speedy system. COVID has helped us in some respects with that because the system has changed temporarily. I think we have learnt we can be much more streamlined in our approach and get services in quicker, so there are some lessons learnt there that we might want to take forward into the future.⁵⁴³

- 4.293 The President of PCWA, Dr Campbell, noted:

I had colleagues from outside of palliative care saying to me that the palliative care network at the health department seemed to be doing a lot of work and putting out some very useful resources as part of COVID planning. Clearly, they have the ability to do it.⁵⁴⁴

</media/Files/Corporate/Reports-and-publications/End-of-life/end-of-life-palliative-care-strategy-IP1.pdf>. Viewed 27 October 2020.

⁵⁴¹ Submission 23 from Department of Health, 10 July 2020, p 22.

⁵⁴² Submission 37 from The Australian and New Zealand Society of Palliative Medicine, 10 July 2020, p 10.

⁵⁴³ Assoc Prof Alison Parr, Clinical Lead Palliative Care, WA Cancer and Palliative Care Network, transcript of evidence, 15 July 2020, p 5.

⁵⁴⁴ Dr Elissa Campbell, President, Palliative Care Western Australia, transcript of evidence, 31 July 2020, pp 10–11.

4.294 As noted in paragraph 4.53, the Department of Health recognised the benefits of the increased use of telehealth during COVID-19.

4.295 AMA(WA) commented:

in terms of telehealth the success we have seen around COVID with the quick transition to telehealth on the part of a huge part of the general practice population and the specialist population so that specialists are now available outside of the geographic area of West Perth to a lot of people in the rest of the state that they were never available to pre-COVID because Medicare has in 10 days changed their schedule more than they have in 10 years to facilitate this.

...

We have demonstrated that we can deliver that so let us raise our expectation of what we can give in this respect.⁵⁴⁵

4.296 Witnesses also noted that the uptake of online training and resources during COVID-19 had increased dramatically and resulted in successful delivery of programs to a wider audience.⁵⁴⁶

⁵⁴⁵ Dr Andrew Miller, President, Australian Medical Association (WA), transcript of evidence 31 July 2020, p 11.

⁵⁴⁶ Submission 12 from Busselton Hospice Care Inc., 9 July 2020, p 1; Dr David Joske, Clinical Haematologist and Medical Co-Director, Sir Charles Gairdner Hospital; Founder, Solaris Cancer Care, transcript of evidence, 30 July 2020, pp 7–8.

CHAPTER 5

Term of reference (a)—implementation of the recommendations of the Joint Select Committee on End of Life Choices

5.1 The Committee is to inquire into and report on:

the progress in relation to palliative care, in particular implementation of recommendations of the Joint Select Committee into End of Life Choices.⁵⁴⁷

5.2 This Chapter discusses the progress of implementation of the recommendations of the JSCEOLC and makes findings and further recommendations about the progress made to date.

Joint Select Committee on End of Life Choices

5.3 The JSCEOLC was established in 2017 to inquire into the ‘need for laws in Western Australia to allow citizens to make informed decisions regarding their own end of life choices’.⁵⁴⁸ The JSCEOLC was asked to pay particular attention to, amongst other things, ‘current medical practices for those at the end of life, including palliative care’.⁵⁴⁹

5.4 In its report, *My Life, My Choice*, published in August 2018, the JSCEOLC noted that it had received a wide range of evidence relating to palliative care in Western Australia and conducted investigative travel to various locations in Western Australia in order to gain an improved first-hand understanding of palliative care service delivery.⁵⁵⁰

Findings and recommendations

5.5 The JSCEOLC made 52 findings and 24 recommendations. The government accepted all 24 recommendations.⁵⁵¹

5.6 Twenty of those findings and 12 of those recommendations related directly to end-of-life and palliative care.⁵⁵² Eight findings and six recommendations related to advance care planning.⁵⁵³

5.7 The findings and recommendations of the JSCEOLC relating to palliative care, end-of-life care and advance care planning are set out in Appendix 8.

⁵⁴⁷ Term of reference (a): Western Australia, Legislative Assembly, *Parliamentary Debates (Hansard)*, 20 May 2020, p 2948.

⁵⁴⁸ Western Australia, Legislative Assembly and Legislative Council, Joint Select Committee on End of Life Choices, report 1, *My Life, My Choice*, August 2018, p 6.

⁵⁴⁹ *ibid.*

⁵⁵⁰ *ibid.*, p 56.

⁵⁵¹ Tabled Paper 2077, Legislative Council, Western Australian Government Response, Joint Select Committee on End of Life Choices Report, *My Life, My Choice*, 27 November 2018 (corrected by Tabled Paper 2276, Legislative Council, Erratum, 12 May 2019).

⁵⁵² Western Australia, Legislative Assembly and Legislative Council, Joint Select Committee on End of Life Choices, report 1, *My Life, My Choice*, August 2018, findings 9–28 and recommendations 7–18, pp 67–130.

⁵⁵³ *ibid.*, findings 1–8 and recommendations 1–6, pp 46–54.

Recommendations about advance care planning

- 5.8 Chapter 2 of the JSCEOLC Report, 'Advance Health Care Planning', discusses the important role of ACP in the context of palliative care and voluntary assisted dying, including but not limited to the role of Advance Health Directives (AHD) under the *Guardianship and Administration Act 1990*.
- 5.9 During its inquiry, the Committee received evidence about the importance of ACP in relation to palliative care, including a view that palliative care cannot be considered in isolation to ACP:
- The Joint Select Committee on End of Life Choices identified three streams of work: advance care planning; palliative care and voluntary assisted dying. It is important to recognise that these streams are not discrete, there is much overlap and they can't be seen in isolation.⁵⁵⁴
- 5.10 The Committee accepts this view of ACP in a broad sense and understands that palliative care as a whole should not be seen in isolation from ACP. However, given the limitations of its inquiry and its terms of reference, the Committee took the view that it was required to focus its inquiry on the delivery of palliative care services.
- 5.11 Chapter 9 of this report discusses the role of ACP in relation to the effective delivery of palliative care services, and summarising the evidence the Committee received in relation to ACP.

Recommendations about end-of-life and palliative care

- 5.12 Under its term of reference (a), the Committee has considered the progress of the implementation of recommendations 7 to 18 (inclusive) of the JSCEOLC.
- 5.13 This Chapter considers the implementation of those recommendations.

Department of Health approach to implementation of recommendations

End-of-life and palliative care team

- 5.14 The Department advised in its submission to the Committee's inquiry:

The End-of-Life and Palliative Care agenda has become highly complex, with a challenging program of work, with some priorities that must be delivered with urgency over the next 2-3 years and some longer-term deliverables which must remain a focus over the next 5-10 years. In February 2020, an integrated End-of-Life Care Program team was established in WA Health to continue to progress this agenda. The three key areas of work for the program are:

- Advance Health Directives (AHD),
- End of Life and Palliative Care and
- Voluntary Assisted Dying.

This new team will ensure the coordination of interdependencies, stakeholder, community and clinician engagement to ensure an appropriate state-wide focus on end of life care going forward.⁵⁵⁵

⁵⁵⁴ Submission 36 from Palliative Care Western Australia, 10 July 2020, p 23; Lana Glogowski, Chief Executive Officer, Palliative Care Western Australia, transcript of evidence, 31 July 2020, p 2.

⁵⁵⁵ Submission 23 from Department of Health, 10 July 2020, p 7.

- 5.15 The Project Director, End of Life Care with Department of Health, Amanda Bolleter, advised the Committee that 'many of [the recommendations] needed to be progressed together to achieve the lasting and comprehensive service improvement that was recognised as being needed in end-of-life and palliative care'.⁵⁵⁶

Impact of COVID-19 on the implementation program

- 5.16 The Department advised in its submission:

Whilst in some ways the onset of the COVID-19 pandemic slowed the ability to progress some of the more practical aspects of the implementation, it highlighted the importance of being prepared, and having adequate measures in place in relation to palliative care.⁵⁵⁷

Evidence about implementation generally

- 5.17 Evidence to the Committee varied regarding the general progress of implementation of the JSCEOLC recommendations. Some views received by the Committee included:

- RACGP:

To date, on the ground reports from our Members indicate that hardly anything has changed in the area of Palliative Care since the report of the Joint Select Committee into End of Life Choices. There appear to be few if any extra nurses, and it remains difficult to get doctors (in particular general practitioners) to be involved in Palliative Care.⁵⁵⁸

- AMA(WA):

The AMA (WA) recognises that funding has been allocated and work has begun on implementing many of the recommendations made in The Report of the Joint Select Committee on End of Life Choices (My Life, My Choice Report), but the sector has observed very few improvements to palliative care on the ground.⁵⁵⁹

The AMA (WA) believes that the My Life, My Choice Report outlined some important areas of reform, however, unless progress is seen within the sector, additional reports, plans and further inquiries may be counterproductive to facilitating progress.⁵⁶⁰

- 5.18 The Steering Committee, Western Australian Catholic Sector Response to Voluntary Assisted Dying, submitted:

This inquiry is somewhat premature given the focus of the inquiry is the performance of the State of Western Australia in implementing the [JSCEOLC] recommendations.⁵⁶¹

Communication of progress of implementation measures

- 5.19 PCWA advised that its consultations and survey undertaken to inform its submission to the inquiry revealed that:

⁵⁵⁶ Amanda Bolleter, Project Director, End of Life Care, Department of Health, transcript of evidence, 15 July 2020, p 6.

⁵⁵⁷ Submission 23 from Department of Health, 10 July 2020, p 4.

⁵⁵⁸ Submission 13 from Royal Australian College of General Practitioners, 9 July 2020, p 2.

⁵⁵⁹ Submission 41 from Australian Medical Association (WA), 17 July 2020, p 3.

⁵⁶⁰ *ibid.*, p 6.

⁵⁶¹ Submission 7 from The Steering Committee, WA Catholic Sector Response to Voluntary Assisted Dying, 7 July 2020, p 2.

very few people within the sector have any idea about what is happening in terms of implementing the recommendations of the 2018 joint select committee. From our perspective, we really encourage WA Health to engage in much more transparent—no, that is unfair. I do not want to assert that they have not been transparent, but they are certainly not communicating their progress in a way that the sector understands, so for us that was a very clear outcome from our consultation processes.⁵⁶²

5.20 The AMA(WA) advised in its submission:

Implementing reform and ensuring improvements are seen within the sector is paramount. There is a strong perception that palliative care funding has been consumed by bureaucratic processes and report writing. Reports and inquiries must be justified by tangible outcomes in service delivery. Without tangible outcomes on the ground and improved service delivery, reports and inquiries remain futile.⁵⁶³

FINDING 31

The progress on implementing the recommendations of the Joint Select Committee on End of Life Choices has been inconsistently communicated to key stakeholders.

RECOMMENDATION 13

WA Health regularly communicate the progress of implementation of the recommendations of the Joint Select Committee on End of Life Choices to stakeholders in the palliative care sector, and the Department of Health include a summary of those communications in its Annual Report.

Implementation of recommendation 7

JSCEOLC recommendation 7:

The Minister for Health should facilitate the establishment of an inpatient specialist palliative care hospice providing publicly funded beds in the northern suburbs of Perth.⁵⁶⁴

Background

5.21 Recommendation 7 arose from the JSCEOLC's findings that:

- access to inpatient specialist palliative care in Perth is limited⁵⁶⁵
- apart from a small number of private beds at Glengarry Hospital, there is no inpatient specialist palliative care hospice in the northern suburbs of Perth.⁵⁶⁶

5.22 The JSCEOLC described the inpatient services available in the northern suburbs at the time of its report as follows:

⁵⁶² Lana Glogowski, Chief Executive Officer, Palliative Care Western Australia, transcript of evidence, 31 July 2020, p 7.

⁵⁶³ Submission 41 from Australian Medical Association (WA), 17 July 2020, p 4.

⁵⁶⁴ Western Australia, Legislative Assembly and Legislative Council, Joint Select Committee on End of Life Choices, report 1, *My Life, My Choice*, August 2018, p 67.

⁵⁶⁵ *ibid.*, finding 9, p 67.

⁵⁶⁶ *ibid.*, finding 10, p 67.

On-site specialist palliative care is currently not available at Osborne Park Hospital, Midland Health Campus (public and private), Armadale Hospital, Fremantle Hospital, Peel Health Campus and Joondalup Health Campus (in development). If patients in these hospitals are at end of life, they may receive palliative care from their treating teams. If their symptoms become complex, access to specialist palliative care is available through a 24-hour telephone consultancy service. In certain cases, when the patient's needs are particularly complex they may require a transfer from their place of care to a dedicated specialist palliative care unit.⁵⁶⁷

5.23 The Committee has considered two issues in relation to recommendation 7:

- the progress towards implementation
- the extent to which the announced measures meet the inpatient palliative care needs of the northern suburbs as identified by the JSCEOLC.

Progress of implementation

Evidence from the Department of Health

5.24 The Department of Health advised it is increasing the number of inpatient palliative care beds in the northern suburbs:

- five beds came online at the Joondalup Health Campus from 1 July 2019⁵⁶⁸
- five interim beds are available at the Joondalup Health Campus from 15 September 2020 to 15 March 2021⁵⁶⁹
- ten beds are currently being procured by the North Metropolitan Health Service through an open tender. These beds are expected to come online in early 2021 and will replace the ten beds referred to above.⁵⁷⁰

5.25 The delivery of these additional facilities is discussed in Chapter 6.⁵⁷¹

Evidence from the palliative care sector

5.26 In relation to the tender process, HCC advised:

There is no clarity for HCC to know if the specifications for those beds have been developed with community input... We urge coordination and clarity in relation to implementing new services, to ensure there is a partnership approach with consumers and carers to develop the right kind of service.⁵⁷²

5.27 Similarly, the Liam James McLaughlin Memorial Hospice submitted:

We request that, if this hasn't happened already, that consumers and community members have the opportunity to be actively involved as partners in scoping,

⁵⁶⁷ *ibid.*, p 66.

⁵⁶⁸ Mr DJ Russell-Weisz, Director General, Department of Health, Answer to question on notice no 4, dated 14 August 2020, p 5.

⁵⁶⁹ Anthony Dolan, Chief Executive, North Metropolitan Health Service, transcript of evidence, 18 September 2020, p 41.

⁵⁷⁰ Dr DJ Russell-Weisz, Director General, Department of Health, letter, 16 October 2020, Attachment 2, p 4; Amanda Bolleter, Project Director, End of Life Care, Department of Health, email, 2 November 2020, Attachment 1, Answer to question 6.

⁵⁷¹ Paragraphs 6.40–6.51.

⁵⁷² Submission 26 from Health Consumers' Council (WA), 10 July 2020, p 5.

designing, planning, delivering and evaluating this hospice service, as per Recommendation 4 in the Sustainable Health Review (SHR).⁵⁷³

- 5.28 A number of submitters and witnesses commented that they were not aware of progress in relation to recommendation 7.⁵⁷⁴

Effectiveness of announced measures

- 5.29 The JSCEOLC did not identify a specific number of inpatient palliative care beds that may be required in the northern suburbs. The Department's examination of unmet need, as discussed in relation to JSCEOLC recommendation 10,⁵⁷⁵ should inform the need for beds in the area. Dr Derek Eng and the ANZSPM submitted that the palliative care need in the northern suburbs, considering its large ageing population, would be more realistically met with a 20-bed unit.⁵⁷⁶ Dr Eng submitted that a 20-bed unit was 'desperately needed'.⁵⁷⁷

- 5.30 The Committee also received evidence of concern amongst some stakeholders that the additional inpatient beds should be provided in a 'hospice' setting as referred to in JSCEOLC recommendation 7. PCWA noted that its consultation with the community and service providers had recognised that:

recommendation 7 in the report of the Joint Select Committee into End of Life Choices identified the need for publicly funded hospice beds and what has been developed is palliative care beds in an acute setting. This does not appear to acknowledge the significant differences between a hospice and acute care setting and is still not offering residents in the northern suburbs a choice.⁵⁷⁸

- 5.31 Similarly, the Liam James McLaughlin Memorial Hospice submitted that hospice care, as referred to in JSCEOLC recommendation 7, is very different from care in a hospital.⁵⁷⁹
- 5.32 The Committee noted the Department of Health's definition of 'hospice' in a hospital setting, as set out in Chapter 2.⁵⁸⁰
- 5.33 Dr Eng noted that the JSEOLC Report did not address the additional funding needs of the existing in-hospital palliative care teams:⁵⁸¹

Ideally, in-hospital palliative care teams should be involved in over 50% of predictable deaths and more specifically, involved for longer than one week before death. In-hospital specialist palliative care teams are currently working at their full capacity. Funding for staff increases in specialist palliative care is essential.⁵⁸²

⁵⁷³ Submission 28 from Liam James McLaughlin Memorial Hospice, 10 July 2020, p 2.

⁵⁷⁴ Submission 36 from Palliative Care Western Australia, 10 July 2020, p 17; Submission 26 from Health Consumers' Council (WA), 10 July 2020, p 5; Submission 28 from Liam James McLaughlin Memorial Hospice, 10 July 2020, p 2; Submission 41 from Australian Medical Association (WA), 17 July 2020, p 13; Submission 16 from Dr David Joske, 9 July 2020, p 2.

⁵⁷⁵ Paragraphs 5.62–5.84.

⁵⁷⁶ Submission 37 from The Australian and New Zealand Society of Palliative Medicine, p 9; Submission 8 from Dr Derek Eng, 8 July 2020, p 2.

⁵⁷⁷ Submission 8 from Dr Derek Eng, 8 July 2020, p 2.

⁵⁷⁸ Submission 36 from Palliative Care Western Australia, 10 July 2020, p 21.

⁵⁷⁹ Submission 28 from Liam James McLaughlin Memorial Hospice, 10 July 2020, p 5.

⁵⁸⁰ Paragraph 2.36.

⁵⁸¹ See paragraphs 4.189 and 4.195.

⁵⁸² Submission 8 from Dr Derek Eng, 8 July 2020, p 2.

FINDING 32

There has been substantial progress on the implementation of recommendation 7 of the Joint Select Committee on End of Life Choices (regarding the number of publicly funded beds in the northern suburbs of Perth), but this progress has not been effectively communicated to stakeholders in the palliative care sector.

RECOMMENDATION 14

WA Health undertake an evaluation of whether the ten additional inpatient beds in the northern suburbs of Perth referred to in the funding announcement of 10 October 2019:

- a) will meet the unmet inpatient palliative care needs of the northern suburbs of Perth as identified by the Joint Select Committee on End of Life Choices
- b) constitute an 'inpatient specialist palliative care hospice' for the purposes of recommendation 7 of the Joint Select Committee on End of Life Choices.

RECOMMENDATION 15

The North Metropolitan Health Service and the Department of Health report on the progress of implementation of recommendation 7 of the Joint Select Committee on End of Life Choices in their next Annual Reports.

Implementation of recommendation 8

JSCEOLC recommendation 8:

The Minister for Health should ensure that community palliative care providers, such as Silver Chain, are adequately funded to provide for growing demand.⁵⁸³

Background

- 5.34 The JSCEOLC found that Silver Chain was, as at August 2018, providing community palliative care to more patients than for which it was funded.⁵⁸⁴ Silver Chain advised the Committee that this is still the case, and in addition that its funding is based on a 'length of stay' with the service that is less than the average length of stay for which care is actually delivered, based on clinical need.⁵⁸⁵ The issue is recognised by the Department of Health.⁵⁸⁶
- 5.35 JSCEOLC recommendation 8, however, goes further than recommending that Silver Chain be funded for the services it provides, and recommends that community palliative care providers be 'adequately funded to provide for growing demand'.
- 5.36 Dr Derek Eng gave evidence about the limitations of Silver Chain's capacity to accept referrals:

⁵⁸³ Western Australia, Legislative Assembly and Legislative Council, Joint Select Committee on End of Life Choices, report 1, *My Life, My Choice*, August 2018, p 68.

⁵⁸⁴ *ibid.*, p 67.

⁵⁸⁵ Tish Morrison, Silver Chain Group, Answer to question on notice 3 asked at hearing held 31 July 2020, dated 18 August 2020, p 4.

⁵⁸⁶ Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 29.

Silver Chain providing specialist palliative care in metro Western Australia is really funded for the last 90 days of life and they really struggle with anyone outside of cancer. If we are saying that the greatest need is this huge non-cancer group, Silver Chain has no capacity often to take them on board. We are seeing a lot of our referrals to Silver Chain get rejected.⁵⁸⁷

5.37 The Department of Health advised that the palliative care service delivered by Silver Chain is block funded with an indicative number of clients and bed days associated with the total amount of funding:

The funded amount is based on historical arrangements however the service has received both indexation and growth in funding to meet increased need on multiple occasions since 2000.⁵⁸⁸

5.38 The Committee has considered two issues in relation to recommendation 8:

- adequate funding for community palliative care
- the progress towards implementation of recommendation 8.

'Adequate funding to provide for growing demand'

5.39 The National Strategy states:

Research and experience have identified the benefits for individuals and families in remaining at home as much as possible. Investment is needed into community-based models that are flexible to accommodate increased demand and public expectations.⁵⁸⁹

5.40 Adequate funding 'to provide for growing demand' is difficult to assess. It requires an assessment of:

- the relationship between funding and service delivery
- the demand for palliative care services and the way in which that demand is growing
- whether the services delivered are consistent with existing and growing demand.

5.41 Silver Chain estimated that additional funding of \$2.5 million annually would be required if its funding was to match its actual service provision.⁵⁹⁰

5.42 In addition to Silver Chain delivering more services than for which it is funded, the Department of Health advised:

Service delivery by Silver Chain cannot be provided to clients early in their disease trajectory as there is a high demand for Silver Chain services for patients in their terminal phase.⁵⁹¹

⁵⁸⁷ Dr Derek Eng, Palliative Care Physician and Member, Australian and New Zealand Society of Palliative Medicine, transcript of evidence, 30 July 2020, p 7.

⁵⁸⁸ Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 14, dated 18 September 2020, p 2.

⁵⁸⁹ Australian Government, Department of Health, *National Palliative Care Strategy 2018*, December 2018, p 20. See <https://www.health.gov.au/resources/publications/the-national-palliative-care-strategy-2018>. Viewed 23 October 2020.

⁵⁹⁰ Tish Morrison, Silver Chain Group, Answer to question on notice 3 asked at hearing held 31 July 2020, dated 18 August 2020, p 4.

⁵⁹¹ Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 29.

- 5.43 As noted in paragraph 5.36, Silver Chain’s capacity to accept referrals for non-cancer patients is limited.
- 5.44 The Committee heard from a number of witnesses about the adequacy of current funding for community specialist palliative care. Evidence on this issue included:

PCWA:

Community services remain overwhelmed and adequate funding needs to be allocated to ensure they can respond to demand.⁵⁹²

AMA(WA):

There is a chronic shortage of in home and community palliative care.⁵⁹³

Bethesda:

The funding available for community palliative care service provision in Perth has not grown at a sufficient rate to meet increasing demand, affecting service quality and outcomes. A substantial injection of additional funding is urgently required.⁵⁹⁴

Dr Derek Eng:

The workforce in community palliative care (Silver Chain primarily) is at an all-time low and there continues to be very minimal capacity to care for non-cancer patients. Little to no psychologist or social work input can be provided...⁵⁹⁵

SMHS:

[T]o meet the findings and recommendations of the [JSCEOLC] Report requires significant additional funding to ensure equity of access across the metropolitan area.⁵⁹⁶

ANZSPM:

Services must be funded adequately to provide the staff to support emergency calls (crises in relation to care for pain, dyspnoea and falls) and level 4 home care packages to support caregivers for all palliative care patients who choose to die at home.⁵⁹⁷

HCC:

Our understanding is that it is now harder for people to access the practical care they need [from community palliative care service providers] than it was 10 years ago.⁵⁹⁸

⁵⁹² Submission 36 from Palliative Care Western Australia, 10 July 2020, p 24.

⁵⁹³ Submission 41 from Australian Medical Association (WA), 17 July 2020, p 13.

⁵⁹⁴ Submission 34 from Bethesda Health Care, 10 July 2020, p 4.

⁵⁹⁵ Submission 8 from Dr Derek Eng, 8 July 2020, p 2.

⁵⁹⁶ Submission 25 from South Metropolitan Health Service, 10 July 2020, p 6.

⁵⁹⁷ Submission 37 from The Australian and New Zealand Society of Palliative Medicine, 10 July 2020, p 9.

⁵⁹⁸ Submission 26 from Health Consumers’ Council (WA), 10 July 2020, p 5.

Progress of implementation

- 5.45 Of the funding announced on 10 October 2019,⁵⁹⁹ \$6.3 million was committed to improving metropolitan and regional community-based palliative care services.⁶⁰⁰
- 5.46 The Department of Health advised that, of the \$6.3 million:
- \$4.3 million has been allocated to community palliative care in the metropolitan area⁶⁰¹
 - \$2 million has been provided to WACHS to provide domiciliary homecare services to community palliative care patients.⁶⁰²
- 5.47 The delivery of services associated with this funding announcement is discussed in detail in Chapter 6.⁶⁰³
- 5.48 Several witnesses and submitters commented that the funding allocated to community palliative care has not yet produced noticeable improvements, or that they were not aware of any progress.⁶⁰⁴
- 5.49 In particular, Silver Chain stated in its evidence that it had not yet been provided with any increased funding.⁶⁰⁵ The Department of Health advised:
- an invoice was received from Silver Chain for developing palliative care capability and medical equipment and has been approved for payment⁶⁰⁶
 - part of the additional \$4.3 million funding will be allocated to Silver Chain, but the proportion is yet to be determined.⁶⁰⁷
- 5.50 PCWA stated:
- It seems unfortunate that while the delivery of community palliative care was highlighted and prioritised via recommendation 8 of the report from the Joint Select Committee into End of Life Choices, it has not yet attracted funding to provide for growing demand.⁶⁰⁸
- 5.51 The Committee notes that the Department of Health's contract with Silver Chain is currently subject to review,⁶⁰⁹ and that the outcomes of this review could include re-alignment and improvement of services.

⁵⁹⁹ See paragraphs 6.7–6.9.

⁶⁰⁰ Hon M McGowan MLA, Premier; Hon R Cook MLA, Minister for Health, *Massive boost for palliative care services across Western Australia*, media statement, 10 October 2019.

⁶⁰¹ Amanda Bolleter, Project Director, End of Life Care, Department of Health, transcript of evidence, 15 July 2020, p 8.

⁶⁰² *ibid.*; Submission 23 from Department of Health, 10 July 2020, p 18.

⁶⁰³ Paragraphs 6.52–6.61.

⁶⁰⁴ Submission 8 from Dr Derek Eng, 8 July 2020, p 2; Submission 36 from Palliative Care Western Australia, 10 July 2020, p 17; Submission 26 from Health Consumers' Council (WA), 10 July 2020, p 5; Submission 41 from Australian Medical Association (WA), 17 July 2020, p 13; Submission 28 from Liam James McLaughlin Memorial Hospice, 10 July 2020, p 2; Submission 24 from TPG Aged Care, 10 July 2020, p 1.

⁶⁰⁵ Tish Morrison, Director, Clinical Operations, Palliative and End-of-life Care, Silver Chain, transcript of evidence, 31 July 2020, p 11.

⁶⁰⁶ Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 11, dated 18 September 2020, p 2.

⁶⁰⁷ Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 10, dated 18 September 2020, p 2.

⁶⁰⁸ Submission 36 from Palliative Care Western Australia, 10 July 2020, p 21.

⁶⁰⁹ See paragraph 4.75.

- 5.52 In addition, the Department of Health confirmed that the additional funding for community based services is expected to allow service delivery by Silver Chain to clients earlier in their disease trajectory.⁶¹⁰
- 5.53 It should be noted that the workforce availability issues discussed in Chapter 4⁶¹¹ impact on the ability of increased funding to translate into increased services. Workforce issues must also be addressed if any funding increase is to be effective. Dr Derek Eng noted in his evidence:
- quite often I hear that Silver Chain are running over census ... We can increase their funding support, but who is going to do that work?⁶¹²
- 5.54 The Committee requested and received from the Department of Health a copy of its current contract with Silver Chain.⁶¹³ Despite providing a copy of advice from the State Solicitor's Office that the Department was able to disclose to the Committee the pricing of the palliative care service under the contract,⁶¹⁴ all pricing information was redacted in the documents provided to the Committee.

FINDING 33

The Committee was not provided with unredacted information to enable it to assess the progress of implementation of recommendation 8 of the Joint Select Committee on End of Life Choices, that the Minister for Health ensure that community palliative care providers, such as Silver Chain, are adequately funded to provide for growing demand.

RECOMMENDATION 16

WA Health use the results of the independent review undertaken pursuant to recommendation 9 of the Joint Select Committee on End of Life Choices, and the audit undertaken pursuant to recommendation 10 of the Joint Select Committee on End of Life Choices, to quantify the funding required to enable community palliative care providers including Silver Chain to provide for:

- a) existing demand; and
- b) growing demand.

⁶¹⁰ Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 18, dated 18 September 2020, p 3.

⁶¹¹ Paragraphs 4.186–4.204.

⁶¹² Dr Derek Eng, Palliative Care Physician and Member, Australian and New Zealand Society of Palliative Medicine, transcript of evidence, 30 July 2020, pp 8–9.

⁶¹³ Dr DJ Russell Weisz, Director General, Department of Health, Answer to question prior to hearing no 15, dated 18 September 2020, p 2.

⁶¹⁴ *ibid.*

Implementation of recommendation 9

JSCEOLC recommendation 9:

WA Health should conduct an independent review, from a patient's perspective, of the three models of palliative care in Western Australia: inpatient, consultative and community. The review should examine the benefits and risks of each model and the accessibility of each across the state as well as the admission criteria for hospice care (see Finding 18).⁶¹⁵

Background

5.55 Recommendation 9 followed the JSCEOLC's observation that 'there are difficulties with continuity of care under the existing palliative care models'.⁶¹⁶ The JSCEOLC also noted that it was concerned that:

the emphasis on community care is coming at the expense of optimal symptom relief and may also be placing carers and family under significant pressure in dealing with very distressing and unmanageable situations. Patients should be afforded autonomy to make their own health care decisions; this includes deciding the best setting of care.⁶¹⁷

Progress of implementation

5.56 The Department of Health advised that an independent review is underway to explore patients' preferences in how and where they receive palliative care:

The aims of the Review are to:

1. Provide critical analysis of the three models of service provision in WA including the:
 - a. Risks and benefits of each model
 - b. Accessibility of each model based on the referral pathway
2. Investigate how the targeted community-based cohort wishes to receive palliative care
3. Provide a description of hospice services and review the admission practices for patients seeking to access hospice care
4. Analyse interjurisdictional and international service models used in other health services. This includes identifying programs or models that may be adapted for the WA setting
5. Provide recommendations, based on analyses, for future service models for palliative care provision in WA, including consideration of how they would fit in the WA health service delivery model.⁶¹⁸

⁶¹⁵ Western Australia, Legislative Assembly and Legislative Council, Joint Select Committee on End of Life Choices, report 1, *My Life, My Choice*, August 2018, p 74.

⁶¹⁶ *ibid.*, p 73.

⁶¹⁷ *ibid.*, p 74.

⁶¹⁸ Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 14.

- 5.57 Professor Samar Aoun from the Perron Institute for Neurological and Translational Science commenced the review on 11 May 2020. The review is anticipated to take six months and is due to be finalised in the final quarter of 2020.⁶¹⁹ The Department of Health advised the Committee that the review was expected to be completed in November 2020.⁶²⁰
- 5.58 The Department of Health advised:
- The structure for this review includes a national and international literature review, and a comprehensive survey of patients and carers. The survey results will then be used for a consultation process with service providers to identify how service provision will be improved in line with patient preferences. The survey includes opportunities to explore admission to inpatient palliative care and the changing nature of the palliative care patient pathway. The way in which people access end of life in palliative care in the last 10 years has changed significantly and we need a contemporary model that reflects and supports that.⁶²¹
- 5.59 As an interim measure pending the completion of the independent review, the Department of Health, in collaboration with HCC, held a Palliative Care Consumer Workshop in December 2019. The Department advised that the event was held to help inform the body of work currently being undertaken by exploring consumers' ideas on palliative care delivery in Western Australia.⁶²²
- 5.60 On 18 September 2020, the Department of Health advised that there were 430 responses to the public survey undertaken by the independent review,⁶²³ and that of the useable responses:
- approximately 70 per cent were from bereaved carers
 - 30 per cent were from people with a non-cancer illness
 - 31 per cent were from regional and rural areas
 - the most reported setting for care was home at 43 per cent, followed by hospital and hospice at 26 per cent and 23 per cent respectively, with 8 per cent coming from residential aged care.⁶²⁴
- 5.61 The Department of Health's Implementation Plan One recommends that:
- the results of the independent review be used to identify and develop contemporary models of care, based on best evidence, to most effectively meet the needs of Western Australian adults
 - the Department collaborate with service providers, stakeholders and consumers to implement appropriate models.⁶²⁵

⁶¹⁹ *ibid.*

⁶²⁰ Assoc Prof Alison Parr, Clinical Lead Palliative Care, WA Cancer and Palliative Care Network, transcript of evidence, 15 July 2020, p 18.

⁶²¹ Amanda Bolleter, Project Director, End of Life Care, Department of Health, transcript of evidence, 15 July 2020, p 9.

⁶²² Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 14.

⁶²³ Assoc Prof Alison Parr, Clinical Lead, Palliative Care, WA Cancer and Palliative Care Network, transcript of evidence, 18 September 2020, p 32.

⁶²⁴ *ibid.*, pp 32–3.

⁶²⁵ Department of Health, WA Cancer and Palliative Care Network, *WA End-of-Life and Palliative Care Strategy 2018–2028 Implementation Plan One 2020–2022*, 2020, p 9. See: <https://pch.health.wa.gov.au/>

FINDING 34

From May 2020, there has been significant progress in the implementation of recommendation 9 of the Joint Select Committee on End of Life Choices, that WA Health conduct an independent review, from a patient's perspective, of the three models of palliative care in Western Australia: inpatient, consultative and community.

RECOMMENDATION 17

The Minister for Health table in Parliament the independent review undertaken pursuant to recommendation 9 of the Joint Select Committee on End of Life Choices, and thereafter the Government's response.

Implementation of recommendation 10

JSCEOLC recommendation 10:

WA Health should implement a process to determine the unmet demand for palliative care and establish an ongoing process to measure the delivery of palliative care services with the aim of making those services available to more Western Australians.⁶²⁶

Background

5.62 Recommendation 10 followed the JSCEOLC's finding that:

[T]here is inconsistency in the data regarding the number of patients with conditions amenable to receiving palliative care. This is perhaps reflective of the uncertainty regarding which diseases or conditions are appropriate for palliative care.⁶²⁷

5.63 The JSCEOLC expressed concern that 'health professionals, even specialists, may not recognise the need for palliative care or may not know how to refer their patients into the service'.⁶²⁸

5.64 The Committee notes that there are two limbs to recommendation 10:

- implementation of a process to determine the unmet demand for palliative care
- implementation of an ongoing process to measure the delivery of palliative care services.

5.65 In response to recommendation 10, the Department of Health produced the Current State Report as a working document to provide an overview and summary of the current state of palliative care service provision in Western Australia and summarise key issues and gaps.⁶²⁹

</media/Files/Corporate/Reports-and-publications/End-of-life/end-of-life-palliative-care-strategy-IP1.pdf>. Viewed 27 October 2020.

⁶²⁶ Western Australia, Legislative Assembly and Legislative Council, Joint Select Committee on End of Life Choices, report 1, *My Life, My Choice*, August 2018, p 78.

⁶²⁷ *ibid.*, p 77.

⁶²⁸ *ibid.*, p 78.

⁶²⁹ Amanda Bolleter, Project Director, End of Life Care, Department of Health, transcript of evidence, 15 July 2020, p 9.

Progress of implementation

Process to determine unmet demand

5.66 The Department of Health advised:

a decision was made by the department to use unmet need rather than unmet demand as the metric for this analysis. Unmet need provides a broader definition of need for palliative care that looks beyond waitlists and identifies those people who may not be aware that palliative care is available to them.⁶³⁰

5.67 Palliative care need has been defined as ‘the population’s ability to benefit from palliative care’.⁶³¹

5.68 According to the Current State Report:

Validation and refinement of methodology to estimate unmet need for palliative care is ongoing. The Department of Health participates in the national Palliative Care and End-of-Life Care Data Development Working Group and is working internally with the Epidemiology Branch to refine modelling estimates for unmet need for palliative care.⁶³²

5.69 The Department of Health advised that ‘the process to estimate unmet demand for palliative care is a complex and multilayered challenge that is not unique to WA’.⁶³³

5.70 To estimate unmet need in accordance with recommendation 10, the Department used methodology based on AIHW contemporary research methods.⁶³⁴ The methodology was summarised as follows:

WA mortality data was extracted to determine the number of people who died in 2017 with a medical condition that might have benefited from palliative care. These conditions are determined in the literature as including cardiopulmonary disease; dementia and Alzheimer’s disease; heart failure; liver failure; malignant neoplasms, more commonly known as cancer; motor neurone disease; Parkinson’s disease; renal failure; HIV/AIDS; multiple sclerosis; muscular dystrophy; and Huntington’s disease.⁶³⁵

The data was linked to WA hospital data to determine the number of people with those conditions who received or did not receive inpatient palliative care in their last 12 months of life.⁶³⁶

⁶³⁰ *ibid.*

⁶³¹ Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 22.

⁶³² *ibid.*

⁶³³ Amanda Bolleter, Project Director, End of Life Care, Department of Health, transcript of evidence, 15 July 2020, p 9.

⁶³⁴ *ibid.*

⁶³⁵ These conditions used to measure unmet need are listed in Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, Appendix 4, Table 13, p 38.

⁶³⁶ Amanda Bolleter, Project Director, End of Life Care, Department of Health, transcript of evidence, 15 July 2020, pp 9–10.

- 5.71 A detailed explanation of the methodology is contained in the Current State Report.⁶³⁷
- 5.72 Based on the above methodology, the Department of Health concluded that in 2017, 44 per cent of the people who died of a condition amenable to palliative care did not receive inpatient palliative care in a public palliative care bed in Western Australia.⁶³⁸
- 5.73 The Department noted that this represents hospital admissions only, and does not include those who may have received palliative care in the community and did not have any hospital admissions in the year prior to death.
- 5.74 Silver Chain noted in its submission that ‘the number of those accessing palliative care very late in the trajectory of their illness and therefore not receiving timely referrals’ form part of the ‘unmet need’ for palliative care which the Department is attempting to quantify pursuant to recommendation 10 of the JSCEOLC.⁶³⁹ The Committee noted that the Department’s methodology does not include late access to palliative care.
- 5.75 In relation to this, the Department of Health advised:
- Further work to refine this estimate will seek to further measure the profile of patients that receive palliative care at different stages in the illness trajectory to provide an understanding of different care settings and illnesses.⁶⁴⁰
- 5.76 A further issue in the determination of unmet need is that the Department of Health does not have access to GP or primary care data, due to constraints in accessing MBS billing data. The Department advised:
- This is a national challenge and needs to be addressed by states and territories on a national level.⁶⁴¹
- 5.77 In relation to further refinement of the methodology, the Department of Health advised:
- The end-of-life care team in the department is working with our colleagues in the information and system performance directorate and the epidemiology branch in the department to further refine the modelling estimates for unmet need for palliative care, which would draw on the advancements in data linkage capability and provide for a more accurate picture of what is happening on the ground.⁶⁴²

Ongoing process to measure delivery of palliative care services

- 5.78 The Current State Report:
- details the various processes used by WA Health for measuring delivery of palliative care activity under the various models and settings⁶⁴³

⁶³⁷ Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, pp 22–24.

⁶³⁸ Amanda Bolleter, Project Director, End of Life Care, Department of Health, transcript of evidence, 15 July 2020, p 10.

⁶³⁹ Submission 42 from Silver Chain Group Limited, 14 July 2020, p 6.

⁶⁴⁰ Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 41, dated 18 September 2020, p 10.

⁶⁴¹ Amanda Bolleter, Project Director, End of Life Care, Department of Health, transcript of evidence, 15 July 2020, p 10.

⁶⁴² *ibid.*

⁶⁴³ Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, pp 15–20.

- advises that data systems used in WA to collect palliative care activity data include webPAS and ePalCIS (for those sites who have it) for recording specific palliative care measures.⁶⁴⁴ These systems are outlined in greater detail in Chapter 3.⁶⁴⁵

5.79 In relation to inpatient services:

Palliative care inpatient activity data is mostly captured in the WA Department of Health Subacute and Non-acute Care Data Collection from data entered via the web-based patient administration system webPAS subacute module. Some specialist palliative care sites also have access to a purpose-built palliative care data collection tool ePalCIS.⁶⁴⁶

5.80 In relation to non-admitted services, the Department of Health advised that its information and system performance directorate has implemented patient-level reporting from 1 July 2020 and that:

[t]his will greatly improve the granularity of reporting for community service providers and inform future work.⁶⁴⁷

5.81 As noted in paragraph 5.76, the Department of Health does not have access to GP or primary care data. The Department advised that, if available, these data could be used 'to further refine the model and provide a picture of what is happening earlier on in the palliative care journey'.⁶⁴⁸

FINDING 35

The accessibility of Medicare Benefits Schedule data remains a challenge that restricts the scope of WA Health's measurement of the delivery of palliative care services.

Electronic Palliative Care Information System (ePalCIS)

5.82 The Department of Health's Electronic Palliative Care Information System (ePalCIS) is outlined in Chapter 3.⁶⁴⁹

5.83 The Department advised:

- an independent investigation into the current use of ePalCIS has recently been completed by Ernst and Young⁶⁵⁰
- the results of this investigation are informing a renewed rollout and refresh to enable current users to improve data recording.⁶⁵¹

⁶⁴⁴ *ibid.*, p 25.

⁶⁴⁵ Paragraphs 3.139–3.147.

⁶⁴⁶ Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 15.

⁶⁴⁷ Amanda Bolleter, Project Director, End of Life Care, Department of Health, transcript of evidence, 15 July 2020, p 10.

⁶⁴⁸ *ibid.*

⁶⁴⁹ Paragraphs 3.142–3.147.

⁶⁵⁰ Submission 23 from Department of Health, 10 July 2020, p 16; Amanda Bolleter, Project Director, End of Life Care, Department of Health, transcript of evidence, 15 July 2020, p 10.

⁶⁵¹ Amanda Bolleter, Project Director, End of Life Care, Department of Health, transcript of evidence, 15 July 2020, p 10.

Proposed next steps

- 5.84 The Department of Health advised the following 'next steps' in relation to JSCEOLC recommendation 10:
- Continuing work with data linkage and system performance areas to further refine the methodology for a more robust measure; this would include linking of public hospital outpatient data, Silver Chain data and public and private hospital data.
 - Progress of implementation of the findings of the recommendations of the Current State Report regarding improved data collection tools and evaluation measures.
 - Implementation of patient-level reporting for non-admitted services from 1 July 2020; this will greatly improve the granularity of reporting for community service providers and inform future work.
 - Finalisation of a review of the Admission Policy Reference Manual which mandates the correct counting and classification of admitted care activity to support improved inpatient data quality; following its release a Palliative Care Q&A session with service providers will be undertaken to improve understanding and engagement in the data capture.⁶⁵²

FINDING 36

The Department of Health's decision to seek to determine unmet need, rather than unmet demand as recommended by recommendation 10 of the Joint Select Committee on End of Life Choices, is appropriate.

FINDING 37

While there has been some progress in determining unmet need for palliative care pursuant to recommendation 10 of the Joint Select Committee on End of Life Choices, the current methodology adopted by WA Health does not fully measure unmet need.

RECOMMENDATION 18

WA Health further refine the methodology for determining the unmet need for palliative care, and ensure the measure of unmet need includes:

- a) the number of those accessing palliative care for the first time very late in the trajectory of their illness and therefore not receiving timely referrals
- b) general practitioner and primary care data
- c) patients who received palliative care in the community and did not have any hospital admissions in the year prior to death.

FINDING 38

There has been limited progress in relation to the implementation of an ongoing process to measure the delivery of palliative care services as recommended by recommendation 10 of the Joint Select Committee on End of Life Choices.

⁶⁵² Submission 23 from Department of Health, 10 July 2020, p 11.

RECOMMENDATION 19

WA Health undertake a full roll-out of the Electronic Palliative Care Information System known as ePalCIS.

Implementation of Recommendation 11

JSCEOLC recommendation 11:

To improve understanding of palliative care in Western Australia, WA Health should:

- establish a consistent definition of palliative care to be adopted by all health professionals;
- provide comprehensive, accessible and practical information and education services about palliative care to health professionals and the community;
- encourage knowledge sharing by palliative care specialists with their generalist colleagues; and
- establish a palliative care information and community hotline.⁶⁵³

Background

5.85 Recommendation 11 followed the JSCEOLC's identification of the need for:

- public and professional education in relation to the benefits of palliative care⁶⁵⁴
- a fully funded community telephone support and information line for palliative care services.⁶⁵⁵

5.86 The impact on service delivery of misperceptions about palliative care amongst health professionals and the general public are outlined in Chapter 2.⁶⁵⁶

Progress of implementation—consistent definition of palliative care

5.87 In its submission to the inquiry, the Department of Health provided the following definition of palliative care,⁶⁵⁷ which 'is now used consistently throughout WA Health publications and communications and across the End-of-Life Care program of work':⁶⁵⁸

Palliative care is an approach that improves the quality of life of individuals, their families and carers facing problems associated with life-threatening illness/condition, through the prevention and relief of suffering. Palliative care recognises the person and the importance and uniqueness of their family/carer. It serves to maximise the quality of life and considers physical, social, financial,

⁶⁵³ Western Australia, Legislative Assembly and Legislative Council, Joint Select Committee on End of Life Choices, report 1, *My Life, My Choice*, August 2018, p 79.

⁶⁵⁴ *ibid.*, p 78, quoting Assoc Prof Alison Parr, then Director of Medical Services, St John of God Health Care.

⁶⁵⁵ *ibid.*, p 79.

⁶⁵⁶ Paragraph 2.13.

⁶⁵⁷ Together with definitions of 'End of life', 'End-of-life care', 'Specialist palliative care' and 'Terminal care' as set out in Chapter 2, paragraphs 2.21–2.29.

⁶⁵⁸ Submission 23 from Department of Health, 10 July 2020, p 12.

emotional, and spiritual distress. Such distress not only influences the experience of having a life-limiting illness but also influences treatment outcomes.⁶⁵⁹

- 5.88 To establish consistent use of the definition, the Department of Health advised:
- from an activity data recording perspective, 'the definition of what is Palliative Care Activity' will be contained within the Department's policies following a review of the policies in collaboration with all HSPs
 - the provision of education, fact sheets and other resources will strengthen the correct recording of palliative care activity
 - the Health Professional Training and Education Framework and Resource Hub will support the uptake of the definition through its delivery of resources and training.⁶⁶⁰
- 5.89 Silver Chain submitted:
- [Recommendation 11] has not been delivered. Silver Chain looks forward to the development of consistent definitions to describe palliative care services and improved information resources to support people to better access palliative care in the community.⁶⁶¹
- 5.90 AMA(WA) advised that WA Health has not communicated its consistent definition of palliative care.⁶⁶²
- 5.91 Similarly, Dr Michael Verheggen, Psychiatrist and Western Australian Branch Committee Representative of RANZCP, advised the Committee that he was not aware of a consistent definition of palliative care.⁶⁶³

FINDING 39

If a consistent definition of palliative care has been established by WA Health pursuant to recommendation 11 of the Joint Select Committee on End of Life Choices, the communication of it to key stakeholders remains a problem.

RECOMMENDATION 20

WA Health communicate to key stakeholders its consistent definition of palliative care established pursuant to recommendation 11 of the Joint Select Committee on End of Life Choices.

⁶⁵⁹ *ibid.*, 10 July 2020, p 11.

⁶⁶⁰ Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 43, dated 18 September 2020, p 11.

⁶⁶¹ Submission 42 from Silver Chain Group Limited, 14 July 2020, p 6.

⁶⁶² Dr Andrew Miller, Australian Medical Association (WA), Answer to question on notice 1 asked at hearing held 31 July 2020, dated 26 August 2020, p 1.

⁶⁶³ Dr Michael Verheggen, Psychiatrist, Western Australian Branch Committee Representative of the Royal Australian and New Zealand College of Psychiatrists, transcript of evidence, 30 July 2020, pp 10–1.

Progress of implementation—comprehensive, accessible and practical information and education services

Palliative Care Community Awareness Campaign

5.92 The Department of Health advised:

- a communications plan for a Palliative Care Community Awareness Campaign was approved in March 2020, but that progress of the campaign had been delayed due to COVID-19
- the timing of the campaign may now be impacted by a Palliative Care Australia campaign launch scheduled for late 2020 and the PCWA campaign launch in early 2021 due to the risk of confused or mixed messaging
- as at July 2020, a review of the proposed campaign and its timeline was underway.⁶⁶⁴

Print education materials

5.93 The Department of Health advised:

- existing print education materials for consumers regarding palliative care were audited by WA Health in late 2020
- a print brochure focusing on the key messages of the Consumer Awareness Campaign which complements existing education resources has been developed, providing information for consumers early in their journey with a life-limiting illness
- the brochure is currently being finalised for release in partnership with PCWA.⁶⁶⁵

Other measures

5.94 The Department of Health advised of the following additional information and education measures:

- a comprehensive revision of WA Health's consumer and corporate facing websites, focussing on improving content accessibility, readability, and reducing duplication
- publication of existing education and training resources for health professionals on WA Health's corporate website. This preliminary 'information-hub' was fast-tracked because of the COVID-19 response
- a current state review of health professional education and training across primary care, community, inpatient residential aged care and consultative settings
- establishment of an Education and Training Reference Group to work on the creation of an Education and Training Framework for health professionals
- the Reference Group has given support to the creation of an Education and Training Hub to support health professionals in accessing appropriate education and training, due for completion in November 2020⁶⁶⁶
- funding for PCWA to reprint and distribute the PCWA publication 'Palliative Caring: Information for the families and carers who are caring for a person with a life limiting illness or condition', which was distributed to hospital and health services across WA.⁶⁶⁷

⁶⁶⁴ Submission 23 from Department of Health, 10 July 2020, p 12.

⁶⁶⁵ *ibid.*

⁶⁶⁶ *ibid.*, p 14.

⁶⁶⁷ *ibid.*, p 13.

- 5.95 The Department also noted that an important contribution to improving community understanding and access to information regarding palliative care is the collaboration between WA Health and PCWA, and that WA Health is currently negotiating a five-year service agreement with PCWA from 2020-21 to 2024-25. Under this service agreement, it is proposed that PCWA will facilitate:
- community awareness and uptake of advance care planning
 - knowledge of palliative care and palliative care services
 - enabling a compassionate community framework to support residents through grief and loss.⁶⁶⁸

- 5.96 According to the Department, the service agreement with PCWA:

is aimed at increasing community awareness and education around End-of-Life and Palliative Care and involves initiatives such as community education workshops via online and face-to-modalities, covering advance care planning, palliative care and grief and loss. Other important initiatives forming part of this program of work include continuation of the Advance Care Planning Consortium, Sector development projects, the development and distribution of community information resources and a biennial palliative care summit – the first of which is occurring on 26 November 2020.⁶⁶⁹

FINDING 40

While some progress has been made to implement the part of recommendation 11 of the Joint Select Committee on End of Life Choices that WA Health ‘provide comprehensive, accessible and practical information and education services about palliative care to health professionals and the community’, most of the initiatives to achieve this are yet to materialise.

Progress of implementation—encouragement of knowledge sharing by palliative care specialists

- 5.97 The Committee heard evidence that the capacity of palliative care specialists to participate in knowledge-sharing outside their clinical work was very limited.⁶⁷⁰ Dr Derek Eng advised:

Very simply, we need the specialist palliative care medical, nursing and allied health workforce to double before there can be any capacity (beyond day to day clinical work) to educate others and grow services.⁶⁷¹

- 5.98 Bethesda commented in its submission:

The development and maintenance of relationships which maximise the effect of knowledge sharing takes time. Specialist providers need to be resourced to undertake this work in a more intentional and strategic manner.⁶⁷²

⁶⁶⁸ *ibid.*

⁶⁶⁹ Amanda Bolleter, Project Director, End of Life Care, Department of Health, email, 2 November 2020, Attachment 1, Answer to question 4.

⁶⁷⁰ Dr Mark Monaghan, Emergency Physician, Director of Medical Services, South West Coastal, WA Country Health Service, Busselton Health Campus, transcript of evidence, 31 August 2020, p 16; Dr Andrew Miller, President, Australian Medical Association (WA), transcript of evidence 31 July 2020, p 6; Dr Derek Eng, Palliative Care Physician and Member, Australian and New Zealand Society of Palliative Medicine, transcript of evidence, 30 July 2020, pp 3–4.

⁶⁷¹ Submission 8 from Dr Derek Eng, 8 July 2020, pp 3–4.

⁶⁷² Submission 34 from Bethesda Health Care, 10 July 2020, p 8.

- 5.99 The Department of Health acknowledged the difficulties associated with knowledge-sharing by specialists who are under time pressures, and the need to 'make good use of a scarce resource'.⁶⁷³ The Department advised:
- the sector has requested a joint approach to improve knowledge sharing
 - this is part of the work underway through the Education and Training Framework and Resource Hub, including investigation into contemporary training methods and opportunities to ensure that specialist palliative care clinicians' information-sharing actions are well targeted for maximum impact.⁶⁷⁴
- 5.100 In addition, the Department of Health advised that EMHS is leading work to establish a palliative care centre of excellence, to be co-located on the Kalamunda Hospital site. The service model envisaged by EMHS includes 'a staged roll-out of education and training for Junior Medical Officers to increase knowledge and skills, plus the engagement [of] staff champions to support and build capacity across EMHS'.⁶⁷⁵
- 5.101 It is clear to the Committee that some attention must be paid to the workforce issues outlined in Chapter 4⁶⁷⁶ before there is to be any realistic capacity for knowledge-sharing by palliative care specialists with their generalist colleagues.

FINDING 41

Addressing workforce issues is a prerequisite to facilitating capacity for palliative care specialists to share knowledge with their generalist colleagues pursuant to recommendation 11 of the Joint Select Committee on End of Life Choices.

Progress of implementation—palliative care information and community hotline

- 5.102 The Department of Health has addressed this part of JSCEOLC recommendation 11 in two stages. It has contracted PCWA to operate a Palliative Care Information and Support Line for six months while it procures a non-clinical hotline through a restricted tender process.
- 5.103 The interim community hotline commenced on 1 May 2020 and is expected to provide:
- non-clinical information and support about end of life and palliative care service navigation
 - information about how to access general and specialist palliative care services available in Western Australia
 - redirection to appropriate points of contact for clinically-related queries
 - information about advance care planning and grief and bereavement.⁶⁷⁷
- 5.104 The Government will spend nearly \$100 000 on the interim hotline.⁶⁷⁸

⁶⁷³ Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 46, dated 18 September 2020, p 12.

⁶⁷⁴ *ibid.*

⁶⁷⁵ Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question on notice 2 asked at hearing held 15 July 2020, dated 14 August 2020, p 4.

⁶⁷⁶ Paragraphs 4.186–4.209.

⁶⁷⁷ Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 119, dated 18 September 2020, pp 23–4.

⁶⁷⁸ See paragraph 6.81.

- 5.105 The Department of Health advised that the contract for the ongoing hotline is expected to be awarded by October 2020⁶⁷⁹ and commence when the interim hotline concludes in November 2020.⁶⁸⁰ The hotline is expected to cost \$720 000 over four years.⁶⁸¹
- 5.106 A more detailed explanation of these measures and the associated funding is contained in Chapter 6.⁶⁸²
- 5.107 PCWA advised that the conversations occurring over the interim hotline were essentially about ACP, and expressed concern that the tender document for the ongoing operation of the hotline excludes the provision of information about ACP.⁶⁸³ This issue is discussed further in Chapter 9.⁶⁸⁴
- 5.108 In relation to calls to the hotline regarding paediatric palliative care, CAHS noted there has been a collaborative approach between PCWA and the WA Paediatric Palliative Care Service leading to calls being re-directed to that service. CAHS noted:

We welcome the initiative to respond and direct calls re paediatric palliative queries in a timely manner by specialist nursing and medical professionals.⁶⁸⁵

FINDING 42

Substantial progress has been made on the implementation of that part of recommendation 11 of the Joint Select Committee on End of Life Choices that WA Health establish a palliative care information and community hotline.

Implementation of recommendations 12 and 13

JSCEOLC 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 (*sic*).⁶⁸⁶

JSCEOLC recommendation 13:

The Minister for Health should ensure regional palliative care be adequately funded to meet demand.⁶⁸⁷

⁶⁷⁹ Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 47, dated 18 September 2020, p 12; Amanda Bolleter, Project Director, End of Life Care, Department of Health, transcript of evidence, 15 July 2020, p 12.

⁶⁸⁰ Amanda Bolleter, Project Director, End of Life Care, Department of Health, transcript of evidence, 15 July 2020, p 12.

⁶⁸¹ Submission 23 from Department of Health, 10 July 2020, p 20.

⁶⁸² Paragraphs 6.76–6.85.

⁶⁸³ Lana Glogowski, Chief Executive Officer, Palliative Care Western Australia, transcript of evidence, 31 July 2020, p 2; Dr Margherita Nicoletti, Consultant in Palliative Care, Rockingham Hospital, transcript of evidence, 31 July 2020, p 9.

⁶⁸⁴ Paragraph 9.27.

⁶⁸⁵ Submission 6 from Child and Adolescent Health Service, 6 July 2020, p 6.

⁶⁸⁶ Western Australia, Legislative Assembly and Legislative Council, Joint Select Committee on End of Life Choices, report 1, *My Life, My Choice*, August 2018, p 83.

⁶⁸⁷ *ibid.*

5.109 The progress of implementation of recommendations 12 and 13 is discussed in Chapter 8.⁶⁸⁸

Implementation of recommendation 14

JSCEOLC recommendation 14:

Once a consistent definition of palliative care has been established by WA Health in accordance with Recommendation 11, the Minister for Health should appoint an independent reviewer to audit:

- The level of palliative care activity actually provided in Western Australia's hospitals and compare it against the level of recorded palliative care activity.
- The actual spend by WA Health on palliative care on a year-by-year and like-for-like basis, across all aspects of palliative care provision, including community service providers, area health services (including WA Country Health Services) and delineating between inpatient, consultancy and community care.⁶⁸⁹

Background

5.110 The JSCEOLC found:

Palliative care activity in Western Australia's hospitals is not being accurately recorded. It is important that the extent and cost of palliative care service delivery is clarified.⁶⁹⁰

Progress of implementation

Department of Health evidence

5.111 The Department of Health has not progressed this recommendation, advising:

In light of the comprehensive nature of the Current State Report, its key findings and subsequent data improvement initiatives, consideration of the benefits of an independent review are currently being assessed by the end-of-life care project team in collaboration with the information and system performance directorate within the Department of Health. The current proposal is to conduct a review of the "Current State" report in 2022 to measure the impact of initiatives undertaken as part of the implementation of the joint select committee recommendations.⁶⁹¹

5.112 According to the Department, at this point in time, prior to the full implementation of improved data collection and reporting mechanisms:

an independent audit would not provide additional information or more granular details than what is currently available using this methodology.⁶⁹²

⁶⁸⁸ Paragraphs 8.15–8.21 and 8.23–8.42.

⁶⁸⁹ Western Australia, Legislative Assembly and Legislative Council, Joint Select Committee on End of Life Choices, report 1, *My Life, My Choice*, August 2018, p 91.

⁶⁹⁰ *ibid.*, finding 22, p 91. Palliative care activity in Western Australia's hospitals is not being accurately recorded. It is important that the extent and cost of palliative care service delivery is clarified.

⁶⁹¹ Amanda Bolleter, Project Director, End of Life Care, Department of Health, transcript of evidence, 15 July 2020, pp 12–3.

⁶⁹² Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 81, dated 18 September 2020, p 14.

FINDING 43

Notwithstanding the Government's stated acceptance of recommendation 14 of the Joint Select Committee on End of Life Choices in November 2018 and May 2019, recommendation 14 will not be implemented by the Department of Health, as it considers that an independent audit would not provide additional information or more granular details than what is available under the current methodology.

Implementation of recommendations 15, 16 and 17

JSCEOLC recommendation 15:

WA Health should provide ongoing professional development for all health professionals – beyond undergraduate training – about the right of a patient to refuse medical treatment. WA Health should also specifically amend the Consent to Treatment Policy to provide comprehensive information in relation to a competent patient's absolute right to refuse medical treatment.⁶⁹³

JSCEOLC recommendation 16:

WA Health should provide ongoing professional development – beyond undergraduate training – for all health professionals regarding the absolute right of a competent patient to refuse food and water. Training should also include those working in aged care.⁶⁹⁴

JSCEOLC recommendation 17:

WA Health should provide ongoing professional development – beyond undergraduate training – for health professionals about the transition from curative to non-curative end of life care and effective discussions with patients and families about futile treatments

WA Health should consider how it might effectively educate the community about end of life decision-making, and implement appropriate health promotion in this area.⁶⁹⁵

Background—ongoing professional development for health professionals

5.113 JSCEOLC recommendations 15, 16 and 17 relate to ongoing professional development for all health professionals about:

- the absolute right of a competent patient to refuse medical treatment (recommendation 15)
- the absolute right of a competent patient to refuse food and water (recommendation 16)
- the transition from curative to non-curative end of life care (recommendation 17).

5.114 The recommendations followed findings by the JSCEOLC of uncertainty among health professionals regarding these issues.⁶⁹⁶

⁶⁹³ Western Australia, Legislative Assembly and Legislative Council, Joint Select Committee on End of Life Choices, report 1, *My Life, My Choice*, August 2018, p 113.

⁶⁹⁴ *ibid.*, p 119.

⁶⁹⁵ *ibid.*, p 16.

⁶⁹⁶ *ibid.*, finding 24, p 113; finding 25, p 119; finding 27, p 122.

Progress of implementation—ongoing professional development for health professionals

5.115 The Department of Health advised:

The Palliative and Supportive Care Education (PaSCE) service based with the Cancer Council of WA provides education for health, aged and community care professionals across the state. PaSCE has confirmed that topics such as the patient's right to refuse medical treatment, to refuse food and water, the transition of curative to non-curative care and discussions around futile treatments are already integrated in their current training programs.

The Education and Training Reference Group has given support to the creation of an Education and Training Hub to support health professionals to access appropriate education and training covering these topics.⁶⁹⁷

5.116 The Department confirmed that the education opportunities through the Palliative and Supportive Care Education (PaSCE) service will be made available to all health professionals inclusive of paid carers (health care workers) and palliative care volunteers.⁶⁹⁸

5.117 The Department also confirmed that the PaSCE training will be made available to aged care workers as required by recommendation 16. The Department explained further:

Training provided by PaSCE would include modules that address recommendation 16 and would be made available to those working in aged care. The work currently being undertaken by the department to implement the National Partnership Agreement into improving palliative care in residential aged care includes significant training and capacity building; increasing aged care workforce competency is a critical part of the program of work to be delivered.⁶⁹⁹

5.118 The Department of Health's 'next steps' in the provision of ongoing professional development as referred to in JSCEOLC recommendations 15, 16 and 17 are:

- liaison with PaSCE regarding the potential development of training modules that will specifically address JSCEOLC recommendations 15, 16, 17
- explicit identification of these learning needs on the online Training and Education Resource Hub,⁷⁰⁰ scheduled for completion in November 2020.⁷⁰¹

FINDING 44

There has been preliminary progress on the implementation of recommendations 15, 16 and 17 of the Joint Select Committee on End of Life Choices relating to ongoing professional development.

Additional progress of implementation—recommendation 15

5.119 Recommendation 15 also recommended that WA Health specifically amend the Consent to Treatment Policy to provide comprehensive information in relation to a competent patient's absolute right to refuse medical treatment.

⁶⁹⁷ Submission 23 from Department of Health, 10 July 2020, p 16.

⁶⁹⁸ Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 82, dated 18 September 2020, p 14.

⁶⁹⁹ Amanda Bolleter, Project Director, End of Life Care, Department of Health, email, 2 November 2020, Attachment 1, Answer to question 3.

⁷⁰⁰ Submission 23 from Department of Health, 10 July 2020, pp 16–7.

⁷⁰¹ Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 85, dated 18 September 2020, p 15.

- 5.120 The Department of Health advised that the Consent to Treatment Policy is currently under review, and that approval in principle has been given to transition the Operational Directive into a Mandatory Policy under the Clinical Governance, Safety & Quality Policy Framework.⁷⁰²

Additional progress of implementation—recommendation 17

- 5.121 Recommendation 17 also recommended that WA Health ‘consider how it might effectively educate the community about end of life decision-making, and implement appropriate health promotion in this area’.

- 5.122 This followed a finding by the JSCEOLC that ‘decision-making in the area of futility of treatment is fraught for patients, families and health professionals’.⁷⁰³

- 5.123 Bethesda advised in its submission:

In the past year, Bethesda’s Metropolitan Palliative Care Consultancy Service has actively sought to address the long-standing issue of identifying the transition from curative to non-curative care and treatment, developing an evidence-based Deteriorating Phase Nursing Assessment (available on request), and providing additional education and training for facility staff in how to identify and respond to ‘increasing decline’.⁷⁰⁴

- 5.124 Bethesda provided the Committee with a copy of the ‘Deteriorating Phase Nursing Assessment’⁷⁰⁵ and advised:

Detecting when an individual is moving into the deteriorating phase and from the deteriorating phase into the terminal phase can be very difficult, depending on the individual presentation and the sorts of diagnoses they have. It is a long-term project for MPaCCS to coach people in care facilities to be able to do that in a timely fashion.⁷⁰⁶

- 5.125 In relation to this part of recommendation 17, the Department of Health referred to its contract with PCWA to provide services aimed at increasing community awareness and education around end-of-life and palliative care, as referred to in paragraphs 5.95 and 5.96 of this report.⁷⁰⁷

FINDING 45

The recommendation in recommendation 17 of the Joint Select Committee on End of Life Choices that WA Health consider how it might effectively educate the community about end-of-life decision-making, and implement appropriate health promotion in this area, is being progressed by negotiations for a five-year service agreement between WA Health and Palliative Care Western Australia.

⁷⁰² *ibid.*

⁷⁰³ Western Australia, Legislative Assembly and Legislative Council, Joint Select Committee on End of Life Choices, report 1, *My Life, My Choice*, 23 August 2018, Finding 27, p 122.

⁷⁰⁴ Submission 34 from Bethesda Health Care, 10 July 2020, p 9.

⁷⁰⁵ Bethesda Health Care, Metropolitan Palliative Care consultancy Service, *Palliative Deteriorating Phase Nursing Assessment*, Tabled by Will Hallahan, Project Officer, Palliative Care, Bethesda Health Care, during hearing held 30 July 2020, p 9.

⁷⁰⁶ Will Hallahan, Project Officer, Palliative Care, Bethesda Health Care, transcript of evidence, 30 July 2020, p 9.

⁷⁰⁷ Amanda Bolleter, Project Director, End of Life Care, Department of Health, email, 2 November 2020, Attachment 1, Answer to question 4.

Implementation of recommendation 18

JSCEOLC recommendation 18:

WA Health should provide specific guidelines on the use of terminal sedation by health professionals for patients at the end of life. These guidelines should include an agreed name and definition of the treatment.

As per any other medical treatment, the requirement for informed consent must be clear.

The treatment must be specifically noted in the medical record as 'terminal sedation'.⁷⁰⁸

Background

5.126 The JSCEOLC found:

The committee received evidence from government agencies, medical professional bodies and medical educators providing a consistent explanation of terminal sedation and its use as an appropriate and lawful treatment option for patients suffering refractory symptoms at end of life.

There remains some confusion amongst health professionals as to the legal status and reasonableness of the clinical practice of terminal sedation and this confusion is likely to result in the denial of adequate symptom relief to some patients at end of life.⁷⁰⁹

Progress of implementation

5.127 The Department of Health advised:

- Draft Clinical Guidelines have been developed by a working group, following consultation with the End-of-Life and Palliative Care Advisory Committee and the WA Palliative Medicine Specialists Group, WA Country Health Service palliative care clinicians and teams, and local, national and international palliative care specialists.
- The WA Clinical Guidelines are based on the European Association for Palliative Care Recommended Framework for Palliative Sedation, modified to the Western Australia context.
- The working group proposed a change of title to better reflect the appropriateness of this area of clinical practice and recommended that the term 'Palliative Sedation' be adopted.⁷¹⁰

5.128 As at September 2020, the draft guidelines were open for wider consultation, closing 24 September 2020, and were expected to be released by the final quarter of 2020.⁷¹¹

⁷⁰⁸ Western Australia, Legislative Assembly and Legislative Council, Joint Select Committee on End of Life Choices, report 1, *My Life, My Choice*, August 2018, p 130.

⁷⁰⁹ *ibid.*, finding 28, p 130.

⁷¹⁰ Submission 23 from Department of Health, 10 July 2020, p 17; Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 88, dated 18 September 2020, p 16.

⁷¹¹ Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 88, dated 18 September 2020, p 16.

FINDING 46

There has been substantial progress on the implementation of recommendation 18 of the Joint Select Committee on End of Life Choices that WA Health provide specific guidelines on the use of terminal sedation by health professionals for patients at the end of life.

RECOMMENDATION 21

The Department of Health report on the progress of implementation of recommendations 8, 10 and 11 of the Joint Select Committee on End of Life Choices in its next Annual Report.

CHAPTER 6

Term of reference (b) – Palliative care funding announcements

- 6.1 The Committee is to inquire into and report on:
- the delivery of the services associated with palliative care funding announcements in 2019–2020.⁷¹²
- 6.2 This chapter will summarise the major funding announcements made in 2019 and 2020 (up to and including 20 August 2020). It will discuss the intended impact of those announcements on palliative care services and progress made to date. Some measures relate to palliative care-specific JSCEOLC recommendations, which were discussed in the previous chapter or will be discussed in Chapter 8.
- 6.3 Funding announcements tend to provide a single dollar amount for the announcement or individual measures within the announcement. For example, \$30.2 million to expand palliative care services in the regions, as noted in paragraph 6.5. The Department of Health provided an expected year-by-year spending profile for each of these announcements.

Summary of funding announcements

- 6.4 In 2019 and 2020, the Government announced three separate packages and several standalone measures on palliative care. The Government also issued updates outlining progress in certain measures.

9 May 2019 package

- 6.5 As part of the 2019-20 Budget, the Government announced⁷¹³ a \$41 million ‘commitment for an end-of-life choices and palliative care package for Western Australians’.⁷¹⁴ The package comprises:
- \$30.2 million to expand palliative care services in the regions
 - \$5.8 million to progress the JSCEOLC recommendations
 - \$5 million for the Carnarvon Aged and Palliative Care facility.⁷¹⁵
- 6.6 The \$41 million will be spent over five years (2018-19 to 2022-23).

⁷¹² Term of reference (b): Western Australia, Legislative Assembly, *Parliamentary Debates (Hansard)*, 20 May 2020, p 2948.

⁷¹³ The package was approved in March 2019, but not announced until May 2019 (Submission 23 from Department of Health, 15 July 2020, p 19).

⁷¹⁴ Hon R Cook MLA, Minister for Health, *Palliative care package to support sickest Western Australians*, media statement, 9 May 2019.

⁷¹⁵ Hon R Cook MLA, Minister for Health, Answer to question on notice A1b, Legislative Council Standing Committee on Estimates and Financial Operations (2019–20 Budget Estimates), 29 July 2019, p 1. The \$5 million is an additional capital contribution to an existing Asset Investment Program project.

10 October 2019 package

- 6.7 The Government announced an additional \$17.8 million to 'enhance palliative care services, which delivers on the recommendations of the Joint Select Committee Report on End of Life Choices'.⁷¹⁶ The package comprises:
- \$9 million towards an additional 10 inpatient palliative care beds in the northern metropolitan suburbs
 - \$6.3 million to expand community-based services across Western Australia
 - \$2.5 million to enhance rural and regional palliative care services by improving governance.⁷¹⁷
- 6.8 The \$17.8 million will be spent over four years (2019-20 to 2022-23).
- 6.9 The announcement also provided further detail on measures contained in the 9 May 2020 package.

20 August 2020 package

- 6.10 The Government announced⁷¹⁸ a \$16.3 million 'injection that will strengthen end-of-life care and support implementation of the Voluntary Assisted Dying legislation'.⁷¹⁹ The package comprises:
- \$5.7 million for greater palliative care support for residential aged care facilities⁷²⁰
 - \$3.7 million to strengthen end-of-life care
 - \$2.6 million to support implementation and continued operation of voluntary assisted dying
 - \$2.4 million for Advance Health Directives⁷²¹
 - \$1.9 million for five northern suburbs palliative care beds.⁷²²
- 6.11 The \$16.3 million will be spent over four years (2020-21 to 2023-24).

⁷¹⁶ Hon M McGowan MLA, Premier; Hon R Cook MLA, Minister for Health, *Massive boost for palliative care services across Western Australia*, media statement, 10 October 2019.

⁷¹⁷ *ibid.*

⁷¹⁸ The package was approved in March 2020, but not announced until August 2020 (Submission 23 from the Department of Health, 15 July 2020, p 20).

⁷¹⁹ Hon R Cook MLA, Minister for Health, *\$16.3 million in State funding to enhance end of life supports*, media statement, 20 August 2020.

⁷²⁰ This represents the State's contribution to the Project Agreement for Comprehensive Palliative Care in Aged Care. The Commonwealth will provide an additional \$5.7 million over five years (2019-20 to 2023-24) as part of this Agreement. The total expected spend from the Agreement will be \$11.4 million over five years.

⁷²¹ The \$2.4 million for Advance Health Directives comprises the \$1.65 million to implement the recommendations of the Ministerial Expert Panel Advance Directives report and \$720 000 for the community awareness and support line (Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 124, dated 18 September 2020).

⁷²² Hon R Cook MLA, Minister for Health, *\$16.3 million in State funding to enhance end of life supports*, media statement, 20 August 2020.

Standalone announcements

6.12 The Government announced on:

- 12 May 2020: \$100 000 for an information and support line⁷²³
- 7 August 2020: the establishment of Western Australia's first children's hospice⁷²⁴
- 13 August 2020: \$9.5 million to enhance palliative care services at Kalamunda Hospital, as part of its \$5.5 billion WA Recovery Plan in response to COVID-19.⁷²⁵

Delivery of services associated with the funding announcements

Expand palliative care services in the regions (9 May 2020)

Summary

6.13 As part of the 2019-20 Budget, the Government committed to spend \$30.2 million to expand palliative care services in the regions. There were three aspects to this expansion:

- review of current service delivery models
- additional regional services (with an increase in the regional workforce)
- additional telehealth support services.

These individual aspects are discussed in more detail in paragraphs 6.17–6.33.

6.14 This commitment relates to the implementation of recommendation 13 of the JSCEOLC (discussed in Chapter 8)⁷²⁶ that:

The Minister for Health should ensure regional palliative care be adequately funded to meet demand.⁷²⁷

6.15 The expected spending on these measures is shown in Table 3.

Table 3. *Spending on expanded palliative care services in the regions (9 May 2020 announcement)*

	2019-20 \$	2020-21 \$	2021-22 \$	2022-23 \$	Total \$
Regional services (including review)	4 208 894	5 795 332	7 312 098	9 867 288	27 183 612
Telehealth	872 023	687 144	702 604	718 413	2 980 184
TOTAL	5 080 917	6 482 479	8 014 702	10 585 701	30 163 796

[Source: Submission 23 from the Department of Health, 10 July 2020, p 19.]

⁷²³ Hon R Cook MLA, Minister for Health, *Information and support line to enhance end-of-life support*, media statement, 12 May 2020.

⁷²⁴ Hon M McGowan MLA, Premier; Hon R Cook, Minister for Health, *Western Australia set to welcome first children's hospice*, media statement, 7 August 2020.

⁷²⁵ Hon R Cook MLA, Minister for Health, *Funding to enhance palliative care services at Kalamunda Hospital*, media statement, 13 August 2020.

⁷²⁶ Paragraphs 8.23–8.42.

⁷²⁷ Western Australia, Legislative Assembly and Legislative Council, Joint Select Committee on End of Life Choices, report 1, *My Life, My Choice*, August 2018, p 83.

6.16 In 2019-20, WACHS spent \$2.4 million on regional services (including review) and \$358 735 on telehealth, just over half of the original allocation of \$5.1 million.⁷²⁸

RECOMMENDATION 22

The Minister for Health explain how the remaining funds allocated to expanded regional palliative care services in 2019-20 will be spent.

Review of current service delivery models

6.17 Regional patients have access to nurse-led multidisciplinary teams that operate during business hours Monday to Friday and an on-call 24 hour specialist nurse. A patient may contact the on-call nurse for support through a state-wide phone number or via appropriate electronic devices (iPads and Samsung tablets).⁷²⁹

6.18 At the time of the 2019-20 Budget, WA Health advised:

The WA Country Health Service (WACHS) is currently undertaking a comprehensive review of existing models of service delivery for palliative care, to focus on the implementation of models of care that best support the needs of those patients with potential access challenges along with addressing current service demands.⁷³⁰

6.19 The review was 'near completion' in July 2020.⁷³¹

6.20 More recently, WACHS indicated that the review has three phases:

- Phase one was to understand the current state (completed).
- Phase two includes identifying region specific population and health data and is planned to be completed by October 2020.
- Phase three is to finalise the models by the end of the next financial year 2020/21. At this stage it has been identified that the number of district-based specialist teams established in each region needs to be flexible, and the FTE will also be adjusted to be more individualised to each specialist position within each district-based team.⁷³²

6.21 WACHS elaborated on 'models of care' and how its review interacted with the independent review being undertaken by the Department of Health:

The models of care conversation is quite complex. I know there were questions around our relationship with where the Department of Health was at with that. I guess at the heart of what is going on in that space is really around service delivery... Model of care in terms of the literature and what is out there, there are some interesting conversations that go on around what a model of care actually is by definition and whether it is a model of care for the health service or a model of care specific to the nursing domain. They do vary widely.

⁷²⁸ Jeffrey Moffet, Chief Executive, WA Country Health Service, Answer to question prior to hearing no 123, dated 18 September 2020, Attachment 1, p 5.

⁷²⁹ See paragraphs 7.18–7.27.

⁷³⁰ Hon R Cook MLA, Minister for Health, Answer to question on notice A1c, Legislative Council Standing Committee on Estimates and Financial Operations (2019 20 Budget Estimates), 29 July 2019, p 1.

⁷³¹ Submission 33 from the WA Country Health Service, 13 July 2020, p 8.

⁷³² Jeffrey Moffet, Chief Executive, WA Country Health Service, Answer to question prior to hearing no 54, dated 18 September 2020, p 7.

If you look, though, to the fundamental principles that they use to describe what a model of care is, WACHS is already doing that in terms of how we deliver our services, so we are focusing on community engagement. We are making sure that it is patient centred in its approach. We are also making sure that we tap into specialist level care, that we also have components of nurse-led care and that we factor in multidisciplinary teams into how we run those services. All those points are very evident in the literature. The variance, potentially, with what the department comes up with and what we are doing will really be just around options for service delivery and what that means. I think we will probably find that their review will say that in many ways we are already doing that. We already provide inpatient services to palliative care. We already work very closely with the NGOs and the GPs in that space. We are providing a community-based service that is supported by a multidisciplinary team that is nurse led, with input from specialist palliative care consultants. We are looking at enhancing the telehealth component, the e-palliative care in the home component, so all of those things in isolation are aspects of a model of care. I guess the missing link for us still is around just writing that up in a way that is meaningful for everyone to be able to go, "This is what it looks like across the whole of the WACHS program".⁷³³

Additional regional services

6.22 At the time of the 2019-20 Budget, WACHS advised:

The uplift in the dedicated palliative care investment is premised on establishing district-based teams, so rather than the seven teams we have got at the moment, moving to around 20 team, albeit many of those part-time, with nursing, allied health and to some extent palliative care specialist support in location.⁷³⁴

6.23 The increase in the number of multidisciplinary teams will coincide with an increase in the contact hours for the teams in some districts from 2021, which will operate from 8am to 6pm every day.⁷³⁵ The daily service is expected to commence in 2021, operating initially in the Midwest, the Great Southern and the South West, with other regions to follow shortly after.⁷³⁶

6.24 The Minister for Health later advised that the 'more than 61 full-time equivalent staff will be employed over a phased approach across regional Western Australia', which will 'triple the staffing arrangements for palliative care support in regional WA'. The announcement included an expected breakdown of FTE by region, with a disclaimer that the 'final FTE and configuration will be determined as models of care are established'.⁷³⁷

6.25 WACHS provided an update on the expected roll-out of services and the distribution of FTE:

Mrs NORRIS: In our early submissions we came up with a bit of a mud map on how we thought that might look. Over the course of the year we have been able to adjust that to better meet the needs of the community based on what each of

⁷³³ Marie Norris, Acting Executive Director, Nursing and Midwifery, WA Country Health Service, transcript of evidence, 18 September 2020, p 13.

⁷³⁴ Jeffrey Moffet, Chief Executive, WA Country Health Service, transcript of evidence, Legislative Council Standing Committee on Estimates and Financial Operations (2019-20 Budget Estimates), 18 June 2019, p 12.

⁷³⁵ Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 56, dated 18 September 2020, p 8; Marie Norris, Acting Executive Director, Nursing and Midwifery, WA Country Health Service, transcript of evidence, 18 September 2020, p 18.

⁷³⁶ Marie Norris, Acting Executive Director, Nursing and Midwifery, WA Country Health Service, transcript of evidence, 18 September 2020, p 18.

⁷³⁷ Hon M McGowan MLA, Premier & Hon R Cook MLA, Minister for Health, *Massive boost for palliative care services across Western Australia*, media statement, 10 October 2019.

those regions have identified they will need. We have massaged that around a little bit. Where we thought originally that we might land on something like three district teams per region, we have created some flexibility, I guess, into that thinking around making sure that if one region, for example, needs additional FTE in the Aboriginal health worker stream, the FTE can be massaged so we are not capped in to saying we are going to put on three nurses, one Aboriginal health worker—that there is some flexibility in that, basically. Some regions might need more social work; some might need more nursing specialist services. It is a ballpark.

Hon KYLE McGINN: Are decisions being made based upon the geographical challenges for there to be more in those teams than, for example, in the smaller geographical areas?

Mrs NORRIS: Not on more. It is based on what level of activity they have, what the demographic of those clients is and what he models is or the numbers are that might best meet the needs of that particular region. We are not saying that every region needs the same amount; we are saying that every region needs a model that best meets the needs of the clients within that community.

Hon KYLE McGINN: With the aim to ensure that all regions have the same level of care?

Mrs NORRIS: Absolutely.⁷³⁸

6.26 Table 4 shows the latest expectations for FTE in each region. Each region is expected to have considerably more FTE than it had prior to the announcement.

Table 4. *WA Country Health Services*

	Pre-palliative care investment: FTE at 1 July 2019	FTE at 30 June 2020	Proposed final FTE
Goldfields	3.10	5.80	10.05
Great Southern	3.20	9.90	11.45
Kimberley	3.50	5.50	11.05
Midwest	2.70	7.70	11.05
Pilbara	1.60	4.40	10.05
South West	11.60	15.10	17.50
Wheatbelt	4.40	6.70	11.45
Governance + telehealth	0.00	4.80	7.25
FTE available for allocation			8.35
Total	30.10	59.90	98.20

[Source: Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question on notice no 10, dated 18 September 2020, p 6.]

⁷³⁸ Marie Norris, Acting Executive Director, Nursing and Midwifery, WA Country Health Service, transcript of evidence, 18 September 2020, p 11.

6.27 The Committee followed up on changed expectations for final FTE, which were 91 in October 2020 and 98 in July 2020, in the following exchange:

Hon NICK GOIRAN: you mentioned that the starting point was just over 30 FTE, and since then there has been an additional 27.45 FTE as at 14 September. In the Department of Health's responses to some questions on notice that were taken at the last hearing in July, they advised that WACHS's proposed final FTE for aspirational recruitment is 98.2 FTE. Is that 98 to include the starting point of 30?

Mrs NORRIS: The additional was 61. We started with 30, which basically parks us at 91. The 98 is a figure that we have been playing with based on onboarding some additional positions that we have already talked about this morning what that might look like in terms of GP models, additional support for pastoral care, mental health. At the end of the day when we get to the end of the project, the figure could potentially be anywhere from 91 to 98. It is not an exact science in terms of what it is that we need and what we are going to be able to recruit to.

Hon NICK GOIRAN: I appreciate that clarification; that is helpful. We are about halfway into the additional recruitment process ballpark?

Mrs NORRIS: Yes.

Mr MOFFET: In terms of the program expansion, we are a little ahead of schedule, to be honest, in terms of absolute numbers, which is really pleasing, given where we have been for the last six or seven months in relation to the COVID response. There has been a fabulous job done by Kirsten medically. I think it was Steph Barrett, our program lead, and Marie as well to develop and secure interest in expansion right across the state. Personally, I am extraordinarily surprised that we have got to where we have got to in the circumstances. It really is a fantastic development. We have maintained some agility, and it is true that the numbers will flex a little bit. Sometimes we will contract services out with GPs or other organisations or we will put doctors on to contracts that are not about FTE; they are about a medical services agreement. Fundamentally, in terms of the resource distribution, our intent is to absolutely ensure that people have the same access to care, both locally but also virtually, wherever you happen to be in the state at district level, and then increasingly to town and then out to community and homes ultimately.⁷³⁹

6.28 The Department of Health advised that the Pilbara region faced challenges recruiting enough personnel and has subsequently met this need by contracting Bethesda to provide an in-reach model of care from July 2020.⁷⁴⁰

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.⁷⁴¹

⁷³⁹ Marie Norris, Acting Executive Director, Nursing and Midwifery, and Jeffrey Moffett, Chief Executive, WA Country Health Service, transcript of evidence, 18 September 2020, p 11.

⁷⁴⁰ Amanda Bolleter, Project Director, End of Life Care, Department of Health, email, 2 November 2020, Attachment 1, Answer to question 8.

⁷⁴¹ Submission 23 from the Department of Health, 10 July 2020, p 5.

24-hour support via telehealth

6.29 The Government committed \$3 million to enable '24-hour support via the WA Country Health Service telehealth hub which will ensure staff, patients and families have access to nursing care for patients who wish to die at home'.⁷⁴² This will be supported by an expansion in the telehealth services provided by the WACHS command centre that is based in Perth.

6.30 WACHS described the command centre and its intended role in palliative care in the regions as follows:

the planning for delivery of services generally in country WA relies upon a very generalist workforce, particularly the nursing workforce, in around 68 hospital sites and another 30 or so remote sites. We rely very heavily on generalist staff from Halls Creek through to Dumbleyung and many other places in between. What we have done over the last seven or eight years to support those staff in delivery of, particularly, emergency care and inpatient care is develop the command centre, which is really enabled by telehealth, but the command centre is a team of people who are expert 24 hours a day in supporting out clinical staff on the ground.

As we planned for the palliative care expansion, it was really obvious that the level of support to our nursing staff in particular in healthcare facilities could be improved in a similar way that we had done with inpatient services and emergency telehealth services and, more recently, mental health telehealth services. That relies on a number of things. It is not just a point-to-point consultation or conversation as we are having today; it is really about very clear protocols, as Marie was saying, having standardisation of what we do, complementing our education and development programs virtually by delivering virtual education and support right across country WA, and ensuring that we have a responsive system where there are pre-existing relationships and clinical trust between the receivers of the advice and those actually providing the advice.⁷⁴³

6.31 As well as providing support to clinical staff, the WACHS command centre will provide telehealth consultations between patients in community settings and WACHS specialists based in the command centre from the telehealth hub. WACHS explained:

Tele-palliation, obviously, is a significant opportunity and need for us. Palliation occurs right across the state. As you will see, I think, in the presentation that was previously done, we are moving very much from a regional investment prior to this investment to district level investment, with another layers that is very innovation driven about getting support into homes as well. The command centre and telehealth will be absolutely pivotal in that. Those systems are currently being designed.⁷⁴⁴

6.32 WACHS elaborated on the complementary nature of telehealth services and how it will affect services to patients:

Mr MOFFET: The telehealth is purely complementary, particularly around 24-hour access. For example, the specialist visiting from the south west to go to the wheatbelt is really only available 0.2 and will not spend all of that 0.2 in any given location, obviously. The telehealth access to palliation specialists or palliation advice through the nurse specialist is a 24-hour offering, essentially, just because there are hundreds of locations and getting physical access to a palliative care

⁷⁴² Hon M McGowan MLA, Premier & Hon R Cook MLA, Minister for Health, *Massive boost for palliative care services across Western Australia*, media statement, 10 October 2019.

⁷⁴³ Jeffrey Moffett, Chief Executive, WA Country Health Service, transcript of evidence, 18 September 2020, p 7.

⁷⁴⁴ *ibid.*

specialist is limited at any point in time. Both will still occur—physical reviews by an enhanced palliation specialist team all the way across the state—but most importantly, that really important after-hours support to both our staff in facilities but in time, to families and patients at their home; that is the 24-hour nature of telehealth. They are very complementary.

Mrs NORRIS: At the moment there are consultant-led specialists available through the statewide number. That is up and running and is available regardless. The telehealth component for nursing will be that during those out-of-hours times, the call will go through to the command centre and the nurse will be able to make a call around what is going on. If she needs to dial in and “provision” with that client—bring them up on the screen and do a full assessment—that capability will exist within the command centre function. Provisioning does not have to occur necessarily based in the command centre; there can be a champion in each of the regions that has access to provisioning so they can dial in across the state if they are on call to provide that level of telehealth service out of hours. That will be nurse-led.⁷⁴⁵

- 6.33 The palliative care service through the command centre is expected to operate from January 2021.⁷⁴⁶

Carnarvon Aged and Palliative Care facility (9 May 2020)

- 6.34 The Government committed an additional \$5 million to expand the previously proposed aged care facility in Carnarvon into a ‘purpose-built, 38-bed residential aged and palliative care facility’.⁷⁴⁷ The Director-General of the Department of Health advised:

Over the last few months, there has been planning done to date that shows there is a need for increased capital funding at Carnarvon and increased funding specifically for rural and regional services.⁷⁴⁸

- 6.35 The facility was expected to cost \$16.6 million, with \$4.5 million of the additional contribution to be spent in 2019-20 and the remainder to be spent in 2020-21.
- 6.36 WACHS put construction of the facility out to an open tender. On 8 June 2020, WACHS awarded the tender to Crothers Construction Pty Ltd, a Midwest business, for \$15.0 million.⁷⁴⁹ Construction was expected to commence in August 2020, with practical completion in late 2021.⁷⁵⁰
- 6.37 The construction of the facility has experienced some commencement delays and an increase in the expected total cost since the expansion was announced in the 2019-20 Budget. These changes are shown in Table 5.

⁷⁴⁵ Marie Norris, Acting Executive Director, Nursing and Midwifery, and Jeffrey Moffett, Chief Executive, WA Country Health Service, transcript of evidence, 18 September 2020, p 19.

⁷⁴⁶ Jeffrey Moffet, Chief Executive, WA Country Health Service, Answer to question prior to hearing no 56, dated 18 September 2020, p 8.

⁷⁴⁷ Hon R Cook MLA, Minister for Health, *Palliative care package to support sickest Western Australians*, media statement, 9 May 2019.

⁷⁴⁸ Dr DJ Russell-Weisz, Director General, Department of Health, transcript of evidence, Legislative Council Standing Committee on Estimates and Financial Operations (2019-20 Budget Estimates), 18 June 2019, p 11.

⁷⁴⁹ Hon R Cook MLA, Minister for Health, *Modern aged and palliative care facility on track for Carnarvon*, media statement, 26 June 2020

⁷⁵⁰ *ibid.*; Submission 23 from Department of Health, 10 July 2020, p 15.

Table 5. *Expectations for spending on the Carnarvon Aged and Palliative Care facility**

	2018-19	2019-20	2020-21	2021-22	2022-23	Total
	\$	\$	\$	\$	\$	\$
2019-20 Budget	15,000	5,700,000	9,048,00	1,814,000	-	16,577,000
2020-21 Budget expectations	62,000	316,000	12,240,000	5,531,000	-	18,149,000

[Source: Government of Western Australia, *2019-20 Budget, Budget Statements, Budget Paper No. 2*, report prepared by the Department of Treasury, 9 May 2019, p 282 & Government of Western Australia, *2020-21 Budget, Budget Statements, Budget Paper No. 2*, report prepared by the Department of Treasury, 8 October 2020, p 230.]

* Unrounded numbers are not available.

6.38 The facility is now expected to cost \$19.1 million. The Department of Health advised that 'all resultant tender submissions received for the project were significantly over budget and it was anticipated that an additional \$2.20-\$2.5m in funding would be required for the project'. The additional funding was reallocated to the project from within WACHS's Asset Investment Program.⁷⁵¹

6.39 WACHS spent \$320 000 of the \$4.5 million additional contribution in 2019-20.⁷⁵²

Additional inpatient palliative care beds in the Perth northern suburbs (10 October 2020 and 20 August 2020)

6.40 The establishment of 'an inpatient specialist palliative care hospice providing publicly funded beds in the northern suburbs of Perth' was recommended in recommendation 7 of the JSCEOLC.⁷⁵³ Implementation of this recommendation is discussed in Chapter 5.⁷⁵⁴

6.41 On 10 October 2019, the Government announced that it would provide \$9 million for an additional 10 inpatient palliative care beds in northern metropolitan suburbs. This would represent a 15 per cent increase in the number of metropolitan inpatient beds for palliative care. These additional beds will:

provide better access for patients and brings the service in line with the levels available in the eastern metropolitan suburbs, and delivers on a recommendation from the Joint Select Committee Report on End of Life Choices.⁷⁵⁵

6.42 NMHS will procure this service from third parties. It issued early tender advice in June 2020 and opened the tender on 10 August 2020. The tender closed on 10 September 2020 and is expected to be awarded in January 2021, with services to commence shortly after.⁷⁵⁶

6.43 The tender description noted:

North Metropolitan Health Service requires the provision of an all-inclusive adult inpatient Specialist Palliative Care Service for patients that cannot be managed in the community, a residential facility or within a general hospital service. The facility must be clinically appropriate for palliative patients and provide up to 3650 bed

⁷⁵¹ Dr DJ Russell-Weisz, Director General, Department of Health, letter, 16 October 2020, Attachment 2, p 7.

⁷⁵² Jeffrey Moffet, Chief Executive, WA Country Health Service, Answer to question prior to hearing no 123, dated 18 September 2020.

⁷⁵³ Western Australia, Legislative Assembly and Legislative Council, Joint Select Committee on End of Life Choices, report 1, *My Life, My Choice*, August 2018, p 67.

⁷⁵⁴ Paragraphs 5.21–5.33.

⁷⁵⁵ Hon M McGowan, Premier & Hon R Cook MLA, Minister for Health, *Massive boost for palliative care services across Western Australia*, media statement, 10 October 2019.

⁷⁵⁶ Submission 23 from the Department of Health, 10 July 2020, p 8.

days per annum (10 patient beds equivalent) in the northern suburbs of Perth, Western Australia, preferably in the Joondalup Health Campus catchment area.⁷⁵⁷

- 6.44 The contract will be for three years and three months.⁷⁵⁸
- 6.45 In July 2020, the Department of Health advised that it allocated \$1.1 million to NMHS to procure an additional five inpatient palliative care beds as an interim measure. At the time of its submission to the Committee, the Department was negotiating with providers to meet those needs.⁷⁵⁹
- 6.46 On 20 August 2020, the Government publicly announced the interim arrangements and that these arrangements would cost \$1.9 million.⁷⁶⁰
- 6.47 NMHS purchased the five additional beds at the Joondalup Health Campus. The service commenced on 15 September 2020 and will go through until 15 March 2021.⁷⁶¹
The Committee queried the contract date:

Mr Z.R.F. KIRKUP: Why 15 March?

Mr DOLAN: We were supplied with \$1.1 million from the department, and that gives us approximately that arrangement. It also allows for the tender to be let. A transition time is probably the best way to describe it, for the respondent, the successful party, to take up their service.⁷⁶²

- 6.48 NMHS will pay a rate per occupied bed and per unoccupied bed.⁷⁶³
- 6.49 A further commitment of \$4 million was made for 2023-24 in 'recognition of the intention to provide this service on an ongoing basis'.⁷⁶⁴ On this, NMHS advised:

The CHAIR: ... At the hearing on 15 July, it was noted that an additional \$4 million has been allocated to the 2023-24 time. Noting the anticipated ongoing provision of these beds, is this additional amount included in any of the publicly announced funding? Would you like to add your answer there or just elaborate on that?

Mr DOLAN: The comment I would make in response there is that we have the allocation of funding that takes us through to 2022-23, and beyond that we are not aware of funding that will come to North Metro.

The CHAIR: The next one is about the ongoing operations of the additional 10 inpatient beds. How will they be funded beyond 2023-24? And, perhaps, if you want to elaborate on your response there.

⁷⁵⁷ Government of Western Australia, Tenders WA, Department of Finance. See: <https://www.tenders.wa.gov.au/watenders/tender/display/tender-details.do?CSRFNONCE=83E42A62D834AD27EEA99BB992747A&id=46937&action=display-tender-details&returnUrl=%2Ftender%2Fsearch%2Ftender-search.do%3FCSRFNONCE%3DDF089580678CCDA8A33F0B792DE1AE66>. Viewed 10 September 2020.

⁷⁵⁸ Amanda Bolleter, Project Director, End of Life Care, Department of Health, transcript of evidence, 15 July 2020, p 7.

⁷⁵⁹ Submission 23 from the Department of Health, 10 July 2020, p 8.

⁷⁶⁰ The Department of Health later advised that 'the initial allocation of \$1.1 million was increased to \$1.9 million following further consultation with NMHS and as a result of negotiations with Joondalup Health Campus' (Dr DJ Russell-Weisz, Director General, Department of Health, letter, 16 October 2020, Attachment 2, p 4).

⁷⁶¹ Anthony Dolan, Chief Executive, North Metropolitan Health Service, transcript of evidence, 18 September 2020, p 41.

⁷⁶² *ibid.*

⁷⁶³ *ibid.*, p 42.

⁷⁶⁴ Submission 23 from the Department of Health, 10 July 2020, p 8.

Mr DOLAN: I am unable to comment on that final advance, and it is question we can take on notice.

The CHAIR: Is it something that has been contemplated, though?

Mr DOLAN: Not in discussions with me.⁷⁶⁵

6.50 The expected amount spent procuring additional inpatient palliative care beds is shown in Table 6.

Table 6. *Amount spent procuring additional inpatient beds in the northern suburbs*

Measure	2020-21 \$	2021-22 \$	2022-23 \$	2023-24 \$	Comments
Five additional beds (interim)	1 900 000*	-	-	-	15 September 2020 to 15 March 2021.
Ten additional beds (final)	956 672	3 957 713	4 097 222	-	Original commitment.
Ten additional beds (final)	-	-	-	4 000 000*	Additional funds to cover contract period.

[Source: Submission 23 from the Department of Health, 15 July 2020, p 19.]

* Unrounded numbers for the five additional beds (interim) and the allocation for the ten additional beds in 2023-24 are not available.

6.51 NMHS advised:

We have five beds which are being currently supported by the \$1.1 million, which is outside this amount that we are talking about over the forward three years. There is an additional \$1 million for the tender in the last part of this financial year. I would expect that would cover approximately three months of operation, and then the \$4 million will support each quarter following that for the next two years. So, \$4 million would be the amount of money that we understand we will be funded for the operation of the 10 beds in the next two financial years.⁷⁶⁶

Expansion of community-based services (10 October 2019)

6.52 On 10 October 2019, the Government announced that it would spend \$6.3 million on 'community based services to be delivered predominantly through non-government organisations across the State', with \$2 million to be spent in rural and regional Western Australia.⁷⁶⁷ A breakdown of the spending is in Table 7.

⁷⁶⁵ Anthony Dolan, Chief Executive, North Metropolitan Health Service, transcript of evidence, 18 September 2020, p 41.

⁷⁶⁶ Paola Morellini, Director, Clinic Planning, North Metropolitan Health Service, transcript of evidence, 18 September 2020, p 44.

⁷⁶⁷ Hon M McGowan, Premier; Hon R Cook MLA, Minister for Health, *Massive boost for palliative care services across Western Australia*, media statement, 10 October 2019.

Table 7. *Spending on the expansion of community-based services*

	2019-20	2020-21	2021-22	2022-23	Total
	\$	\$	\$	\$	\$
Metropolitan	275 215	769 304	1 318 533	1 932 677	4 295 729
Regional	82 886	341 386	628 022	947 706	2 000 000
Total	358 101	1 110 690	1 946 555	2 880 383	6 295 729

[Source: Submission 23 from the Department of Health, 10 July 2020, p 19.]

6.53 This announcement relates to the implementation of recommendation 8 of the JSCEOLC, that:

The Minister for Health should ensure that community palliative care providers, such as Silver Chain, are adequately funded to provide for growing demand.⁷⁶⁸

6.54 The implementation of this recommendation is discussed in Chapter 5.⁷⁶⁹

Metropolitan services

6.55 The Department of Health advised:

Planning has commenced to identify gaps that may be addressed from 2020-21. An example of this is an after-hours clinical phone line that provides an integrated service for all community services, including residential aged care and primary care providers. It is the value of having that advice available for all providers at end of life, 24 hours a day, when that is necessary. Initial spending of the \$4.3 million has commenced. The 2019-20 funding portion of \$275 000 was provided to Silver Chain to support current palliative care provision. These funds provided equipment for the community palliative care service, and also supported registrars who are providing clinical care in the community.⁷⁷⁰

6.56 The Department later advised that the:

[a]llocation of funding to service providers will be determined on service model planning that is currently underway and that will be informed by the independent review into patient perspectives (recommendation 9).⁷⁷¹

6.57 The Department fully expended its allocation for 2019-20.⁷⁷²

Regional services

6.58 The aim for the regional services is to provide funding to 'patients at risk of hospital or residential care admission ... for domiciliary care services (including personal care, cleaning, respite care) in a responsive timeframe'.⁷⁷³ WACHS advised:

⁷⁶⁸ Western Australia, Legislative Assembly and Legislative Council, Joint Select Committee on End of Life Choices, report 1, *My Life, My Choice*, August 2018, p 68.

⁷⁶⁹ Paragraphs 5.34–5.53.

⁷⁷⁰ Amanda Bolleter, Project Director, End of Life Care, Department of Health, transcript of evidence, 15 July 2020, p 8.

⁷⁷¹ Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 8, dated 18 September 2020, p 2.

⁷⁷² Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 123, dated 18 September 2020, p 25.

⁷⁷³ Department of Health, *Palliative Care in WA*, PowerPoint presentation, tabled by Angela Kelly, Acting Director General, Department of Health, during hearing held 15 July 2020, p 14.

The packages were designed to pick up the people who were currently having [Commonwealth Home Support Program] approvals in the system or [National Disability Insurance Scheme] approvals that were taking a long time to get approved, so there was no other provision there for them. While they are waiting for those packages to be approved, they can access the current packages that we offer. Also, it covers a whole range of other scenarios where the criteria for the eligibility is pretty broad in terms of who can access it.⁷⁷⁴

- 6.59 WACHS advised that it was implementing its own patient care assistant palliative care model in regions where they had no providers:

We are going to create pools in each of the regions for [patient care assistants] to sit in specifically to provide those home-type services in addition to the nursing care that they would get. Those traditional packages include assistance with activities of daily living, shopping, getting to appointments and home care—cooking, cleaning, whatever that might look like. It is variable. Each of the patients liaise with the social worker and they work up exactly what their needs are and what we are going to build into the package. They range in cost from \$250 to \$680 a week.⁷⁷⁵

- 6.60 WACHS had approved 15 packages as at 18 September 2020, down from 16 packages on 15 July 2020.⁷⁷⁶

- 6.61 The Department spent \$69 416 of the \$82 886 allocated in 2019-20.⁷⁷⁷

Improved regional governance (10 October 2019)

- 6.62 On 10 October 2019, the Government announced funding of \$2.5 million to:

enable the WA Country Health Service to enhance rural and regional palliative care services by improving governance to refine models of palliative care and roll-out the services, ensuring the best support the needs of rural and regional patients.

The boost to governance means an additional 3.2 FTE [full-time equivalents] will be employed to ensure high-quality palliative care in the regions that is patient centred and provided in the patient's place of choice.⁷⁷⁸

- 6.63 This announcement relates to the implementation of recommendation 12 of the JSCEOLC, that:

The Minister for Health should prioritise policy development and improved governance structures for the delivery of palliative care by WA Country Health Services.⁷⁷⁹

- 6.64 The implementation of this recommendation is discussed in Chapter 8.⁷⁸⁰

⁷⁷⁴ Marie Norris, Acting Executive Director, Nursing and Midwifery, WA Country Health Service, transcript of evidence, 18 September 2020, p 17.

⁷⁷⁵ *ibid.*

⁷⁷⁶ *ibid.*; Department of Health, *Palliative Care in WA*, PowerPoint presentation, tabled by Angela Kelly, Acting Director General, Department of Health, during hearing held 15 July 2020, p 14.

⁷⁷⁷ Jeffrey Moffet, Chief Executive, WA Country Health Service, Answer to question prior to hearing no 123, dated 18 September 2020.

⁷⁷⁸ Hon M McGowan MLA, Premier; Hon R Cook MLA, Minister for Health, *Massive boost for palliative care services across Western Australia*, media statement, 10 October 2019.

⁷⁷⁹ Western Australia, Legislative Assembly and Legislative Council, Joint Select Committee on End of Life Choices, report 1, *My Life, My Choice*, 23 August 2018, p 83.

⁷⁸⁰ Paragraphs 8.15–8.21.

- 6.65 The \$2.5 million will fund the following positions:
 - Clinical Director Palliative Care (0.2 FTE)
 - Program Manager (1 FTE)
 - Senior Project Officer (1 FTE)
 - Nurse Practitioner/Clinical Nurse Consultant (1 FTE).
- 6.66 WACHS has appointed people to the first three positions. It has experienced some difficulties appointing a nurse practitioner, and is now advertising for a clinical nurse consultant:

We advertised and did not get any suitable applicants. They were either not a practitioner or they were not a nurse practitioner with a palliative care background. So we have gone out to further readvertise that position to a broader national market hoping that we might attract someone but there is a shortage of nurse practitioner specialists within that discipline...

As an interim, as I said, we are looking at a clinical nurse consultant, which is not at that level, but certainly has the strengths and expertise to support the team in the interim. We are looking at a number of options around potentially what we might do to fill that gap, one of which is conversations that I am having with the Chief Nursing and Midwifery Office around candidacy models where we might be able to grow our own nurse practitioners in that space. The shortage is not just in the discipline of palliative care; the shortage is in the nurse practitioner workforce across all specialty areas.⁷⁸¹

- 6.67 WACHS advised that it intended to appoint a clinical nurse consultant by the end of October 2020.⁷⁸²
- 6.68 Table 8 sets out the spending allocation for each year.

Table 8. *Spending on improve regional governance*

	2019-20	2020-21	2021-22	2022-23	Total
	\$	\$	\$	\$	\$
Improved regional governance	621 221	626 777	632 214	637 777	2 517 989

[Source: Submission 23 from the Department of Health, 10 July 2010, p 19.]

- 6.69 WACHS spent \$358 735 of the \$621 221 allocated in 2019-20.⁷⁸³ The underspend is due to the later start date of the Senior Project Officer⁷⁸⁴ and the unfilled nurse practitioner role.
- 6.70 The annual employment costs of the currently filled positions (including relevant on cost, such as superannuation and workers' compensation) is expected to be \$416 580 in 2020-21.⁷⁸⁵

⁷⁸¹ Jeffrey Moffet, Chief Executive, WA Country Health Service, Answer to question prior to hearing no 51, dated 18 September 2020, p 8.

⁷⁸² Marie Norris, Acting Executive Director, Nursing and Midwifery, WA Country Health Service, transcript of evidence, 18 September 2020, pp 19– 20.

⁷⁸³ Jeffrey Moffet, Chief Executive, WA Country Health Service, Answer to question prior to hearing no 123, dated 18 September 2020, Attachment 1, p 5.

⁷⁸⁴ Sinqobizitha Mndebele commenced in the role on 17 February 2020 (Mr DJ Russell Weisz, Director General, Department of Health, Answer to question on notice no 11 asked at hearing held 15 July 2020, dated 14 August 2020, p 8).

⁷⁸⁵ Mr DJ Russell Weisz, Director General, Department of Health, Answer to question on notice no 11 asked at hearing held 15 July 2020, dated 14 August 2020, p 8.

6.71 Further details of the measures to improve regional governance pursuant to recommendation 12 are set out in Chapter 8.⁷⁸⁶

Palliative care in residential aged care facilities (20 August 2020)

6.72 In May 2020, the Commonwealth and State Ministers for Health signed the National Partnership Agreement. The purpose of the National Partnership Agreement is to:

support the delivery of projects that expand existing models of care or new approaches to the way care is delivered or commissioned, to improve palliative and end of life coordination for older Australians living in residential aged care facilities.⁷⁸⁷

6.73 Each jurisdiction's financial contribution is set out in Table 9. The State's contribution was publicly announced on 20 August 2020.

Table 9. *Financial contribution to the Project Agreement for Comprehensive Palliative Care in Aged Care**

	2019-20	2020-21	2021-22	2022-23	2023-24	Total
	\$	\$	\$	\$	\$	\$
Commonwealth	1 034 000	1 088 000	1 147 000	1 970 000	1 256 000	5 722 000
State		1 622 000	1 644 000	1 197 000	1 256 000	5 719 000

[Source: Submission 23 from the Department of Health, 10 July 2020, p 20.]

* Unrounded numbers are not available.

6.74 The Department of Health advised:

The draft scope included projects that fell under two of the three NPA [National Partnership Agreement] outputs. The following original projects met outputs a) in-reach consultancy services and c) training, education and mentoring services:

Project 1 - Metropolitan Palliative Care Consultancy Service (MPaCCS) - In-Reach Specialist Palliative Care Consultancy Service that includes an assessment to establish residents' current and emerging palliative care needs.

Project 2 – Palliative and Supportive Care Education (PaSCE) - Residential Aged Care: Training, education and mentoring to build workforce capability in palliative care.

Additional projects will be considered that support end-of-life care decision making and the development of agreed goals of care in order to meet the needs of individual residents: Project 3 – Care Coordination to Support End of Life Care Decision Making. Collectively, the projects will explore options for a RACFs [Residential Aged Care Facilities] to ensure model sustainability, and revise existing systems, processes and policies. In this respect, the revised approach refers to improvement of current RACF practices (expansion of and introduction of new approaches) as informed by contemporary evidence-based models of care and practice.⁷⁸⁸

⁷⁸⁶ Paragraphs 8.15–8.22

⁷⁸⁷ Governments of Australia, *Project Agreement for Comprehensive Palliative Care in Aged Care*, October 2019, p 1.

⁷⁸⁸ Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 101, dated 18 September 2020, p 19.

- 6.75 As at 15 July 2020, the Department of Health had not allocated the National Partnership Agreement spending amounts as negotiations were still underway, and there was no target date for conclusion.⁷⁸⁹ More recently, the Department advised:

The End of Life Care (EOLC) team has been negotiating with both Bethesda Health Care (BHC) and Cancer Council WA to scope specific projects that satisfies the National Partnership Agreement (NPA) on Comprehensive Palliative Care in Aged Care requirements and guidelines and meet the need of RACF residents. Negotiations between the Department and both BHC and CCWA are nearing completion with a final budget and program proposal to be provided to WA Health Executive for approval by late September.⁷⁹⁰

Community awareness and support line (12 May 2020)

- 6.76 The establishment of a 'palliative care information and community hotline' was recommended as part of recommendation 11 of the JSCEOLC.⁷⁹¹ Implementation of this recommendation is discussed in Chapter 5.⁷⁹²
- 6.77 The community awareness and support line will provide callers with 'non-clinical palliative care ... information and advice for palliative care services in Western Australia'.⁷⁹³ The Department of Health explained:

That phone service will be an option for people to call up to say, for example, "I've just been referred for palliative care. I have no idea what that means. Where do I go now? What services are available? What are the next steps for me and my family?" That phone line will be able to provide people with that information and advice, talk them through what the implications are for them, and then to provide them with contact details and link in with relevant services for them.⁷⁹⁴

- 6.78 The Department of Health advised on the background to the support line:

WA Health undertook a review of palliative care hotlines across Australia that informed the development of an options paper. This options paper identified a preferred approach for a service that provides callers with non-clinical information and advice and a service that is well informed about local needs and resources. It was clear that it needed to be a WA-based service, not a national phone number. WA Health approved the commencement of a restricted tender process to procure community services in February this year.⁷⁹⁵

⁷⁸⁹ Amanda Bolleter, Project Director, End of Life Care, Department of Health, transcript of evidence, 15 July 2020, pp 28-9.

⁷⁹⁰ Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 100, dated 18 September 2020, p 19.

⁷⁹¹ Western Australia, Legislative Assembly and Legislative Council, Joint Select Committee on End of Life Choices, report 1, *My Life, My Choice*, August 2018, p 79.

⁷⁹² Paragraphs 5.102–5.108.

⁷⁹³ Government of Western Australia, Tenders WA, Department of Finance. See: <https://www.tenders.wa.gov.au/watenders/tender/display/tender-details.do?CSRFNONCE=CD636B409A0D0E518A72912688FABA9C&id=46774&action=display-tender-details&returnUrl=%2Ftender%2Fsearch%2Ftender-search.do%3FCSRFNONCE%3D97EB86BF375452D018899CC49A11E98B>. Viewed 10 September 2020.

⁷⁹⁴ Amanda Bolleter, Project Director, End of Life Care, Department of Health, transcript of evidence, 18 September 2020, p 61.

⁷⁹⁵ Amanda Bolleter, Project Director, End of Life Care, Department of Health, transcript of evidence, 15 June 2020, p 12.

- 6.79 The Government approved \$720 000 for a community awareness and support line in March 2020.⁷⁹⁶
- 6.80 As an interim measure, the Government launched the Palliative Care Information and Support Line on 1 May 2020. PCWA will deliver service for six months, 'offering essential information and support to Western Australians who are dealing with palliative care or end-of-life issues'.⁷⁹⁷
- 6.81 The interim service is estimated to cost nearly \$100 000, with the funding sourced from:
the repurposing of funds that had initially been earmarked for Advance Care Planning workshops, that could not go ahead due to COVID19 restrictions; the information line was deemed a crucial component in facilitating community access, support and information to palliative care and advance care planning.⁷⁹⁸
- 6.82 The Department of Health put the establishment of a non-clinical care hotline out to tender in July 2020. The tender closed on 21 August 2020 and is expected to be awarded in October 2020, with services to commence on 1 November 2020 unless 'otherwise notified by the State Party'.⁷⁹⁹ The timing of the successful tender commencement is intended to align with the existing hotline to ensure that there is no gap in service for the community.⁸⁰⁰
- 6.83 The initial contract period will be for four years with no extension options available for a total estimated cost of \$156 452 (excluding GST), \$172 097 (including GST), in the first year.⁸⁰¹
- 6.84 The Government announced the establishment of the support line as part of the \$16.3 million package on 20 August 2020.
- 6.85 On the uptake of the existing support line, the Department advised:
The results of the first four months have been encouraging with 88 calls to the hotline. It is expected that this number will increase as the service builds up, is promoted and understanding of palliative care is increased in the community.⁸⁰²

New children's hospice (7 August 2020)

- 6.86 CAHS outlined the state of paediatric palliative care services in Western Australia. CAHS hosts the WA Paediatric Palliative Care Service, the only specialist palliative care service for children. There is only one paediatric palliative medicine specialist and there are no specialist paediatric palliative care beds in Western Australia.⁸⁰³

⁷⁹⁶ Submission 23 from Department of Health, 10 July 2020, p 20.

⁷⁹⁷ Hon R Cook MLA, Minister for Health, *Information and support line to enhance end-of-life support*, media statement, 12 May 2020.

⁷⁹⁸ Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 48, dated 18 September 2020, p 12.

⁷⁹⁹ Government of Western Australia, *Community service request for: Establishment of a non-clinical palliative care hotline*, issued and prepared by the Department of Health, July 2020, p 13.

⁸⁰⁰ Amanda Bolleter, Project Director, End of Life Care, Department of Health, transcript of evidence, 15 July 2020, p 12.

⁸⁰¹ Government of Western Australia, *Community service request for: Establishment of a non-clinical palliative care hotline*, issued prepared by the Department of Health, July 2020, p 4.

⁸⁰² Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 119, dated 18 September 2020.

⁸⁰³ Submission 7 from Child and Adolescent Health Services, 6 July 2020, pp 3 and 6.

6.87 On 7 August 2020, the Government announced that Perth Children’s Hospital Foundation⁸⁰⁴ will fund the construction, fit-out and ongoing non-operational cost of a new children’s hospice. The CAHS will provide the ongoing clinical, governance and management funding. The hospice will:

support children and their families throughout all stages of their journey – from early diagnosis, during the continuum of their condition, through to end of life with support for families in bereavement.⁸⁰⁵

6.88 The Government further advised:

CAHS will also extend the current Paediatric Palliative Care Service to provide specialist staff at the hospice in the following key service areas:

- care for children who have a life-limiting diagnosis who often require 24/7 care. The hospice will care for these children for a period of time allowing their families much needed respite;
- support for families – parents, siblings, grandparents, aunts and uncles – as this affects them all;
- end of life care for children with the safety net of clinical care in the comfort of a highly respectful and supported environment; and
- a State-wide bereavement service for families following the death of a child.⁸⁰⁶

6.89 The ongoing management of the children’s hospice does not form part of the funding announcements for the palliative care announced in 2019 and is separately funded.⁸⁰⁷

6.90 The Committee sought further information on the staffing arrangements underpinning this announcement:

Mr R.S. LOVE: will that require recruitment of new staff or are the staff who will be providing that service already in the hospital environment? ...

Ms BOLLETER: It is probably a question that is most appropriately directed to CAHS, but my understanding is that as the service is likely not to be collocated within Perth Children’s Hospital, you would reasonably expect that it would require a separate workforce. How that is actually structured and worked would need to be a question for CAHS and may well be part of their current planning.⁸⁰⁸

Enhanced palliative care services at Kalamunda Hospital (13 August 2020)

6.91 The Kalamunda Hospital is a small specialist hospital that provides inpatient palliative care, geriatric medicine and low risk endoscopic surgery services.⁸⁰⁹

⁸⁰⁴ The Perth Children’s Hospital Foundation is the ‘official fundraising body and largest private funder of Perth Children’s Hospital (PCH), as well as the wider Child & Adolescent Health Service (CAHS) (Perth Children’s Hospital Foundation. See: https://www.facebook.com/pg/PCHFVA/about/?ref=page_internal. Viewed 9 October 2020).

⁸⁰⁵ Hon M McGowan MLA, Premier; Hon R Cook MLA, Minister for Health, *Western Australia set to welcome first children’s hospice*, media statement, 7 August 2020.

⁸⁰⁶ Hon M McGowan MLA, Premier; Hon R Cook MLA, Minister for Health, *Western Australia set to welcome first children’s hospice*, media statement, 7 August 2020.

⁸⁰⁷ Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 115, dated 18 September 2020, p 22.

⁸⁰⁸ Amanda Bolleter, Project Director, End of Life Care, Department of Health, transcript of evidence, 18 September 2020, p 57.

⁸⁰⁹ East Metropolitan Health Service. See: <https://emhs.health.wa.gov.au/Hospitals-and-Services/Hospitals/Kalamunda-Hospital>. Viewed 1 October 2020.

6.92 On 13 August 2020, the Government announced a \$9.5 million refurbishment of palliative care services at Kalamunda Hospital. The planned works will incorporate:

[a] reconfiguration of the patient rooms to create single rooms with ensuite and improved access to outdoor spaces, and upgrading of facilities and amenities for families and carers...

additional therapeutic spaces such as improved gardens and landscaping outdoors and incorporation of an indoor art/therapy room...

proactive outreach models of care and improved service linkages, supports and capacity within East Metropolitan Health Services, in addition to a day hospice and outpatient services including Telehealth.⁸¹⁰

The Minister advised that planning would start immediately, with construction to start mid-2021.⁸¹¹

6.93 The Department advised that the project will be delivered by the Department of Finance (Building Management and Works), supported by EMHS.⁸¹²

6.94 The \$9.5 million allocation includes planning costs and will be spent over two years, with \$2.4 million in 2020-21 and \$7.1 million in 2021-22.⁸¹³

⁸¹⁰ Hon R Cook MLA, Minister for Health, *Funding to enhance palliative care services at Kalamunda Hospital*, media statement, 13 August 2020.

⁸¹¹ *ibid.*

⁸¹² Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 121, dated 18 September 2020, p 24.

⁸¹³ Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 121 & 124, dated 18 September 2020 pp 24 and 25.

CHAPTER 7

Term of reference (c) – Palliative care in regional and remote areas

- 7.1 The Committee is to inquire into and report on:
the delivery of palliative care into regional and remote areas.⁸¹⁴
- 7.2 This Chapter sets out the structure for delivery of palliative care services in regional and remote areas, and highlights some issues in service delivery which have been raised with the Committee during its inquiry.
- 7.3 The progress on ensuring greater equity of access to palliative care services between metropolitan and regional areas under the Committee's term of reference (d) is discussed in Chapter 8.

Overview of regional and remote palliative care

- 7.4 Health services, including palliative care services, are provided in regional and remote Western Australia over vast geographical distances.
- 7.5 Community specialist palliative care services in regional and remote areas are provided by WACHS, through nurse-led specialist palliative care teams located in each of the seven regions, as well as GPs, ACCHS and some private providers.⁸¹⁵ Additional specialist support is provided through the WACHS 'command centre' based in Perth.⁸¹⁶
- 7.6 There are inpatient palliative care units in four regional centres, and the WACHS regional palliative care teams consult to regional and district hospitals.⁸¹⁷
- 7.7 The WACHS regional palliative care teams link with other health, community and aged care services in each region to provide and assist in the provision of specialist palliative care services.⁸¹⁸
- 7.8 Telehealth plays an increasingly important role in regional and remote areas, as discussed in Chapter 4.⁸¹⁹ Telehealth services are delivered within the regions by specialist physicians and nurses, and through the WACHS telehealth hub, which is currently in development within the command centre in Perth.
- 7.9 The Committee was greatly assisted by the comprehensive and timely evidence provided to the inquiry by WACHS.

⁸¹⁴ Term of reference (c): Western Australia, Legislative Assembly, *Parliamentary Debates (Hansard)*, 20 May 2020, p 2948.

⁸¹⁵ For example, Hall & Prior in the Albany area: Submission 31 from Hall & Prior Health & Aged Care Group, 10 July 2020, p 5.

⁸¹⁶ See paragraph 3.20.

⁸¹⁷ Appendix 3, Department of Health map of regional services; Department of Health Service Summaries. See: https://ww2.health.wa.gov.au/Articles/F_1/Guide-to-specialist-palliative-care-services. Viewed 15 October 2020.

⁸¹⁸ Department of Health Service Summaries. See: https://ww2.health.wa.gov.au/Articles/F_1/Guide-to-specialist-palliative-care-services. Viewed 15 October 2020.

⁸¹⁹ Paragraphs 4.55–4.63.

Committee's inquiry into palliative care in regional and remote areas

7.10 The Committee received submissions from and/or held hearings with the following witnesses based in regional and remote areas:

- Dr Mark Monaghan (Busselton Health Campus)
- Busselton Hospice Care Inc
- Albany Community Hospice
- Chittering Health Advisory Group
- Hall & Prior Health & Aged Care Group (Albany)
- East Pilbara Independence Support
- 'A positive view on Palliative Care Service Delivery in a remote indigenous community' from a private citizen.
- Ord Valley Aboriginal Health Service
- Derby Aboriginal Health Service
- Kimberley Aboriginal Medical Services
- WACHS Wheatbelt Palliative Care Service
- WACHS Midwest Palliative Care Service
- WACHS Goldfields Regional Palliative Care Service.

7.11 In addition, a number of other submissions specifically addressed the issue of regional and remote palliative care service delivery.⁸²⁰

7.12 The Committee conducted site visits at the:

- Busselton Health Campus Palliative Care Unit, speaking with WACHS staff and volunteers.
- Geographe Bay Centre operated by Busselton Hospice Care Inc, speaking with board members, staff and volunteers.

Structure of palliative care services in regional and remote areas

WA Country Health Service

Structure

7.13 As noted in Chapter 3, WACHS is organised into seven regions: Kimberley, Pilbara, Midwest, Goldfields, Wheatbelt, South West and Great Southern.⁸²¹

7.14 WACHS operates 'hub-and-spoke' models in most of the regions, consisting of a central regional centre, smaller hospitals and smaller facilities delivering services located in district sites.⁸²²

⁸²⁰ Submission 33 from WA Country Health Service, 13 July 2020; Submission 36 from Palliative Care Western Australia, 13 July 2020; Submission 38 from Aboriginal Health Council of WA, 14 July 2020; Submission 40 from WA Primary Health Alliance, 17 July 2020; Submission 41 from Australian Medical Association (WA), 17 July 2020; Submission 26 from Department of Health, 10 July 2020.

⁸²¹ WA Country Health Service, 2011. See: <http://www.wacountry.health.wa.gov.au/index.php?id=961>. Viewed 26 October 2020.

⁸²² Margaret Denton, Acting Chief Executive, WA Country Health Service, transcript of evidence, 15 July 2020, p 14.

- 7.15 Regional staff are supported by specialists at the 'command centre' based at Royal Perth Hospital.⁸²³ The command centre was described as 'a team of people who are expert 24 hours a day in supporting our clinical staff on the ground'.⁸²⁴ The command centre covers a number of specialist areas and is expanding to include palliative care specialists.⁸²⁵
- 7.16 Jeffrey Moffet, the Chief Executive of WACHS, advised:
- the planning for delivery of services generally in country WA relies upon a very generalist workforce, particularly the nursing workforce, in around 68 hospital sites and another 30 or so remote sites.⁸²⁶
- 7.17 The Current State Report contains the following 'notable findings' about WACHS palliative care service activity:
- Outpatient activity makes the majority of overall palliative care activity in the WACHS regions.
 - The South West region had the largest population in WACHS and the largest overall volume of palliative care activity across 2015/16 to 2018/19.
 - Compared to other WACHS regions, the Pilbara region recorded the smallest volume of palliative care activity from 2015/16 to 2018/19.
 - The Midwest region displayed the largest rate of outpatient palliative care activity by population.
 - Access to inpatient care is not equal across the WACHS regional areas.⁸²⁷

Regional palliative care services

- 7.18 The WACHS regional palliative care services are nurse-led multidisciplinary teams based in each of the regional centres, with outreach provided across the region.⁸²⁸
- 7.19 The palliative care services provided by each regional team differ from region to region, but each provides a combination of:
- consultative services to the community, RACFs and regional hospitals
 - visiting palliative care specialist physician clinics (some by telehealth)
 - community palliative care services by a community nurse.⁸²⁹

⁸²³ Jeffrey Moffet, Chief Executive, WA Country Health Service, transcript of evidence, 18 September 2020, p 10.

⁸²⁴ *ibid.*, p 7.

⁸²⁵ Margaret Denton, Acting Chief Executive, WA Country Health Service, transcript of evidence, 15 July 2020, p 14.

⁸²⁶ Jeffrey Moffet, Chief Executive, WA Country Health Service, transcript of evidence, 18 September 2020, p 7.

⁸²⁷ Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 17.

⁸²⁸ Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 12.

⁸²⁹ Department of Health, *Guide to specialist palliative care services*. See: https://www2.health.wa.gov.au/Articles/F_I/Guide-to-specialist-palliative-care-services. Viewed 26 October 2020; Brett Hayes, Wheatbelt Palliative Care Manager, WA Country Health Service, transcript of evidence, 3 September 2020, pp 1–2; Gayle Paterson, Goldfields Regional Palliative Care Manager, Kalgoorlie Health Campus, transcript of evidence, 14 September 2020, pp 2–3; Nathalie Pass, Acting Coordinator of Nursing, Surgical Services, Ambulatory Care, WA Country Health Service Midwest, transcript of evidence, 14 September 2020, pp 1–2.

- 7.20 Services are provided in consultation with local medical practitioners.⁸³⁰
- 7.21 The services provided in each region are:
 managed and adapted to address local need and circumstance with input from a wide range of community representatives and key stakeholders.⁸³¹
- 7.22 Each WACHS palliative care service is led by a senior registered nurse with expert skills in palliative care.⁸³² The coordinating nurses:
 work closely with the WA Cancer and Palliative Care Network and the newly funded Palliative Care Program to provide links to local community services, tertiary services and facilitate the best use of local resources inclusive of other care providers.⁸³³
- 7.23 The regional palliative care specialist teams comprise clinical nurses, social workers, Aboriginal Health Workers, support staff and locally residing experienced GPs (in five regions). For more complex care management, palliative care physicians have been recruited to each region.⁸³⁴ In each region, the palliative care specialist team:
 conducts home visits to community patients including patients in end-of-life care who choose to die at home. The team also offers support to clinicians in acute settings who need advice in caring for palliative care patients.⁸³⁵
- 7.24 Telehealth plays an important role in the delivery of community palliative care by WACHS. A 'Telepalliative Care in the Home' Program using iPads was piloted in the Wheatbelt and has since expanded to the other regions.⁸³⁶ The Committee heard evidence from a number of witnesses providing palliative care services in regional and remote areas about the success and potential of telehealth in palliative care.⁸³⁷
- 7.25 The WACHS regional palliative care services operate Monday to Friday during business hours. As noted in paragraph 6.23, the operational hours of the services are extending to 8am to 6pm every day, including weekends. Until recently, after hours support has not been

⁸³⁰ Brett Hayes, Wheatbelt Palliative Care Manager, WA Country Health Service, transcript of evidence, 3 September 2020, p 9,

⁸³¹ WA Country Health Service. See: <http://www.wacountry.health.wa.gov.au/index.php?id=456>. Viewed 26 October 2020.

⁸³² The Committee heard evidence from the regional coordinators of the WACHS Palliative Care Services in the Wheatbelt, Midwest and Goldfields: Brett Hayes, Wheatbelt Palliative Care Manager, WA Country Health Service, transcript of evidence, 3 September 2020; Carla Jones, Acting Regional Director of Nursing and Midwifery, WA Country Health Service and Gayle Paterson, Goldfields Regional Palliative Care Manager, Kalgoorlie Health Campus, transcript of evidence, 14 September 2020; Nathalie Pass, Acting Coordinator of Nursing, Surgical Services, Ambulatory Care; Robyn Ellis, Clinical Nurse Specialist; and Leanne Sice, Acting Regional Director of Nursing and Midwifery, WA Country Health Service Midwest, transcript of evidence, 14 September 2020.

⁸³³ Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 12.

⁸³⁴ Submission 33 from WA Country Health Service, 13 July 2020, p 8.

⁸³⁵ Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 12.

⁸³⁶ *ibid.*

⁸³⁷ See paragraph 4.56.

funded by WACHS but the Committee heard evidence that after-hours care has been provided by some teams on an ad hoc, unpaid, basis.⁸³⁸

- 7.26 More recently, some after-hours support is being funded by WACHS on an interim basis, while the telehealth hub is in development. These expansions to the WACHS services are outlined in more detail in Chapter 6.⁸³⁹
- 7.27 WACHS advised that it is in the process of recruiting to expand the multidisciplinary teams, as a result of the funding announced for that purpose on 9 May 2019. Details of the expansion of those teams are set out in Chapter 6.⁸⁴⁰

Inpatient facilities

- 7.28 WACHS operates the following inpatient palliative care units:
- Albany Community Hospice
 - Busselton Health Campus
 - St John of God Bunbury Hospital (public/private partnership)
 - St John of God Geraldton Hospital (public/private partnership).
- 7.29 A residential aged care and palliative care facility in Carnarvon was due to commence construction in August 2020, and is expected to operate 38 beds.⁸⁴¹ The Department of Health advised that two of the 'multipurpose rooms' within the facility 'will be flexibly allocated to palliative care'.⁸⁴²

FINDING 47

Notwithstanding the Government's announcement that \$5 million of its five year \$41 million commitment for end-of-life choices and palliative care would be spent on the Carnarvon Aged and Palliative Care facility, it will result in two multipurpose rooms within the facility being 'flexibly allocated to palliative care'.

Role of general practitioners and other primary care providers

- 7.30 GPs play an important role in regional and remote palliative care service delivery across a range of settings.⁸⁴³ The Current State Report advises:

Medical General Practitioners ... provide a substantial proportion of the palliative care provision in WACHS and also engage in end-of-life conversations with

⁸³⁸ Brett Hayes, Wheatbelt Palliative Care Manager, WA Country Health Service, transcript of evidence, 3 September 2020, p 4; Dr Mark Monaghan, Emergency Physician, Director of Medical Services, South West Coastal, WA Country Health Service, Busselton Health Campus, transcript of evidence, 31 August 2020, p 7.

⁸³⁹ Paragraphs 6.29–6.33.

⁸⁴⁰ Paragraphs 6.22–6.28.

⁸⁴¹ See paragraphs 6.34–6.39.

⁸⁴² Amanda Bolleter, Project Director, End of Life Care, Department of Health, email, 2 November 2020, Attachment 1, Answer to question 5.

⁸⁴³ Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 12; Royal Australian College of General Practitioners, *GP-led Palliative Care in Rural Australia*, 2016, p 1. See: <https://www.racgp.org.au/FSDEDEV/media/documents/RACGP/Position%20statements/GP-led-Palliative-Care-in-RuralAustralia.pdf>. Viewed 26 October 2020.

patients and carers. There is limited support from Palliative Care Medical Specialists and this gap is filled to some extent by Senior Palliative Care Nurses.⁸⁴⁴

7.31 The importance of GPs in providing palliative care in regional areas without a specialised palliative care facility was outlined in the RACGP's 2016 position statement, *GP-led Palliative Care in Rural Australia*:

Rural GPs deliver palliative care across a number of primary and secondary care settings and facilitate the broad range of services required to meet diverse patient need in rural areas...

Ensuring this care can be provided in the patient's community requires specific targeted and holistic supports, facilitated through a multidisciplinary team approach, which brings a diversity of specialised skills and expertise across a range of functions.⁸⁴⁵

7.32 The Current State Report advises:

The volume of palliative care activity that occurs in primary care settings across WA is unknown. This is a large gap as GPs have an important role in looking after patients who are receiving palliative care at home in metropolitan WA, and also provide a substantial proportion of the palliative care provision in WACHS regions.⁸⁴⁶

7.33 The amount of services provided in other primary care settings such as ACCHS is also, according to the Current State Report, not currently quantified.⁸⁴⁷

7.34 In its report *GP-led Palliative Care in Rural Australia*, the RACGP made specific recommendations for:

- increased investment for GP-led palliative care in rural communities and targeted action in national planning measures, coordination of care and access to care
- more supportive policies which enable increased participation of rural GPs across all services settings, including:
 - stronger local area planning supported at the state level to increase participation of rural GPs overall but particularly within the hospital setting
 - prioritising credentialing arrangements
 - addressing remuneration issues through the provision of specific GP palliative care items

⁸⁴⁴ Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 12.

⁸⁴⁵ Royal Australian College of General Practitioners, *GP-led Palliative Care in Rural Australia*, 2016, p 1. See: <https://www.racgp.org.au/FSDEDEV/media/documents/RACGP/Position%20statements/GP-led-Palliative-Care-in-RuralAustralia.pdf>. Viewed 26 October 2020.

⁸⁴⁶ Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 30.

⁸⁴⁷ *ibid.*

- stronger investments in palliative care skills through accessible and flexible training options for rural GPs and across the full multidisciplinary team.⁸⁴⁸

7.35 The Committee noted that one of the 'next steps' advised by WACHS in relation to the implementation of recommendation 13 is to increase the number of on-the-ground palliative care GPs.⁸⁴⁹

7.36 WACHS advised that it has recently recruited experienced GPs on a pilot program in five regions. The evidence about this program is discussed in Chapter 8.⁸⁵⁰

FINDING 48

The volume of palliative care activity that occurs in primary care settings in regional and remote Western Australia, including services provided by general practitioners and Aboriginal community-controlled health services, is unknown.

Aboriginal community-controlled health services

7.37 As noted in Chapter 3,⁸⁵¹ there are 23 ACCHS in Western Australia under the umbrella of AHCWA, of which 21 are located in regional areas.⁸⁵²

7.38 The Committee heard that ACCHS provide palliative care services and coordination of care in many regional and remote areas, often in consultation with the regional WACHS services.⁸⁵³

7.39 AHCWA advised:

ACCHS currently support Aboriginal people with a life-limiting illness and their families in line with the holistic Model of Care. Palliative care interventions may involve: organising family meetings to plan palliative and end-of-life care; managing a roster of Aboriginal Health Worker staff who are trusted by the patient and their family to provide care; sourcing appropriate equipment and resources in a timely manner; and, engaging other services as required. As the care needs of a patient increase, many ACCHS are flexible and adaptable to the required changes in medical care and emotional support.

The capacity of ACCHS and clinics to deliver palliative care services varies across the state, however, all ACCHS have a variety of experience, expertise and diversifiable skills to provide culturally secure, primary health care to their communities.⁸⁵⁴

7.40 The Committee heard evidence from:

- Derby Aboriginal Health Service

⁸⁴⁸ Royal Australian College of General Practitioners, *GP-led Palliative Care in Rural Australia*, 2016, pp 3–4. See: <https://www.racgp.org.au/FSDEDEV/media/documents/RACGP/Position%20statements/GP-led-Palliative-Care-in-RuralAustralia.pdf>. Viewed 26 October 2020.

⁸⁴⁹ Submission 33 from WA Country Health Service, 13 July 2020, p 11.

⁸⁵⁰ Paragraphs 8.38–8.40.

⁸⁵¹ Paragraph 3.123.

⁸⁵² See Appendix 6.

⁸⁵³ See for example Shirley Newell, Executive Manager, Policy and Public Health, Aboriginal Health Council of Western Australia, transcript of evidence, 3 September 2020, p 4; Dr Lorraine Anderson, Medical Director and Jenny Bedford, Executive Manager, Kimberley Aboriginal Medical Services, transcript of evidence, 3 September 2020 p 3; Michele Harvey, Nurse Practitioner–Chronic Disease, Ord Valley Aboriginal Health Service, transcript of evidence, 3 September 2020, pp 1–2; Nathalie Pass, Acting Coordinator of Nursing, Surgical Services, Ambulatory Care, WA Country Health Service Midwest, transcript of evidence, 14 September 2020, p 3.

⁸⁵⁴ Submission 38 from the Aboriginal Health Council of Western Australia, 13 July 2020, p 3.

- Ord Valley Aboriginal Health Service
- Kimberley Aboriginal Medical Services

about the specific palliative care services they provide.⁸⁵⁵

7.41 The Committee recognised the integral role of ACCHS in facilitating and providing palliative care services in regional and remote areas, and the geographical and other challenges involved in the delivery of those services. The evidence received from ACCHS and AHCWA, as outlined in this Chapter and in Chapter 3, expanded the Committee’s understanding of the capacity of ACCHS to deliver effective, culturally secure palliative care services, particularly in remote areas.

7.42 AHCWA stated in its submission:

ACCHS staff are passionate about being able to provide quality palliative and end-of-life care to patients in their communities. Key enablers for this to occur include:

- Communication between palliative care specialists and tertiary hospitals, and regional and remote ACCHS;
- Recognition of the current skill and expertise of ACCHS clinics to deliver palliative care services in their local communities; and
- A genuine investment in the capacity and capability of the ACCHS sector to deliver palliative care services.

ACCHS must remain connected to their patients when they are in a tertiary hospital or under the care of a palliative care specialist, especially when discharge planning commences.⁸⁵⁶

7.43 AHCWA noted that telehealth is an effective option for facilitating a collaborative discharge ensuring ACCHS are engaged early in the care of the patient:

Often palliative Aboriginal people are discharged to small local hospitals in their area, with no contact made with the local ACCHS as it is presumed that they do not have the capacity to manage palliative care. Issues also occur when ACCHS are engaged too late in the discharge planning process, at the last minute, and are required to support terminal care.⁸⁵⁷

7.44 The Derby Aboriginal Health Service provided an example of effective communication between WACHS services and ACCHS:

The hospital, of course, in the hospital setting, and when our palliative care patients are admitted are providing care, but we also go up and provide care whilst they are in the hospital ... They will ring and say, “Your patient has come in”, and we go straightaway, basically. We go and suss out what is happening, where they are at, what is going on with the family and then what they want us to do and they will tell us. Then it is very close working with the clinical team at the hospital. But I see our role a lot about that is advocating for that patient and their family

⁸⁵⁵ Christine Waller, Senior Manager, Population Health Programs and Remote Areas, Derby Aboriginal Health Service, transcript of evidence, 3 September 2020, p 2; Michele Harvey, Nurse Practitioner–Chronic Disease, Ord Valley Aboriginal Health Service, transcript of evidence, 3 September 2020, pp 1–2; Dr Lorraine Anderson, Medical Director and Jenny Bedford, Executive Manager, Kimberley Aboriginal Medical Services, transcript of evidence, 3 September 2020, pp 2–3.

⁸⁵⁶ Submission 38 from the Aboriginal Health Council of Western Australia, 13 July 2020, p 2.

⁸⁵⁷ *ibid.*, pp 2–3.

about what they want to happen in hospital as well. Remember, with older people from here, there will be language barriers, there will be cultural concerns.⁸⁵⁸

- 7.45 The Committee is pleased to note that WACHS is developing an inaugural Palliative Care Aboriginal Health Services Coordinator position.⁸⁵⁹

FINDING 49

Aboriginal community-controlled health services play an important role delivering palliative care services in regional and remote areas of Western Australia. The capacity of Aboriginal community-controlled health services and clinics to deliver palliative care services varies across the State, and there are key enablers required to support them in the delivery of those services.

FINDING 50

Aboriginal palliative care patients are often discharged to small local hospitals in their area, with no contact made with the local Aboriginal community-controlled health services.

FINDING 51

The WA Country Health Service is developing an inaugural Palliative Care Aboriginal Health Services Coordinator position.

Community palliative care in regional and remote areas

- 7.46 Community specialist palliative care services in regional and remote areas are provided by the WACHS regional teams, ACCHS and/or GPs depending on availability of services in the particular region.
- 7.47 The Committee heard evidence of substantial variance in the availability of community specialist palliative care in regional and remote areas, particularly away from the regional centres.⁸⁶⁰
- 7.48 In this context, the Committee also notes priority one of the WA Strategy:
care is accessible to everyone, everywhere.⁸⁶¹

⁸⁵⁸ Christine Waller, Senior Manager, Population Health Programs and Remote Areas, Derby Aboriginal Health Service, transcript of evidence, 3 September 2020, p 4.

⁸⁵⁹ Submission 33 from WA Country Health Service, 13 July 2020, p 9.

⁸⁶⁰ Vicki Kershaw, Chief Executive Officer, East Pilbara Independence Support Inc, transcript of evidence, 10 August 2020, p 5; Brett Hayes, Wheatbelt Palliative Care Manager, WA Country Health Service, transcript of evidence, 3 September 2020, pp 1–2; Carla Jones, Acting Regional Director of Nursing and Midwifery, WA Country Health Service, Goldfields Region, and Gayle Paterson, Goldfields Regional Palliative Care Manager, Kalgoorlie Health Campus, transcript of evidence, 14 September 2020, pp 2–3; Robyn Ellis, Clinical Nurse Specialist and Nathalie Pass, Acting Coordinator of Nursing, Surgical Services, Ambulatory Care, WA Country Health Service Midwest, transcript of evidence, 14 September 2020, pp 1–3; Christine Waller, Senior Manager, Population Health Programs and Remote Areas, Derby Aboriginal Health Service, transcript of evidence, 3 September 2020, p 2; Michele Harvey, Nurse Practitioner–Chronic Disease, Ord Valley Aboriginal Health Service, transcript of evidence, 3 September 2020, pp 1–2; Jenny Bedford, Executive Manager, and Dr Lorraine Anderson, Medical Director, Kimberley Aboriginal Medical Services, transcript of evidence, 3 September 2020, pp 2–3.

⁸⁶¹ Department of Health, *WA End-of-Life and Palliative Care Strategy 2018–2028*, 2018, p 6. See: https://ww2.health.wa.gov.au/~/_/media/Files/Corporate/general%20documents/Health%20Networks/Palliative%20care/WA%20End-of-life%20and%20Palliative%20Care%20Strategy%202018-2028.pdf. Viewed 23 October 2020.

Limitations of the hub-and-spoke model across large distances

7.49 Witnesses noted that in some regions, distances from remote areas to the regional centre can be very large. Community palliative care services are based in the regional centres and in more remote areas community specialist palliative care may not be available, or may be available in a limited way, due to the distances involved.⁸⁶²

7.50 East Pilbara Independence Support Incorporated (EPIS), based in Newman, submitted:

Having a palliative nurse 600 kilometres away does not translate to equity [of] access to palliative care for the people of the Shires of the East Pilbara and Ashburton.⁸⁶³

7.51 Similarly, Derby Aboriginal Health Service advised:

I know that palliative care is expanding, but it is all in Broome—it is 220 kilometres and it is not like you can just pop up here. In actual fact, from our perspective, the concentration of WACHS palliative care is 220 kilometres away. It is not much use to a person in Mowanjum in a sense, if you know what I mean, that distance, whereas we are basically five minutes away.⁸⁶⁴

7.52 EPIS advised further:

There is no palliative care service for residential aged care facilities and home care. In fact, there is no residential aged care homes in the Shires of East Pilbara and Ashburton. Nonetheless, there is a critical need for palliative care in home and residential settings. Numerous examples exist of clients in need of palliative care with unfortunate outcomes. For instance, Aboriginal and non-Aboriginal clients at the end-of-life stage being relocated to nursing homes located hundreds of kilometres away from home and family and in different Aboriginal Country land. This practise brings hardships not only to the client in need of palliative services, but also to his or her family and wider community.⁸⁶⁵

7.53 The following evidence from the WACHS Wheatbelt Palliative Care Service illustrates the practical difficulties in providing in-home community palliative care in regional and remote areas across large distances:

Mr R.S. LOVE: ... there are two levels of geography, I suppose—the physical distance but also the nature of the communities that you represent and the services within them; say you have Northam or Narrogin with a fairly well-developed set of medical services located close in town. There are other communities where there are no formal facilities, no nursing staff employed within the shire or within cooee of it. Can you explain some of the difficulties that you see in the geography of the wheatbelt in that broader context?

Mr HAYES: ... travel time is a big thing. Getting somewhere in a timely manner can be problematic; we can travel three hours to see one patient. Again, that is why we

⁸⁶² Vicki Kershaw, Chief Executive Officer, and Juan Andrade, Corporate Services Manager, East Pilbara Independence Support Inc, transcript of evidence, 10 August 2020, p 5; Brett Hayes, Wheatbelt Palliative Care Manager, WA Country Health Service, transcript of evidence, 3 September 2020, p 2; Christine Waller, Senior Manager, Population Health Programs and Remote Areas, Derby Aboriginal Health Service, transcript of evidence, 3 September 2020, p 2; Michele Harvey, Nurse Practitioner—Chronic Disease, Ord Valley Aboriginal Health Service, transcript of evidence, 3 September 2020, pp 1–2.

⁸⁶³ Submission 39 from East Pilbara Independence Support Inc, 15 July 2020, p 2.

⁸⁶⁴ Christine Waller, Senior Manager, Population Health Programs and Remote Areas, Derby Aboriginal Health Service, transcript of evidence, 3 September 2020, p 4.

⁸⁶⁵ Submission 39 from East Pilbara Independence Support Inc, 15 July 2020, p 1.

started using videoconferencing. If you look at the coastal strip for a good example, there is not much in the way of government-type health services until you get up to Jurien Bay. A lot of our work is done out there with patients and the majority of them want to die at home out there and without having a local hospital somewhere or GPs readily available, it is difficult. But, again, we [are] getting better at it. The implementation of videoconferencing has changed that somewhat. We are never going to get to a situation where we are going to have a 24-hour nursing service in someone's home all the time across the Wheatbelt—that would require a workforce of 100 nurses—but we will get to a point where we can be there more often, we can see them more often, we can talk to them more often and manage their symptoms better, get more time with them before they pass away, more time with the families and set them up, have those good conversations.

Mr R.S. LOVE: When you are dealing with someone who is away from hospital inside that coastal area you described, who is taking care of the patient? Is it just family with no formal nursing staff involved in the home setting?

Mr HAYES: No, we would be the nursing staff. So it would be family or friend and sometimes we can get a packaged provider in there as well, but, again, that is not nursing. It is never going to be realistic to have 24/7 nursing care in someone's home like that. It would cost millions and millions; it would cost \$200 million or \$300 million.⁸⁶⁶

- 7.54 In such circumstances, patients living in remote areas do not have genuine choice about their setting of care. A patient in that situation must choose between:
- receiving palliative care many kilometres from home and family
 - receiving palliative care at home on a limited basis
 - not receiving palliative care.
- 7.55 Against this background, the Committee notes the very encouraging evidence it has heard about the potential of telehealth to provide greater choice to patients in regional and remote areas.⁸⁶⁷
- 7.56 The Committee's findings and recommendations about the development of telehealth services are contained in Chapter 4 of this report.⁸⁶⁸
- 7.57 In its submission, Albany Community Hospice proposed a 'hub and node model of hospice care' and greater flexibility in the WACHS boundaries, to:
- ensure many more regional people get improved palliative care, especially for end of life, within or near their home health centre with access to their own doctors.⁸⁶⁹
- 7.58 The Committee also notes advice from WACHS that under the program of expanded regional palliative care teams discussed in Chapter 6,⁸⁷⁰ between two and four district-based

⁸⁶⁶ Brett Hayes, Wheatbelt Palliative Care Manager, WA Country Health Service, transcript of evidence, 3 September 2020, p 13.

⁸⁶⁷ See paragraphs 4.56.

⁸⁶⁸ Paragraphs 4.45–4.66.

⁸⁶⁹ Submission 4 from Albany Community Hospice, 5 July 2020, p 2.

⁸⁷⁰ Paragraphs 6.22–6.28.

teams will be located in each WACHS region,⁸⁷¹ potentially reducing geographical barriers for people living large distances from regional centres.

After-hours care

7.59 As noted in paragraph 7.25, the WACHS multi-disciplinary teams are based in each regional centre and generally provide community palliative care within business hours.

7.60 In regional and remote areas, the availability of after-hours care can depend upon the provider. In Albany, Hall & Prior Health & Aged Care Group (Hall & Prior) provide a 24-hour model of care, including after-hours nursing care, to its publicly funded clients in Albany.⁸⁷² Hall & Prior advised that the on-call component of this service does not form part of its contract with WACHS, and is borne by it as the service provider:⁸⁷³

The service is currently only available to people in the Albany post code (6330). This means that if you live outside this post code in the Great Southern region, people are not eligible for the service. You only receive a service one to two day a week, during business hours. This is not equitable.⁸⁷⁴

7.61 In some regional and remote areas, WACHS regional palliative care teams provide after-hours on-call telephone support services.⁸⁷⁵ Apart from some regional centres, in-home palliative care nursing services are not available after-hours, and patients must rely on telehealth, if available, or wait for services to be available during business hours.

7.62 The WACHS Midwest Palliative Care Service advised that after-hours support is usually provided via phone, and that in addition:

We do have programs for patients who, again, have the ability to administer medications in the home. We have a “medication safety for carers” program, where the team upskill a carer or a loved one to provide medication with on the phone or with telehealth support from the team. It really does depend on what is in place and what is appropriate for the client, and depends on their location and what is around. If they can work with the local team to provide care in the home, and that is the patient’s wish, then they will do everything they can to do that. But, otherwise, sometimes it does mean having to move to a bigger centre where they can have inpatient support.⁸⁷⁶

7.63 Overall, the evidence to the Committee suggests that the gap in after-hours service delivery in more remote areas has the potential to be filled to some extent by the WACHS telehealth hub, assuming it is funded to allow equitable access to telehealth services in all areas, regardless of location.

⁸⁷¹ Jeffrey Moffet, Chief Executive, WA Country Health Service, Answer to question prior to hearing no 53, dated 18 September 2020, p 7.

⁸⁷² Dr Kristi Holloway, Executive Manager, Clarence Estate, Hall & Prior Health and Aged Care Group, transcript of evidence, 10 August 2020, p 4.

⁸⁷³ *ibid.*

⁸⁷⁴ Hall & Prior Health & Aged Care Group, Brief to Hon Chris Tallentire MLA, 10 August 2020, p 2. Tabled by Graeme Prior, Chief Executive Officer, Hall & Prior Health & Aged Care Group, during hearing held 10 August 2020, pp 1–2.

⁸⁷⁵ Brett Hayes, Wheatbelt Palliative Care Manager, WA Country Health Service, transcript of evidence, 3 September 2020, p 4; Nathalie Pass, Acting Coordinator of Nursing, Surgical Services, Ambulatory Care, and Leanne Sice, Acting Regional Director of Nursing and Midwifery, WA Country Health Service Midwest, transcript of evidence, 14 September 2020, pp 3 and 4.

⁸⁷⁶ Nathalie Pass, Acting Coordinator of Nursing, Surgical Services, Ambulatory Care, WA Country Health Service Midwest, transcript of evidence, 14 September 2020, p 3.

FINDING 52

Access to after-hours palliative care services is variable in regional and remote Western Australia, in contrast to the metropolitan area which benefits from Silver Chain's 24/7 palliative care nursing services.

Community networks and the Compassionate Communities model

7.64 PCWA advised that its survey on palliative care service delivery in regional areas revealed:

Several respondents suggested that there were strengths in regional and rural WA that were not replicated in Perth metro. These included a strong community network and an increased capacity to deliver "compassionate communities" supports e.g. emotional support of carers, meals delivered, help to maintain homes and gardens etc. It was also recognised that medical and allied health support staff will often provide services "above and beyond" what might be delivered in the metro region possibly in response to personal connections.⁸⁷⁷

7.65 The Compassionate Communities model is discussed in more detail in Chapter 4.⁸⁷⁸

FINDING 53

There remains a substantial variation in community palliative care in regional and remote areas, particularly away from regional centres.

Palliative Care for Aboriginal people in regional and remote areas

7.66 Issues relating to access to palliative care services by Aboriginal people in Western Australia are discussed in Chapter 4.⁸⁷⁹

Community palliative care for Aboriginal people in regional and remote areas

7.67 As discussed earlier in this Chapter, evidence to the Committee revealed issues with access to home-based community palliative care services in regional and remote areas.⁸⁸⁰ The Current State Report noted that this is particularly problematic for Aboriginal people who want to die on country and with their families and communities.⁸⁸¹

7.68 According to WAPHA:

[T]he availability of culturally appropriate [community palliative care] services close to home for Aboriginal people is particularly limited.⁸⁸²

7.69 The provision of community specialist palliative care services to Aboriginal people on country raises complex issues. The Committee received evidence that some Aboriginal palliative care

⁸⁷⁷ Submission 36 from Palliative Care Western Australia, 10 July 2020, p 22.

⁸⁷⁸ Paragraphs 4.117–4.124.

⁸⁷⁹ Paragraphs 4.210–4.247.

⁸⁸⁰ Paragraphs 7.49–7.58.

⁸⁸¹ Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 31.

⁸⁸² Submission 40 from WA Primary Health Alliance, 17 July 2020, p 7, citing 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.

patients choose to access end-of-life care in an inpatient facility for a complex range of personal and cultural reasons.⁸⁸³ For example, WAPHA submitted:

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.⁸⁸⁴

7.70 Some of the cultural issues which may impact on the choice of an Aboriginal person as to where they receive palliative care are outlined in Chapter 4.⁸⁸⁵ The Committee notes, however, that beliefs and practices vary greatly and that the key issue, as with access to palliative care services generally, is that people have *genuine choice* in relation to their setting of care.⁸⁸⁶

WA Country Health Service

7.71 WACHS advised:

The [Palliative Care Program]'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 [the Department of Health] on the developing Aboriginal End-of-Life and Palliative Care Framework.⁸⁸⁷

7.72 Aboriginal Health Workers form part of the WACHS multidisciplinary teams. WACHS advised:

The [Aboriginal health worker] is an important member to the multi-disciplinary palliative care team and this is supported by the expansion of the Palliative Care [Aboriginal health worker] position within the [Palliative Care Plan] 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 [Aboriginal health worker] position.⁸⁸⁸

Role of Aboriginal community-controlled health services

7.73 The role of ACCHS in regional and remote palliative care is discussed in paragraphs 7.37–7.45.

⁸⁸³ Submission 40 from WA Primary Health Alliance, 17 July 2020, p 7; Christine Waller, Senior Manager, Population Health Programs and Remote Areas, Derby Aboriginal Health Service, transcript of evidence, 3 September 2020, p 3; Gayle Paterson, Goldfields Regional Palliative Care Manager, Kalgoorlie Health Campus, transcript of evidence, 14 September 2020, p 7.

⁸⁸⁴ Submission 40 from WA Primary Health Alliance, 17 July 2020, p 7.

⁸⁸⁵ Paragraphs 4.210 to 4.247.

⁸⁸⁶ See paragraphs 3.46 to 3.50 regarding choice of care setting.

⁸⁸⁷ Submission 33 from WA Country Health Service, 13 July 2020, p 9.

⁸⁸⁸ *ibid.*

- 7.74 Several witnesses referred to the importance of close connections between WACHS services and ACCHS in the local area in achieving coordinated palliative care for Aboriginal people in regional and remote areas.⁸⁸⁹
- 7.75 The Committee noted that ACCHS contribute greatly to the provision of person-centred, culturally safe palliative care with reference to the individual needs and cultural circumstances of the patient.⁸⁹⁰

Palliative Care Western Australia proposed symposium

- 7.76 PCWA's consultation with stakeholders identified that there was 'currently minimal connection between existing Aboriginal palliative care service providers'.⁸⁹¹
- 7.77 To address this situation, PCWA is proposing to organise a symposium focused on Aboriginal approaches to ACP and palliative care. This was identified as:
- a positive opportunity to showcase excellent practice examples in regional and rural communities and facilitate the establishment of a community of practice.⁸⁹²

Diversity of needs in regional and remote areas

Patients with motor neurone disease

- 7.78 As with the wider population, the MND Association submitted that there is a 'marked inequality of access to palliative care services between metropolitan and regional areas for MND patients'.⁸⁹³

Palliative care needs of specific groups in regional and remote areas

- 7.79 Diversity of palliative care needs amongst various groups is discussed in Chapter 4.⁸⁹⁴ The Committee has not had the opportunity to explore the palliative care needs of those diverse groups in regional and remote areas, however the Committee notes that the identification of access gaps referred to in finding 30⁸⁹⁵ would require specific consideration in regional and remote areas.

Equity issues between regional areas

- 7.80 As noted in paragraphs 7.17 and 7.47, the Committee heard evidence of variance in the availability of specialist palliative care within and between regions.
- 7.81 The Current State Report noted that the Pilbara region recorded the smallest volume of palliative care activity from 2015–16 to 2018–19 as compared to other WACHS regions.

⁸⁸⁹ See for example paragraph 7.44; Shirley Newell, Executive Manager, Policy and Public Health, Aboriginal Health Council of Western Australia, transcript of evidence, 3 September 2020, p 4; Dr Lorraine Anderson, Medical Director, Kimberley Aboriginal Medical Services, transcript of evidence, 3 September 2020, p 3; Michele Harvey, Nurse Practitioner–Chronic Disease, Ord Valley Aboriginal Health Service, transcript of evidence, 3 September 2020, pp 1–2; Nathalie Pass, Acting Coordinator of Nursing, Surgical Services, Ambulatory Care, WA Country Health Service Midwest, transcript of evidence, 14 September 2020, p 3; Department of Health, *Sustainable Health Review: Final Report to the Western Australian Government*, 2019, p 53. See: <https://ww2.health.wa.gov.au/-/media/Files/Corporate/general-documents/Sustainable-Health-Review/Final-report/sustainable-health-review-final-report.pdf>. Viewed 27 October 2020.

⁸⁹⁰ See paragraphs 7.39 and 7.41.

⁸⁹¹ Submission 36 from Palliative Care Western Australia, 10 July 2020, p 12.

⁸⁹² *ibid.*

⁸⁹³ Submission 10 from Motor Neurone Disease Association of WA Inc, 8 July 2020, p 2.

⁸⁹⁴ Paragraphs 4.258–4.290.

⁸⁹⁵ Page 102.

The low level of access to services in the Pilbara was explained by the Department of Health as follows:

I think they have got very few services at all in the Pilbara and I think that is one of the reasons that special arrangements have been made with Bethesda Health Care to provide visiting services there.⁸⁹⁶

7.82 WACHS submitted in relation to palliative care services in the Kimberley:

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.⁸⁹⁷

7.83 Dr Mark Monaghan advised:

I was very recently covering the medical director role for the Kimberley, and the palliative care for that region is significantly less advanced than that in the [South West], and would seem a priority to address.⁸⁹⁸

7.84 RACGP discussed the need for targeted service planning in its position statement, *GP-led Palliative Care in Rural Australia*:

Enabling quality end-of-life care in a rural community – whether that is care provided in the home, small hospital or aged care facility – requires particular service planning in the absence of a specialised palliative care centre. In this context there is stronger reliance on funding and programs to support service integration at the local level, in order to address complexities within a reduced service environment.⁸⁹⁹

7.85 Janet Wallace submitted that some local specialist facilities in the Kimberley were underutilised or even unused, and that:

Consulting with the locals must become an essential part of any community project and potentially, avoid a lot of mistakes.

...

Local people know their area. Country people are very resourceful and come up with practical ideas and solutions. But they need to be asked!⁹⁰⁰

⁸⁹⁶ Dr Duncan James Williamson, Assistant Director General, Clinical Excellence Division, Department of Health, transcript of evidence, 18 September 2020, p 30.

⁸⁹⁷ Submission 33 from WA Country Health Service, 13 July 2020, p 11.

⁸⁹⁸ Submission 2 from Dr Mark Monaghan, 15 June 2020, p 3.

⁸⁹⁹ Royal Australian College of General Practitioners, *GP-led Palliative Care in Rural Australia*, 2016, p 1. See: <https://www.racgp.org.au/FSDEDEV/media/documents/RACGP/Position%20statements/GP-led-Palliative-Care-in-RuralAustralia.pdf>. Viewed 26 October 2020.

⁹⁰⁰ Submission 30 from Janet Wallace, 10 July 2020, p 2.

CHAPTER 8

Term of reference (d)—ensuring greater equity of access between metropolitan and regional areas

'In WA, there is an inequity of access to quality palliative care services for rural and regional people with terminal and life-limiting illnesses'

(WA Country Health Service)⁹⁰¹

8.1 The Committee is to inquire into and report on:

the progress on ensuring greater equity of access to palliative care services between metropolitan and regional areas.⁹⁰²

8.2 Under this term of reference, the Committee has considered the proposed and actual measures to improve access to palliative care services in regional and remote areas, including the progress of implementation of JSCEOLC recommendations 12 and 13.

Greater need for palliative care

8.3 WACHS stated in its submission to the inquiry:

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.⁹⁰³

8.4 Specifically, WACHS submitted:

- people living in rural and regional areas generally experience poorer health with higher death rates
- the incidence of cancer, and mortality rates from cancer are significantly higher than in metropolitan Perth
- rates of chronic conditions such as diabetes, cardiovascular and chronic obstructive pulmonary disease, particularly amongst Aboriginal people, are higher
- there is a higher proportion of the elderly living in rural and regional Western Australia, with the projected population of people aged 65+ increasing by 3.5 per cent annually.⁹⁰⁴

Inequity of access

8.5 Evidence to the Committee indicated that access to palliative care services in many regional and remote areas is significantly more limited than in metropolitan areas.⁹⁰⁵ Reasons for this

⁹⁰¹ Submission 33 from WA Country Health Service, 13 July 2020, p 5.

⁹⁰² Term of reference (d): Western Australia, Legislative Assembly, *Parliamentary Debates (Hansard)*, 20 May 2020, p 2948.

⁹⁰³ Submission 33 from WA Country Health Service, 13 July 2020, p 5.

⁹⁰⁴ *ibid.*

⁹⁰⁵ *ibid.*; see also Vicki Kershaw, Chief Executive Officer, and Juan Andrade, Corporate Services Manager, East Pilbara Independence Support Inc, transcript of evidence, 10 August 2020, p 6; Submission 36 from Palliative Care Western Australia, 10 July 2020, p 22; Submission 39 from East Pilbara Independence Support Inc, 15 July 2020, p 2; Submission 40 from WA Primary Health Alliance, 17 July 2020, Submission 40 from WA Primary Health Alliance, 17 July 2020, p 7; Submission 16 from Dr David Joske, 9 July 2020, p 2; Submission 10 from Motor Neurone Disease Association of WA Inc, 8 July 2020, p 2.

included the geographically disperse population and the lack of in-home service provision in many areas outside the regional centres.⁹⁰⁶

8.6 As an example of the disparity of services, the Chittering Health Advisory Group submitted:

The Shire of Chittering is an example of the disparity in provision of palliative care between Metro & Rural areas. Lower Chittering, 6084, is served by the Metro based Silver Chain Palliative Care service, which provides an excellent comprehensive service, daily if required. The Northern part of Chittering, 6052, is covered by the WACHS Palliative Care team from Northam who can only provide 1 or 2 visits a week, & telephone support, probably due to lack of staff or resources.⁹⁰⁷

8.7 As discussed in Chapter 7, where inpatient services are available, they are in many cases a significant distance from the patient's home.⁹⁰⁸

8.8 EPIS submitted:

As a service provider, EPIS has not seen progress on ensuring greater equity of access to palliative care services between metropolitan and regional areas. In the Eastern Pilbara region, people in need of palliative care do not have the option of palliative care in a residential facility; or palliative care provided at their homes by a nursing service; or comprehensive medical, nursing and allied health care based on their unique needs, when facing a life limiting prognosis. Furthermore, there are no culturally appropriate services for the Aboriginal community and many times Aboriginal family members of clients with a life limiting prognosis are left with feelings of guilt and shame when making the decision of transferring their loved ones to residential facilities located outside our region.

Having a palliative nurse 600 kilometres away does not translate to equity access to palliative care for the people of the Shires of the East Pilbara and Ashburton.⁹⁰⁹

8.9 BHCI advised in its submission:

The Board of BHCI wish to express the concern that the recently introduced [voluntary assisted dying] Legislation in Western Australia could be perceived to give people the 'option of choice' when rural and regional people do not yet have the option to receive a full range of end of life services in their local community including the option to receive full support to die at home.⁹¹⁰

Funding announcements for regional and remote palliative care

Summary of funding announcements

8.10 The funding announced in 2019-20 for regional and remote palliative care covers measures relevant to recommendations 12 and 13 of the JSCEOLC.

8.11 WACHS summarised the additional funding as follows:

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:

⁹⁰⁶ Submission 33 from WA Country Health Service, 13 July 2020, p 5.

⁹⁰⁷ Submission 29 from Chittering Health Advisory Group, 10 July 2020, p 1.

⁹⁰⁸ Paragraphs 7.49–7.54.

⁹⁰⁹ Submission 39 from East Pilbara Independence Support Inc, 15 July 2020, p 2.

⁹¹⁰ Submission 12 from Busselton Hospice Care Inc., 9 July 2020, p 3.

- \$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.⁹¹¹

8.12 Details of these announcements and their intended impact on delivery of services in regional areas is discussed in Chapter 6.⁹¹²

The Palliative Care Program

8.13 In July 2019, in response to recommendations 12 and 13 of the JSCEOLC, WACHS advised that a new program of palliative care is being developed 'to complement current service delivery, expand provision of multidisciplinary care, develop policy and improve governance structures'.⁹¹³

8.14 Under the program, titled the 'Palliative Care Program', WACHS advised that it:

has made major steps 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.⁹¹⁴

Progress on recommendation 12—policy development and improved governance structures

JSCEOLC 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 (*sic*).⁹¹⁵

Background

8.15 During its inquiry, the JSCEOLC was advised by WACHS that 'there is no medical oversight, coordination or governance of medical palliative care services across WACHS'.⁹¹⁶ This led to a finding in those terms by the JSCEOLC, and to recommendation 12 that policy development and improved governance structures be prioritised.⁹¹⁷

⁹¹¹ Submission 33 from WA Country Health Service, 13 July 2020, p 4.

⁹¹² Paragraphs 6.13–6.39 and 6.58–6.71.

⁹¹³ Submission 33 from WA Country Health Service, 13 July 2020, p 4.

⁹¹⁴ *ibid.*

⁹¹⁵ Western Australia, Legislative Assembly and Legislative Council, Joint Select Committee on End of Life Choices, report 1, *My Life, My Choice*, 23 August 2018, p 83.

⁹¹⁶ *ibid.*, p 82.

⁹¹⁷ *ibid.*, finding 20, p 83.

Progress of implementation

8.16 The Committee considered the progress of implementation of JSCEOLC recommendation 12 from two perspectives:

- the process changes in WACHS
- the funding provided to improve regional governance.

8.17 This section will focus on the process changes in WACHS, with the funding component previously discussed in Chapter 6.⁹¹⁸

8.18 WACHS advised that its Palliative Care Program is supported by an internal 'Plan', which 'represents a high-level synopsis of planning and stakeholder feedback to date', and a Project Control Group. Other governance enhancements include:

- clarifying the roles and responsibilities of the WACHS executive to palliative care outcomes
- the appointment of a Clinical Director of Palliative Care
- the promotion of regional palliative care steering committees in each region
- greater levels of engagement between relevant parties.⁹¹⁹

8.19 WACHS elaborated on the role of the Project Control Group:

The purpose of the Project Control Group (PCG) is to establish the authority, responsibility and accountability for overall stewardship of the WACHS Palliative Care Program Project and to provide assurance to the WACHS Executive. The PCG will focus on the detailed decision-making:

- Provide advice and support of project activities to ensure milestones and deliverables are met and benefits realised and communicated to the WACHS Executive.
- Provide leadership and purpose across all WACHS regions in relation to palliative care services.
- Provide an appropriate forum with the authority to respond to requests for decisions or recommendations received from the Minister, Director General, Chief Executive or other parties.
- Provide direction and guidance to stakeholders about objectives and strategies of the Program.
- Inform and advise the Chief Executive of project status prior to sign-off of key milestones.
- Ensure any risk to achievement of milestones and deadlines are communicated and action taken to mitigate against delays in a timely manner.
- Advise the Project Team on how to manage project issues and risks to ensure adequate controls are in place.

⁹¹⁸ Paragraphs 6.62–6.71.

⁹¹⁹ Submission 33 from WA Country Health Service, 13 July 2020, p 6.

- Ensure that the organisational and/or work practice changes from the project deliverables are able to be sustained following closure of the project.⁹²⁰

8.20 The Project Control Group includes the following positions:

- Medical/Clinical Director Palliative Care - provides clinical leadership in the provision of comprehensive palliative care services within WACHS using innovative models to deliver contemporary palliative care to country patients in regional WA. In partnership with the Executive Director Medical Services and the Palliative Care Program the position promotes improvement in clinical care and innovation for excellence in Palliative Care.
- Program Manager - responsible for leading, managing and directing the Palliative Care Program development and implementation including the palliative care strategic direction, planning, developing, implementation and evaluating of palliative care projects and lead the achievement of service reform, change programs and transition planning.
- Senior Project Officer – responsible for planning, managing and evaluating projects and activities as part of the Palliative [sic] Care Program, including managing and supporting working groups and project teams as appropriate; monitor performance against plans; and contribute to the achievement of service reform, change programs and transition planning.⁹²¹

8.21 As noted in paragraph 6.66, WACHS has also attempted to recruit a nurse practitioner to the Project Control Group.

8.22 WACHS advised that the Project Control Group, as an entity, is funded from existing resources.⁹²² The Clinical Director Palliative Care, Program Manager Palliative Care Project and Nurse Practitioner Palliative Care are funded from the \$2.5 million for governance announced in October 2019.⁹²³

FINDING 54

There has been significant progress on the implementation of recommendation 12 of the Joint Select Committee on End of Life Choices, that the Minister for Health prioritise policy development and improved governance structures for the delivery of palliative care by the WA Country Health Service.

⁹²⁰ Jeffrey Moffet, Chief Executive, WA Country Health Service, Answer to question prior to hearing no 50, dated 18 September 2020, p 6.

⁹²¹ Jeffrey Moffet, Chief Executive, WA Country Health Service, Answer to question prior to hearing no 49, dated 18 September 2020, p 5.

⁹²² Jeffrey Moffet, Chief Executive, WA Country Health Service, Answer to question prior to hearing no 51, dated 18 September 2020, p 6.

⁹²³ Marie Norris, Acting Executive Director Nursing and Midwifery Services, WA Country Health Services, emailed correction to transcript of evidence of hearing held 15 July 2020, dated 5 October 2020.

Progress on recommendation 13—ensuring regional palliative care is adequately funded to meet demand

JSCEOLC recommendation 13:

The Minister for Health should ensure regional palliative care be adequately funded to meet demand.⁹²⁴

Background

- 8.23 The JSCEOLC inquired into access to palliative care in regional areas, including site visits to the Great Southern and Kimberley regions.⁹²⁵ As a result of those inquiries, the JSCEOLC noted that accessibility of palliative care differs markedly across the state,⁹²⁶ and found that there is limited access to palliative care medical specialists in regional Western Australia.⁹²⁷
- 8.24 In other respects, the JSCEOLC did not spell out ways in which regional palliative care is not, using the words of recommendation 13, 'adequately funded to meet demand'.

Demand for regional palliative care

- 8.25 Assessment of the progress of implementation of recommendation 13 requires a quantification of:
- the demand for regional palliative care
 - adequate funding to meet demand.
- 8.26 On the evidence available to the Committee, an accurate quantification of demand for regional palliative care is not possible.
- 8.27 Evidence from the Department of Health indicates:
- pursuant to recommendation 10 of the JSCEOLC, a process to determine 'unmet need' for palliative care has been decided upon and identified, and is currently being refined⁹²⁸
 - the independent review being undertaken pursuant to recommendation 9 of the JSCEOLC is expected to identify the nature of the demand for palliative care services, in terms of models and settings of care.⁹²⁹
- 8.28 As discussed earlier in this Chapter,⁹³⁰ it is clear from the evidence received by the Committee that demand for regional palliative care varies in scope and nature from region to region. The assessment of demand for 'regional palliative care' must therefore take account of those regional variances.

⁹²⁴ Western Australia, Legislative Assembly and Legislative Council, Joint Select Committee on End of Life Choices, report 1, *My Life, My Choice*, August 2018, p 83.

⁹²⁵ *ibid.*, pp 71–2.

⁹²⁶ *ibid.*, p 80.

⁹²⁷ *ibid.*, finding 19, p 83.

⁹²⁸ See paragraphs 5.66–5.81.

⁹²⁹ See paragraphs 5.56–5.61.

⁹³⁰ Paragraphs 8.5–8.8.

8.29 As outlined in Chapter 6,⁹³¹ WACHS is conducting a 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.⁹³²

8.30 Phase two of this review will identify 'region specific population and health data'.⁹³³ The Committee would expect that the data on 'unmet need' arising from phase two of this review will be sufficiently detailed to inform decisions on service delivery.

8.31 The Committee noted that the demand for palliative care services in the regions may not be known. The Current State Report indicates that overall, 44 per cent of people who died of a condition amenable to palliative care in Western Australia did not receive inpatient palliative care in a public hospital,⁹³⁴ but no equivalent regional-specific data was provided to the Committee.

Progress towards 'adequate funding to meet demand'

8.32 WACHS provided the following on its progress against JSCEOLC recommendation 13:

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.⁹³⁵

8.33 The additional funding to WACHS is discussed in more detail in Chapter 6⁹³⁶ and includes, in summary:

- expansion of the WACHS regional teams
- provision of domiciliary homecare packages

⁹³¹ Paragraphs 6.17–6.21.

⁹³² Jeffrey Moffet, Chief Executive, WA Country Health Service, Answer to question prior to hearing no 54, dated 18 September 2020, p 7.

⁹³³ *ibid.*

⁹³⁴ Dr DJ Russell-Weisz, Director General, Department of Health, Attachment to Answers to questions on notice asked at hearing held 15 July 2020, dated 14 August 2020, *WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper*, June 2020, p 23.

⁹³⁵ Submission 33 from the WA Country Health Service, 13 July 2020, p 8.

⁹³⁶ Paragraphs 6.13–6.39 and 6.58–6.71.

- the Carnarvon aged and palliative care facility
 - the WACHS telehealth hub.
- 8.34 The Committee notes that these expanded services largely relate to community-based and consultative specialist palliative care services, and that only the proposed Carnarvon facility relates to an increase in inpatient services.
- 8.35 As with the Committee’s consideration of recommendation 8,⁹³⁷ it is difficult to assess at what point regional palliative care is ‘adequately funded to meet demand’. It requires an assessment of:
- the demand for palliative care services
 - the relationship between funding and service delivery
 - whether the services delivered are consistent with patient demand.
- 8.36 The Committee received limited data on spending in the regions over time. Department of Health data indicates that the proportion of total community-based palliative care spending allocated to the regions for 2022–23 will increase from 16 per cent prior to the announcements, to 33 per cent after the May and October announcements.⁹³⁸
- 8.37 The additional funding to WACHS—\$39.7 million over four years—as summarised in paragraph 8.11 and detailed in Chapter 6,⁹³⁹ is expected to increase the level of services available to regions. The number of multidisciplinary teams will increase from seven to 20 and the Monday to Friday service delivered by those teams will be available every day in some regions from 2021.⁹⁴⁰ The after-hours assistance will be complemented by additional support from the WACHS command centre, which is developing a palliative care service.⁹⁴¹
- 8.38 In five regions, WACHS has recently recruited experienced GPs on a pilot program to interface between their designated Palliative Care Medical Specialist and the Regional Nursing Coordinator.
- 8.39 The Manager of the Wheatbelt Palliative Care Service, Brett Hayes, told the Committee that the GP pilot program had been ‘a real game changer’ and expressed concern that the program may not be continued beyond mid-2021.⁹⁴²
- 8.40 This is consistent with advice from WACHS that the increase in the number of on-the-ground GPs ‘is only occurring in 2020-2021 as ongoing funding has not been secured past 30 June 2021’.⁹⁴³
- 8.41 Some witnesses noted that the expansion of regional services had not translated into increased availability of services on the ground. For example, in relation to the \$3 million

⁹³⁷ Paragraph 5.40.

⁹³⁸ Staff calculations based on submission 23 from the Department of Health, 10 July 2020, pp 19–20; Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 122, dated 18 September 2020, p 24.

⁹³⁹ Paragraphs 6.13–6.39 and 6.58–6.71.

⁹⁴⁰ Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 56, dated 18 September 2020, p 8; Marie Norris, Acting Executive Director, Nursing and Midwifery, WA Country Health Service, transcript of evidence, 18 September 2020, p 18.

⁹⁴¹ See paragraph 4.61.

⁹⁴² Brett Hayes, Wheatbelt Palliative Care Manager, WA Country Health Service, transcript of evidence, 3 September 2020, p 3.

⁹⁴³ Jeffrey Moffet, Chief Executive, WA Country Health Service, Answer to question prior to hearing no 54, dated 18 September 2020, p 8.

announced for 24-hour support through the telehealth hub, Kimberley Aboriginal Medical Services advised:

We have not seen any impacts of those funds, but we do know that the service exists.⁹⁴⁴

8.42 As an overall comment in relation to recommendation 13, Dr Derek Eng submitted:

The funding announced by the minister was inadequate and more is required if demand is likely to be met.⁹⁴⁵

8.43 Bethesda submitted:

These are welcome initial steps – more will need to be done as rural and regional populations grow.⁹⁴⁶

FINDING 55

The progress of implementation of recommendation 13 of the Joint Select Committee on End of Life Choices, that the Minister for Health ensure regional palliative care be adequately funded to meet demand, cannot be evaluated until a more detailed assessment of demand and/or need for palliative care services in regional and remote areas has been undertaken.

Other measures to address inequity of access

8.44 The Committee heard evidence of capacity in existing providers to provide palliative care services where gaps in service exist, if funding was made available. For example, EPIS submitted:

there is a need to fund in-home palliative care service based here in Newman that could outreach to the Shire of Ashburton and into the Western Desert communities. EPIS Inc. is experienced in providing in-home care for frail clients and has the capacity to deliver palliative care if provided with the necessary funding.⁹⁴⁷

8.45 Hall & Prior indicated their model of care would be transferrable to other areas.⁹⁴⁸

8.46 The Committee also noted that the Department of Health has contracted Bethesda to provide an in-reach model of care in the Pilbara from July 2020.⁹⁴⁹

8.47 Evidence from a number of sources suggests that telehealth has a large role to play in reducing inequity of access in regional and remote areas.⁹⁵⁰ This issue is discussed in detail in Chapter 4.⁹⁵¹ The Committee welcomes the expansion of the use of telehealth by WACHS.

8.48 The Department of Health advised:

other measures to address equity of access are being considered through the proposed procurement of services with Palliative Care WA to provide a statewide

⁹⁴⁴ Dr Lorraine Anderson, Medical Director, Kimberley Aboriginal Medical Services, transcript of evidence, 3 September 2020, p 3.

⁹⁴⁵ Submission 8 from Dr Derek Eng, 8 July 2020, p 4.

⁹⁴⁶ Dr Neale Fong, Chief Executive Officer, Bethesda Health Care, Answer to question on notice 1 asked at hearing held 30 July 2020, dated 28 August 2020, p 4.

⁹⁴⁷ Submission 39 from East Pilbara Independence Support Inc, 15 July 2020, p 2.

⁹⁴⁸ Submission 31 from Hall & Prior Health & Aged Care Group, 10 July 2020, p 3.

⁹⁴⁹ Paragraph 6.28.

⁹⁵⁰ See for example paragraphs 4.55 and 4.56.

⁹⁵¹ Paragraphs 4.55–4.63.

focus for improving the understanding and awareness of palliative care services. This includes educational face-to-face and online forums, as well as electronic and hard copy information resources. To address these requirements, WA Health is in the process of contracting Palliative Care WA to facilitate local communities to create and establish compassionate community groups. Ensuring that all communities within WA have equitable access to grief and bereavement support is an important measure that is being included in the development of these holistic palliative care services and supports.⁹⁵²

Evidence of progress towards equity of access

Department of Health and WA Country Health Service comments

8.49 According to the Department of Health:

Palliative care delivery within regional and remote WA has made significant progress with the establishment of a wellfunctioning workforce model, cohesive in design across regions...

The regions have progressed in their equity to the metropolitan clinical teams of expertise, including social workers, clinical nurses, Aboriginal Health Workers and a central program oversight and management in place.⁹⁵³

8.50 WACHS advised:

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.⁹⁵⁴

Stakeholder comments

8.51 Several stakeholders from regional and remote areas commented that they had not yet seen any impact of the expansion of the WACHS multidisciplinary teams, or after-hours support through the WACHS telehealth hub.⁹⁵⁵

8.52 For example, Michele Harvey from the Ord Valley Aboriginal Health Service advised:

The CHAIR: The WA Country Health Service has advised it is in the process of recruiting new multidisciplinary teams. This is arising from the funding announced for this purpose—an announcement that was made last year. This funding included recruitment of Aboriginal health workers. Have you seen any impact of this funding and the recruitment of multidisciplinary teams in your area?

⁹⁵² Amanda Bolleter, Project Director, End of Life Care, Department of Health, transcript of evidence, 15 July 2020, p 13.

⁹⁵³ Submission 23 from Department of Health, 10 July 2020, p 5.

⁹⁵⁴ Submission 33 from WA Country Health Service, 13 July 2020, p 5.

⁹⁵⁵ Vicki Kershaw, Chief Executive Officer, and Juan Andrade, Corporate Services Manager, East Pilbara Independence Support Inc, transcript of evidence, 10 August 2020, pp 9 and 10; Dr Lorraine Anderson, Medical Director, Kimberley Aboriginal Medical Services, transcript of evidence, 3 September 2020, p 3; Christine Waller, Senior Manager, Population Health Programs and Remote Areas, Derby Aboriginal Health Service, transcript of evidence, 3 September 2020, p 6; Michele Harvey, Nurse Practitioner—Chronic Disease, Ord Valley Aboriginal Health Service, transcript of evidence, 3 September 2020, p 8; Submission 39 from East Pilbara Independence Support Inc, 15 July 2020, p 2.

Mrs HARVEY: No, but we are waiting with bated breath. We are desperately—and we are also, you know, equal opportunity, but we are trying to find people already here that would fit the bill for those sorts of roles, because they know the community, they know how it works, and there are some really good social workers, nurses and health workers. Health workers are probably a little bit harder to find, we are struggling just to get any health worker most of the time, but definitely we are waiting. We really want that service to be filled, because there is a big need.⁹⁵⁶

Committee conclusions in relation to term of reference (d)

- 8.53 During its inquiry, the Committee noted substantial progress towards ensuring greater equity of access to palliative care between metropolitan and regional areas.
- 8.54 However, the Committee heard evidence from a number of witnesses that community specialist palliative care services, in particular, are less accessible to patients living in regional and remote areas than those living in the metropolitan area.
- 8.55 Inpatient services in regional areas are also in many cases located large distances from patients' homes and families.
- 8.56 The Committee commends the work of WACHS to expand its regional palliative care services and to increase the use of telehealth to enable patients in more remote areas to receive specialist palliative care at home.
- 8.57 In the Committee's view, these expansions should continue, as current measures do not appear to be sufficient to meet growing demand.

RECOMMENDATION 23

The Department of Health undertake a detailed assessment of demand and/or need for palliative care services in regional and remote areas of Western Australia.

RECOMMENDATION 24

The WA Country Health Service and the Department of Health report on the progress of implementation of recommendation 13 of the Joint Select Committee on End of Life Choices in their next Annual Reports.

⁹⁵⁶ Michele Harvey, Nurse Practitioner—Chronic Disease, Ord Valley Aboriginal Health Service, transcript of evidence, 3 September 2020, p 8.

CHAPTER 9

Advance Care Planning

- 9.1 Palliative Care WA (PCWA) encouraged the Committee to consider the critical importance of Advance Care Planning (ACP) as an integral part of palliative care.⁹⁵⁷
- 9.2 The Committee recognises the useful role of ACP in relation to the provision of palliative care services and, in this Chapter, highlights some issues in relation to ACP which arose during the course of its inquiry.

What is Advance Care Planning?

- 9.3 The Department of Health advised:

Advance Care Planning is a voluntary person-led process that outlines a future plan for health and personal care. The process enables the person to describe to family, carers and health professionals the treatment and care that they would want for themselves in the event they are unable to make or communicate decisions. Advance Care Planning occurs on a continuum from an Advance Care Plan recognised in common law to an Advance Health Directive/or appointment of an Enduring Power of Guardian which is supported by West Australian legislation. These only come into effect if the person lacks capacity to contribute to decision-making at the time a decision is required. Few West Australians have any form of Advance Care Planning.⁹⁵⁸

- 9.4 Other witnesses and submitters appeared to adopt a similar description of ACP, and it appeared to the Committee that there was broad consistency as to its meaning and scope.

Elements of Advance Care Planning

Advance Health Directives

- 9.5 As noted in the above quote from the Department of Health, ACP occurs on a continuum from a less formal process through to Advance Health Directives (AHDs) and Enduring Powers of Guardianship under the *Guardianship and Administration Act 1990*.
- 9.6 AHDs are binding directions made by competent adults about their future treatment, and are a vehicle through which ACP may be actioned when a patient loses capacity.
- 9.7 The *Guardianship and Administration Act 1990* provides for the making of statutory AHDs and sets out a number of requirements,⁹⁵⁹ including the use of a prescribed form.⁹⁶⁰ The Act also provides that health professionals must comply with the terms of a statutory AHD other than in specified urgent or exceptional circumstances.⁹⁶¹
- 9.8 The JSCEOLC found that the uptake of AHDs and other ACP instruments in Western Australia was very low.⁹⁶²

⁹⁵⁷ Lana Glogowski, Chief Executive Officer, Palliative Care Western Australia, transcript of evidence, 31 July 2020, p 2.

⁹⁵⁸ Dr DJ Russell-Weisz, Director General, Department of Health, Answer to question prior to hearing no 118, dated 18 September 2020, p 23.

⁹⁵⁹ *Guardianship and Administration Act 1990*, Part 9B, Division 1.

⁹⁶⁰ *Guardianship and Administration Act 1990*, ss 110Q(1)(a) and 110ZIA.

⁹⁶¹ *Guardianship and Administration Act 1990*, s 110S(3).

⁹⁶² Western Australia, Legislative Assembly and Legislative Council, Joint Select Committee on End of Life Choices, report 1, *My Life, My Choice*, 23 August 2018, p 46.

- 9.9 Specifically, the Committee heard evidence that the complexity of the prescribed form may inhibit uptake.⁹⁶³ This was illustrated in the evidence from Derby Aboriginal Health Service:

Our patients do not want to know all the lingo, there are too many “therefores” and “why fors”—this is what they say to us. We have worked with a much simpler form and I wanted to show you that because it is a one-pager and there are some notes for the health professionals. Our page is “What I want” and it is “My name is”, “I am from”, “My main worry is”, “As my health gets worse, I may get”, “If I become very sick, what matters the most”... This has come from patients: staying on my country, staying at home, being comfortable, trying every possible treatment to live longer, what I want if my heart stops, whether I want the doctors to do everything, and whether I am prepared to go to Perth.⁹⁶⁴

- 9.10 Similarly, in the metropolitan context, Dr Barry Fatovich, an experienced GP and Silver Chain Hospice doctor practising in Perth, gave evidence that he had also developed a one-page document that he uses as a template for AHD preparation for his patients, and provided a copy of the template to the Committee.⁹⁶⁵

‘Goals of Patient Care’

- 9.11 ‘Goals of Patient Care’ is a term used within the Department of Health to describe a process of discussion about care and treatment at a particular point in time, and a form which documents that discussion.⁹⁶⁶

- 9.12 According to the Department of Health, ‘Goals of Patient Care’ is part of advance care planning.⁹⁶⁷

It is about the here and now decisions, not necessarily the planning ahead: “This is the situation I’m in now. Let’s talk about the appropriate interventions at this point in time.” That actually can be very valuable, particularly in the absence of an advance care plan or advance health directive.⁹⁶⁸

- 9.13 Associate Professor Alison Parr described the connection between Goals of Patient Care and other ACP as follows:

Goals of patient care really sits at the point-of-care. When you have got somebody who comes into hospital, the idea is that it is a focused discussion around what the patient’s wishes are, what their understanding of their illness is, and what we understand it to be. In that context, what are their wishes in terms of what we might do if their clinical condition were to deteriorate during that admission. The value from this comes, if there is an advance health directive or an advance care plan, all of that is taken into account in this discussion. But if it does not exist, it promotes discussion at the point-of-care around: “What are your wishes?”

⁹⁶³ Dr Derek Eng, Answer to question on notice 2 asked at hearing held 30 July 2020, dated 11 August 2020, p 3.

⁹⁶⁴ Christine Waller, Senior Manager, Population Health Programs and Remote Areas, Derby Aboriginal Health Service, transcript of evidence, 3 September 2020, pp 2-3 and Answer to question on notice 1 asked at hearing held 3 September 2020, dated 4 September 2020.

⁹⁶⁵ Dr Barry Fatovich, Silver Chain Hospice Doctor/General Practitioner, transcript of evidence, 31 July 2020, p 9 and Answer to question on notice 2 asked at hearing held 31 July 2020, dated 17 August 2020.

⁹⁶⁶ Assoc Prof Alison Parr, Clinical Lead, Palliative Care, WA Cancer and Palliative Care Network, transcript of evidence, 18 September 2020, p 38.

⁹⁶⁷ *ibid.*, p 37.

⁹⁶⁸ Assoc Prof Alison Parr, Clinical Lead Palliative Care, WA Cancer and Palliative Care Network, transcript of evidence, 15 July 2020, p 18.

Let's understand what's important to you and what do you understand about your illness?"⁹⁶⁹

- 9.14 PCWA and the Department of Health both advised that there was a strong view amongst clinicians that the Goals of Patient Care approach was not properly acknowledged in the JSCEOLC Report.⁹⁷⁰ PCWA submitted:

While the process is directed by clinicians it does seek patient and family input in a shared decision making process. It is important to recognise it as the "here and now" decision making process particularly when advance care planning documentation does not exist but also when a patient still has capacity to decide what they want in the context of a real, rather than hypothetical situation.⁹⁷¹

Ministerial Expert Panel on Advance Health Directives

- 9.15 The Committee noted that the Ministerial Expert Panel on Advance Health Directives, established under recommendation 1 of the JSCEOLC to review the current law and health policy and practice around AHDs, published its final report in August 2019.⁹⁷²

- 9.16 In its final report, the Ministerial Expert Panel on Advance Health Directives made findings and recommendations regarding:

- community awareness and education about ACP
- education for health professionals about ACP
- the AHD template
- the need for a dedicated register of AHDs
- accommodating ACP for people with dementia and cognitive impairment.⁹⁷³

- 9.17 On tabling of the final report, the Attorney General advised:

Together with the Minister for Health, Hon Roger Cook, MLA, I look forward to considering in detail the expert panel's recommendations to improve the understanding and use of advance care planning instruments in Western Australia. As an interim response, I advise the house that the government accepts in principle all the recommendations, except for the final one, recommendation 23, which relates to voluntary assisted dying legislation. The government does not support this proposal now or into the future. The government will never adopt recommendation 23.

- 9.18 Recommendation 23 stated:

If, at a future point, voluntary assisted dying legislation is implemented in Western Australia, the State Government could consider establishing an Expert Panel to provide advice and recommendations on how to provide people with a neurodegenerative condition access to choice regarding voluntary assisted dying, in particular through the potential application of advance directives.⁹⁷⁴

⁹⁶⁹ Assoc Prof Alison Parr, Clinical Lead, Palliative Care, WA Cancer and Palliative Care Network, transcript of evidence, 18 September 2020, p 38.

⁹⁷⁰ Submission 36 from Palliative Care Western Australia, 13 July 2020, p 25; Assoc Prof Alison Parr, Clinical Lead, Palliative Care, WA Cancer and Palliative Care Network, transcript of evidence, 15 July 2020, p 18.

⁹⁷¹ Submission 36 from Palliative Care Western Australia, 13 July 2020, p 25.

⁹⁷² Department of Health, Ministerial Expert Panel on Advance Health Directives, *Final Report*, August 2019.

⁹⁷³ *ibid.*, pp 4–10.

⁹⁷⁴ Department of Health, Ministerial Expert Panel on Advance Health Directives, *Final Report*, August 2019, p 52.

- 9.19 Subsequently, the Government announced funding of \$1.65 million to implement the recommendations of the Ministerial Expert Panel.⁹⁷⁵
- 9.20 The Department of Health advised that it is currently implementing 22 of the 23 recommendations of the Ministerial Expert Panel,⁹⁷⁶ and that the following actions are underway:
- Consultation with service providers and community regarding template design and uptake
 - Planning education regarding the importance of ACP and the completion of AHDs for clinicians, service providers and the community (implementation 2021/2022).
 - Investigating registry options based on contemporary IT solutions – Developing strategies to increase awareness.⁹⁷⁷
- 9.21 In addition, the Department advised that:
- the Council of Australian Governments was in correspondence with the Chair of the MBS Review Taskforce to investigate inclusion of MBS billing for preparation of AHDs by GPs
 - patients presenting to Western Australian hospitals with a completed AHD are now 'flagged' on the hospital Patient Admission System.⁹⁷⁸

Role of Advance Care Planning in palliative care

- 9.22 It was acknowledged by many witnesses and submitters that ACP plays a key role in the provision of palliative care.⁹⁷⁹
- 9.23 The Department of Health commented:
- A community that is well informed around advance care planning and has had those discussions with their family and people close to them, and documented those discussions, is in a much better position to know when and if they might need to access palliative care services and what their wishes are around that.⁹⁸⁰
- 9.24 The End-of-Life Framework document notes the importance of open and honest ACP conversations:

⁹⁷⁵ Submission 23 from the Department of Health, 10 July 2020, p 18. The \$1.65 million is part of the \$2.4 million for Advance Health Directives announced on 20 August 2020 (Dr DJ Russell Weisz, Director General, Department of Health, Answer to question prior to hearing no 124, dated 18 September 2020).

⁹⁷⁶ Submission 23 from the Department of Health, 10 July 2020, p 7; Assoc Prof Alison Parr, Clinical Lead, Palliative Care, WA Cancer and Palliative Care Network, transcript of evidence, 18 September 2020, p 36.

⁹⁷⁷ Department of Health, *Palliative Care in WA*, PowerPoint presentation, tabled by Dr Duncan James Williamson, Acting Director General, Department of Health, during hearing held 18 September 2020, p 14.

⁹⁷⁸ *ibid.*

⁹⁷⁹ For example, Lana Glogowski, Chief Executive Officer, Palliative Care Western Australia, transcript of evidence, 31 July 2020, p 2; Amanda Bolleter, Project Director, End of Life Care, Department of Health, transcript of evidence, 15 July 2020, p 12; Dr Paula Moffat, Medical Director, Palliative Care, Bethesda Health Care, transcript of evidence, 30 July 2020, p 4; Dr Derek Eng, Palliative Care Physician and Member, Australian and New Zealand Society of Palliative Medicine, transcript of evidence, 30 July 2020, p 6.

⁹⁸⁰ Amanda Bolleter, Project Director, End of Life Care, Department of Health, transcript of evidence, 15 July 2020, p 12.

Engaging in open and honest conversations, discussing care preferences and acknowledging the limitations of treatment will assist us to view death and dying as part of life and allow us to live well and die well.⁹⁸¹

- 9.25 The WA Strategy recognises that ACP is an important tool in the facilitation of person-centred palliative care.⁹⁸²
- 9.26 PCWA advised the Committee that, in its view, ACP should be considered as part of palliative care. The Chief Executive Officer of PCWA, Lana Glogowski, advised the Committee:

What I regularly find, particularly in my communications with WA Health, is a notion that advance care planning is separate to palliative care, which I find quite concerning. From our perspective, advance care planning is critical to palliative care and is a really important first step in terms of engaging people in the provision of quality palliative care.⁹⁸³

- 9.27 PCWA noted that the tender document for the palliative care hotline⁹⁸⁴ 'again separates advance care planning from palliative care',⁹⁸⁵ and described the significance of ACP in relation to the interim hotline currently being operated by PCWA:⁹⁸⁶

From our perspective and our experience of piloting the hotline for the last four months, is that often when people ring us they are in a very distressed state because they have just been told that their loved one needs to consider entry to a palliative care service, and so the first part of that conversation is, "Okay, what services are you currently receiving? What are your values or what are your loved one's values and priorities? What do they want to achieve? What do they want to receive as part of their palliative care journey? Do they want to receive palliative care at home? Do they want to be admitted to hospital? Do they want to access palliative care via hospice? Do they want an emphasis on treatment so that they can live for as long as they possibly can? Do they want minimal treatments? Do they want palliative care—a recognition of the need for pain management and symptom control—but do they not want treatments that extend their life for a long period of time?" They are the sorts of conversations we are having on the hotline. That is advance care planning.⁹⁸⁷

- 9.28 As noted in paragraph 5.10, the Committee formed the view that ACP, while a valuable and important tool in relation to palliative care, can and sometimes should be viewed separately from palliative care, depending on the circumstances.

FINDING 56

Advance Care Planning is separate from palliative care, but is an important tool to facilitate the timely delivery of palliative care consistent with the desires of the patient.

⁹⁸¹ Department of Health, *The End-of-Life Framework: A statewide model for the provision of comprehensive, coordinated care at end-of-life in Western Australia*, 2015, p 5. See <https://ww2.health.wa.gov.au/-/media/Files/Corporate/general-documents/End-of-Life/PDF/The-End-of-Life-Framework.pdf>. Viewed 23 October 2020.

⁹⁸² Department of Health, *WA End-of-Life and Palliative Care Strategy 2018–2028*, 2018, p 9. See: https://ww2.health.wa.gov.au/~/_media/Files/Corporate/general%20documents/Health%20Networks/Palliative%20care/WA%20End-of-life%20and%20Palliative%20Care%20Strategy%202018-2028.pdf. Viewed 23 October 2020.

⁹⁸³ Lana Glogowski, Chief Executive Officer, Palliative Care Western Australia, transcript of evidence, 31 July 2020, p 2.

⁹⁸⁴ See paragraphs 5.102–5.107.

⁹⁸⁵ Lana Glogowski, Chief Executive Officer, Palliative Care Western Australia, transcript of evidence, 31 July 2020, p 2.

⁹⁸⁶ See paragraph 5.103.

⁹⁸⁷ Lana Glogowski, Chief Executive Officer, Palliative Care Western Australia, transcript of evidence, 31 July 2020, p 2.

Need for education about Advance Care Planning

9.29 The JSCEOLC identified the need for education about ACP both amongst health professionals and in the general community. These were the subject of JSCEOLC recommendations 2 and 3.⁹⁸⁸

9.30 Dr Derek Eng submitted that:

Many of the barriers to ACP in the community and in hospitals can be overcome by medical practitioner education. ACP conversations are welcome by most patients but they need a skilled practitioner to guide them. Medical practitioners have very limited experience in nuanced and complex ACP which is a learnable communication skill. Education programs for medical practitioners are mostly unavailable as they require highly trained facilitators, small group simulation workshops, mentorship and clinical practice. Workshops such as these are expensive and health care organisations have not been aware or to prioritised these for their health practitioners. Consumers are more likely to engage in ACP if they know what it is and the rationale. This can be achieved through community awareness campaigns and programs.⁹⁸⁹

9.31 The practical effect of a lack of community understanding was illustrated by ACSA in its evidence:

We still have people who arrive with their husband or wife who has got significant dementia and they want to write an advance health directive now. Well, they cannot do that, but they struggle to understand that.⁹⁹⁰

Lack of Medicare rebate for Advance Care Planning

9.32 Several witnesses raised the issue that the MBS does not provide for a Medicare rebate for consultations regarding ACP, including the preparation of AHDs.⁹⁹¹ This issue was identified by the JSCEOLC and led to its recommendation 5, that the issue be progressed by the Minister for Health through the Council of Australian Governments.⁹⁹²

9.33 WAPHA raised:

the lack of MBS items for end-of-life care, advance care planning and advance health directives... If there was appropriate time and funding for those richer conversations, I think that is when clinicians would be able to spend more time on understanding a person's emotional mental health issues.⁹⁹³

9.34 AMA(WA) advised:

GPs are best placed to help their patients understand their disease and prognosis, so the patient and their family can plan and make decisions about the end of their life. An amendment to the Medicare rebate schedule to include preparation of advance health directives (AHD) with GPs should adequately remunerate GPs for

⁹⁸⁸ Western Australia, Legislative Assembly and Legislative Council, Joint Select Committee on End of Life Choices, report 1, *My Life, My Choice*, 23 August 2018, p 53.

⁹⁸⁹ Submission 8 from Dr Derek Eng, 8 July 2020, pp 1–2.

⁹⁹⁰ Amanda Crook, General Manager, Care Services, Coolibah Care, transcript of evidence, 10 August 2020, p 8.

⁹⁹¹ Submission 41 from Australian Medical Association (WA), 17 July 2020, p 2.

⁹⁹² Western Australia, Legislative Assembly and Legislative Council, Joint Select Committee on End of Life Choices, report 1, *My Life, My Choice*, 23 August 2018, p 54.

⁹⁹³ Christine Kane, General Manager, Strategy and Engagement, WA Primary Health Alliance, transcript of evidence 30 July 2020, p 5.

having many conversations with their patients about the end of their life – not just for completing a document.⁹⁹⁴

9.35 TPG Aged Care submitted that:

Professionals working in the aged care sector have identified that an AHD is not something that you can develop in one session. It is also identified that success is more probable if information and education is provided by a person that has developed a relationship with the person over time and provided the opportunity to build trust in the relationship.⁹⁹⁵

9.36 RACGP gave evidence that this is a ‘massive issue’:

[I]t is a huge waste of resources. Particularly with cognitive impairment, people ... will not make an advance care directive, but their family is saying, you know, “Look, this is what they would have wanted”, but it was never made, there was time never made. GPs are so busy, you know, it is difficult for us to raise it, and, you know, so it does make it very, very difficult. Whereas if that system was streamlined and reimbursed properly and, again, uploaded to My Health Record, then it would save an enormous amount of resources at the state hospital level to prevent futile interventions or unwanted interventions.⁹⁹⁶

Proposals to improve uptake of Advance Care Planning

9.37 As previously noted, the Committee did not conduct a detailed inquiry into ACP and its role in relation to palliative care.

9.38 However, in addition to highlighting the above issues, the Committee notes the Department of Health’s advice that it is:

- progressing significant changes in relation to ACP and AHDs, as per the recommendations of the Ministerial Expert Panel
- giving consideration to establishing a service agreement with PCWA to facilitate community awareness and uptake of ACP.⁹⁹⁷

⁹⁹⁴ Dr Andrew Miller, Australian Medical Association (WA), Answer to question on notice 4 asked at hearing held 31 July 2020, dated 26 August 2020, p 2.

⁹⁹⁵ Submission 24 from TPG Aged Care, 10 July 2020, p 1.

⁹⁹⁶ Dr Sean Stevens, Chair, Royal Australian College of General Practitioners, transcript of evidence, 31 July 2020, p 9.

⁹⁹⁷ Amanda Bolleter, Project Director, End of Life Care, Department of Health, transcript of evidence, 15 July 2020, p 12.

CHAPTER 10

Conclusions

- 10.1 During its inquiry, the Committee heard evidence of progress in relation to palliative care, particularly in the following areas:
- expansion of the WACHS multidisciplinary specialist palliative care teams in all WACHS regions
 - a comprehensive review of existing service-delivery models in regional areas, which is near completion
 - improved governance structures within WACHS, pursuant to recommendation 12 of the JSCEOLC
 - the independent review, from a patient's perspective, of the models of palliative care in Western Australia, being undertaken by Professor Samar Aoun from the Perron Institute for Neurological and Translational Science, pursuant to recommendation 9 of the JSCEOLC
 - the increased use of telehealth, including the establishment of the WACHS 'telehealth hub'
 - the availability in regional areas of domiciliary homecare packages to patients not able to obtain assistance from other sources.
- 10.2 Progress was noted to varying degrees in the implementation of the recommendations of the JSCEOLC.
- 10.3 The Committee noted the following areas in which further progress is required:
- care coordination between palliative care services (for example, in the transition from hospital to home-based care, the transition between metropolitan and regional services, and the transition from RACFs to hospital settings)
 - development of a palliative care navigator model
 - continuation of the roll-out of telepalliative care services in regional and remote areas, and an evaluation of the benefits of the increased use of telepalliative care in metropolitan areas
 - support for informal carers of community specialist palliative care patients, including the increased availability of respite care
 - availability of domiciliary homecare services for community specialist palliative care patients in the metropolitan area aged under 65
 - funding and support for volunteer services providing support and training of volunteers involved in the delivery of palliative care services, including through the Compassionate Communities model
 - change in the referral culture to facilitate earlier and more proactive referrals to specialist palliative care
 - access to after-hours community specialist palliative care services in regional and remote areas
 - the provision of specialist palliative care in RACFs
 - availability of consultation-liaison psychiatry for palliative care patients

- increasing the palliative care workforce and the availability of education and training in palliative care
 - culturally secure palliative care for Aboriginal people
 - equity of access to specialist palliative care in parts of the Perth metropolitan area, including the south metropolitan region
 - completion and ongoing funding of the proposed new children’s hospice
 - improving access to palliative care for condition-specific and other diverse groups.
- 10.4 In relation to palliative care in regional and remote areas, as noted above the Committee found that substantial progress has been made in the expansion of the WACHS multidisciplinary specialist palliative care teams, and in the improved governance structures within WACHS pursuant to recommendation 12 of the JSCEOLC. However, the Committee was not able to evaluate the progress of implementation of recommendation 13, that the Minister for Health ensure regional palliative care be adequately funded to meet demand, without a more detailed assessment of demand for palliative care services in regional and remote areas.
- 10.5 In its consideration of term of reference (d), ‘the progress on ensuring greater equity of access to palliative care services between metropolitan and regional areas’, the Committee found that there had been substantial progress, but noted evidence that community palliative care services in particular remain less accessible to patients living in regional and remote areas.
- 10.6 Whilst commending the work of WACHS in expanding its regional palliative care services and development of the telehealth hub, the Committee concluded that further expansion of these services is necessary to both meet existing and growing demand, and to ensure greater equity of access between metropolitan and regional areas.

RECOMMENDATION 25

A Committee in the 41st Parliament monitor the progress of recommendations arising from this inquiry.



Mr Chris Tallentire MLA
Chair

APPENDIX 1

STAKEHOLDERS, SUBMISSIONS RECEIVED AND PUBLIC HEARINGS

Stakeholders contacted

Number	To
1.	Department of Health
2.	WA Cancer and Palliative Care Network, Department of Health
3.	WA Country Health Service, Department of Health
4.	Office of the Chief Health Officer, Department of Health
5.	Palliative Care Australia
6.	Palliative Care WA
7.	Silver Chain Group
8.	Metropolitan Palliative Care Consultancy Service
9.	WA Paediatric Palliative Care Service
10.	Home Instead Senior Care - Perth
11.	Sir Charles Gairdner Hospital Palliative Care Service
12.	Australian and New Zealand Society of Palliative Medicine
13.	Australian Medical Association
14.	Australian Medical Association (WA) Inc.
15.	Royal Australian College of General Practitioners WA
16.	WA Primary Health Alliance
17.	Royal Australian and New Zealand College of Psychiatrists
18.	Office of the Chief Psychiatrist of Western Australia
19.	Australian and New Zealand College of Anaesthetists
20.	Australian Nursing and Midwifery Federation
21.	Allied Health Professions Australia
22.	Australian Psychological Society
23.	Aboriginal Health Council of WA
24.	Aboriginal Legal Service WA
25.	South West Aboriginal Medical Service
26.	Kimberley Aboriginal Medical Services Ltd.
27.	Rural Health West
28.	Carers WA
29.	Australian Federation of Disability Organisations

Number	To
30.	People with Disabilities WA
31.	Council on the Ageing WA
32.	Office of the Public Advocate
33.	Health and Disability Services Complaints Office
34.	Cancer Council Western Australia
35.	Motor Neurone Disease Association of WA
36.	Huntington's WA
37.	Multiple Sclerosis WA
38.	Alzheimer's WA
39.	Dementia Australia
40.	Fiona Stanley Hospital Palliative Care Consultancy Service
41.	Perth Children's Hospital
42.	Palliative Care, Royal Perth Hospital
43.	Sir Charles Gairdner Hospital Osborne Park Health Care Group
44.	Armadale Health Service
45.	Osbourne Park Hospital
46.	Rockingham General Hospital
47.	Kalamunda District Community Hospital, Palliative Care Service
48.	Bentley Health Service
49.	Fremantle Hospital and Health Service
50.	Joondalup Health Campus
51.	Peel Health Campus
52.	St John of God Midland Public Private Hospital Palliative Care Service
53.	Hollywood Private Hospital
54.	St John of God Subiaco Hospital Palliative Care Service
55.	St John of God Murdoch Hospital Community Hospice
56.	St John of God Murdoch Hospital
57.	Bethesda Hospital Palliative Care Service
58.	Glengarry Hospital - Sandalwood Palliative Care Unit
59.	Albany Community Hospice
60.	St John of God Bunbury Hospital Palliative Care Unit (Granada)
61.	St John of God Geraldton Hospital Palliative Care Unit (St Raphael)
62.	Busselton Hospice Care Inc.
63.	St John of God Group

Number	To
64.	Western Australian Centre for Rural Health
65.	Faculty of Health and Medical Sciences, University of Western Australia
66.	School of Medicine, University of Notre Dame
67.	School of Health Professions, Murdoch University
68.	Faculty of Health Sciences, Curtin University
69.	School of Medical and Health Sciences, Edith Cowan University
70.	Australian Centre for Health Law Research
71.	Western Australia Local Government Association
72.	WA Department of Health, Older Adult Mental Health Sub Network
73.	Amana Living Aged Care
74.	Edward Collick Nursing Home
75.	Southern Cross Care (Victoria Park Nursing Home, Kalgoorlie)
76.	Leading Aged Services of Australia
77.	Juniper
78.	Brightwater Group
79.	Margaret Quirk, Co-convenor of the Parliamentary Friends of Palliative Care
80.	Regis Aged Care
81.	Aegis Aged Care
82.	Bupa Aged Care
83.	HenderCare Perth
84.	Southern Cross Care
85.	Bethanie Aged Care Homes
86.	Baptistcare
87.	WACHS Kimberley
88.	Broome Regional Health Campus
89.	Derby Fitzroy Valley Health Service, Derby Hospital
90.	WACHS Kimberley, Kununurra Hospital
91.	WACHS Pilbara
92.	WACHS East Pilbara, Hedland Health Campus
93.	WACHS West Pilbara, Karratha Health Campus
94.	WACHS West/Inland Pilbara, Newman Hospital
95.	WACHS Midwest
96.	Geraldton Regional Hospital
97.	WACHS Gascoyne, Carnarvon Hospital

Number	To
98.	WACHS Goldfields
99.	Kalgoorlie Health Campus
100.	Esperance Hospital
101.	WACHS Wheatbelt
102.	WACHS Western Wheatbelt, Northam Hospital
103.	Merredin Hospital
104.	WACHS Wheatbelt Southern, Narrogin Health Service
105.	WACHS South West
106.	Bunbury Hospital
107.	Wellington Health, Collie Health Service
108.	Busselton Health Campus
109.	Margaret River Hospital
110.	Warren District Health Services
111.	WACHS Great Southern
112.	Albany Health Campus
113.	WACHS Great Southern
114.	Goldfields Regional Palliative Care Service
115.	Great Southern Palliative Care Service
116.	Midwest Palliative Care Service
117.	Pilbara Palliative Care Service
118.	South West Palliative Care Service
119.	Wheatbealt Palliative Care Service
120.	Kimberley Palliative Care Service
121.	Commissioner for Children and Young People WA
122.	Spinifex Health Service
123.	Bega Garnbirringu Health Service
124.	Ngangganawili Aboriginal Health Service
125.	South West Aboriginal Medical Service
126.	Moorditj Koort Aboriginal Corporation
127.	Derbarl Yerrigan Health Service Aboriginal Corporation
128.	Geraldton Regional Aboriginal Medical Service
129.	Carnarvon Medical Service Aboriginal Corporation
130.	Puntukurnu Aboriginal Medical Service
131.	Mawarnkarra Health Service Aboriginal Corporation

Number	To
132.	Wirraka Maya Aboriginal Health Service
133.	Bidyadanga Aboriginal Community Health Service
134.	Broome Regional Aboriginal Medical Service
135.	Milliya Rumurra Aboriginal Corporation
136.	Kimberley Aboriginal Medical Services Council
137.	Nirrumbuk Aboriginal Corporation
138.	Beagle Bay Community Health Service
139.	Derby Aboriginal Health Service
140.	Nindillingarri Cultural Health Service
141.	Yura Yungi Aboriginal Medical Service
142.	Ngnowar Aerwah Aboriginal Corporation
143.	Ord Valley Aboriginal Health Service
144.	Great Southern Aboriginal Health Service
145.	Ngaanyatjarra Health Service
146.	National LGBTI Health Alliance
147.	GLBTI Rights in Ageing Inc.
148.	Ethnic Communities Council of WA
149.	Office of Multicultural Interests (DLGSCI)
150.	Western Australia Multicultural Association
151.	Country Women's Association
152.	National Seniors Australia
153.	Aged and Community Services Australia
154.	Ramsay Australia Health Care
155.	Fiona Stanley Hospital
156.	Pilbara Multicultural Association
157.	Midwest Multicultural Association
158.	Bunbury Multicultural Group
159.	Fiona Stanley Hospital
160.	Health Consumers' Council (WA) Inc.
161.	Developmental Disability WA
162.	Hannah's House
163.	Langford Aboriginal Association
164.	Central Desert Native Title Services
165.	Ngaanyatjarra Council

Number	To
166.	Goldfields Land and Sea Council
167.	South West Aboriginal Land and Sea Council
168.	Aboriginal Family Law Services
169.	Aboriginal Advisory Council of WA
170.	Kimberley Land Council
171.	Yamatji Marlpa Aboriginal Corporation
172.	Native Title Services Goldfields
173.	Wungening Aboriginal Corporation – METRO
174.	Yorgum Aboriginal Corporation – METRO
175.	Noongar Family Safety and Well-being Council
176.	Pilbara Aboriginal Voice
177.	Midwest Aboriginal Organisations Alliance
178.	Ngnowar Aerwah Aboriginal Corporation

Submissions received

Number	From
1.	Private citizen
2.	Dr Mark Monaghan
3.	L J Goody Bioethics Centre, Catholic Archdiocese of Perth
4.	Dementia Australia
5.	FamilyVoice Australia
6.	Child and Adolescent Health Services (CAHS)
7.	WA Catholic Sector Steering Committee
8.	Dr Derek Eng
9.	Private citizen
10.	Motor Neurone Disease Association of WA
11.	St John of God Health Care
12.	Busselton Hospice Care Inc.
13.	Royal Australian College of General Practitioners (RACGP)
14.	Catholic Homes Incorporated
15.	Amana Living Incorporated
16.	Dr David Joske
17.	Aged and Community Services Australia (ACSA)
18.	Private citizen

Number	From
19.	University of Notre Dame Australia
20.	Private citizen
21.	Royal Australian and New Zealand College of Psychiatrists
22.	Private citizen
23.	Department of Health
24.	TPG Aged Care
25.	South Metropolitan Health Service
26.	Health Consumers' Council (WA) Inc.
27.	Albany Community Hospice
28.	Liam James McLaughlin Memorial Hospice Ltd.
29.	Chittering Health Advisory Group
30.	Janet Wallace
31.	Hall & Prior Health & Aged Care Group
32.	Office of Multicultural Interests
33.	WA Country Health Service
34.	Bethesda Health Care
35.	Developmental Disability WA
36.	Palliative Care WA
37.	The Australian & New Zealand Society of Palliative Medicine
38.	Aboriginal Health Council of Western Australia
39.	East Pilbara Independence Support
40.	WA Primary Health Alliance
41.	Australian Medical Association (WA)
42.	Silver Chain

Public hearings

Number	From
15 July 2020	<p>WA Health</p> <ul style="list-style-type: none"> • Department of Health <ul style="list-style-type: none"> ○ Angela Kelly, Acting Director General ○ Amanda Bolleter, Project Director, End of Life Care • WA Country Health Service <ul style="list-style-type: none"> ○ Margaret Denton, Acting Chief Executive ○ Marie Norris, Acting Executive Director, Nursing and Midwifery • WA Cancer and Palliative Care Network <ul style="list-style-type: none"> ○ Associate Professor Alison Parr, Clinical Lead, Palliative Care
30 July 2020	<ul style="list-style-type: none"> • The Royal Australian and New Zealand College of Psychiatrists <ul style="list-style-type: none"> ○ Dr Michael Verheggen, Psychiatrist, WA Branch Committee representative • Dr Derek Eng, Palliative Care Physician; Member, Australian and New Zealand Society of Palliative Medicine (representing) • Dr David Joske, Clinical Haematologist and Medical Co-Director, Sir Charles Gairdner Hospital; Founder, Solaris Cancer Care • Health Consumers' Council <ul style="list-style-type: none"> ○ Pip Brennan, Executive Director ○ Clare Mullen, Engagement Manager • WA Primary Health Alliance <ul style="list-style-type: none"> ○ Christine Kane, General Manager, Strategy and Engagement • Bethesda Health Care <ul style="list-style-type: none"> ○ Will Hallahan, Project Officer, Palliative Care ○ Dr Paula Moffat, Medical Director, Palliative Care

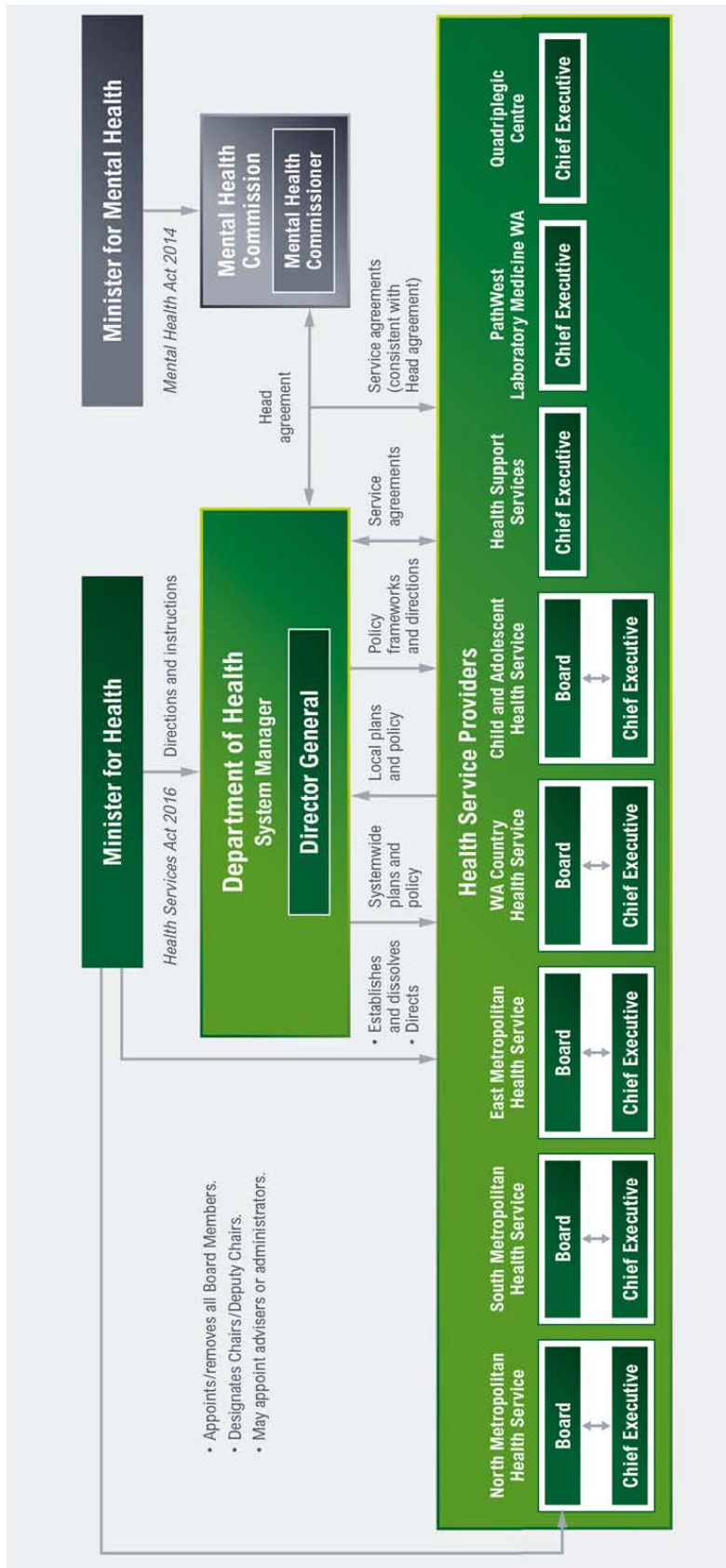
Number	From
31 July 2020	<ul style="list-style-type: none"> • Palliative Care (WA) <ul style="list-style-type: none"> ○ Lana Glogowski, Chief Executive Officer ○ Dr Elissa Campbell, President ○ Dr Margherita Nicoletti, Consultant • Busselton Hospice Care Incorporated <ul style="list-style-type: none"> ○ Rosie Brown, Chief Executive Officer ○ Jennifer Monson, Chairperson • Australian Medical Association (WA) <ul style="list-style-type: none"> ○ Dr Andrew Miller, President • Silver Chain Group <ul style="list-style-type: none"> ○ Tish Morrison, Director of Clinical Operations, Palliative and End of Life Care. • The Royal Australian College of General Practitioners <ul style="list-style-type: none"> ○ Dr Sean Stevens, Chairperson ○ Dr Barry Fatovich, Hospice Doctor/General Practitioner
10 August 2020	<ul style="list-style-type: none"> • Aged and Community Services Australia <ul style="list-style-type: none"> ○ Trevor Lovelle, Executive Director ○ Irene Mooney, Chief Executive Officer, MYVISTA ○ Amanda Crook, General Manager, Care Services, Coolibah Care • Hall & Prior Residential Health and Aged Care Group <ul style="list-style-type: none"> ○ Graeme Prior, Chief Executive Officer ○ Penny Fielding, Director, Social and Community Impact ○ Dr Kristi Holloway, Executive Manager, Clarence Estate • East Pilbara Independent Support <ul style="list-style-type: none"> ○ Vicki Kershaw, Chief Executive Officer ○ Juan Andrade, Corporate Services Manager
31 August 2020	<ul style="list-style-type: none"> • Dr Mark Monaghan, Emergency Physician, Director of Medical Services, South West Coast, WA Country Health Service, Busselton Health Campus

Number	From
03 September 2020	<ul style="list-style-type: none"> • Chittering Health Advisory Group <ul style="list-style-type: none"> ○ Alison Barnard, Chairperson • Wheatbelt Palliative Care Service <ul style="list-style-type: none"> ○ Brett Hayes, Wheatbelt Palliative Care Manager • Ord Valley Aboriginal Health Service <ul style="list-style-type: none"> ○ Michele Harvey, Nurse Practitioner - Chronic Disease • Aboriginal Health Council WA <ul style="list-style-type: none"> ○ Shirley Newell, Executive Manager, Policy & Public Health • Derby Aboriginal Health Service <ul style="list-style-type: none"> ○ Christine Waller, Senior Manager, Population Health Programs and Remote Areas • Kimberley Aboriginal Medical Services <ul style="list-style-type: none"> ○ Dr Lorraine Anderson, Medical Director ○ Jenny Bedford, Executive Manager
14 September 2020	<ul style="list-style-type: none"> • Midwest Palliative Care Service <ul style="list-style-type: none"> ○ Robyn Ellis, Clinical Nurse Specialist ○ Nathalie Pass, Acting Coordinator of Nursing, Surgical Services, Ambulatory Care ○ Leanne Sice, Acting Regional Director of Nursing and Midwifery • Goldfields Regional Palliative Care Service <ul style="list-style-type: none"> ○ Carla Jones, Acting Regional Director of Nursing and Midwifery ○ Gayle Paterson, Goldfields Regional Palliative Care Manager, Kalgoorlie Health Campus

Number	From
18 September 2020	<p>WA Health</p> <ul style="list-style-type: none"> • Department of Health <ul style="list-style-type: none"> ○ Dr Duncan James Williamson, Assistant Director General, Clinical Excellence Division ○ Amanda Bolleter, Project Director, End of Life Care • WA Country Health Service <ul style="list-style-type: none"> ○ Jeffery Moffet, Chief Executive ○ Marie Norris, Acting Executive Director, Nursing and Midwifery ○ Associate Professor Kirsten Auret, Clinical Director, Palliative Care • WA Cancer and Palliative Care Network <ul style="list-style-type: none"> ○ Associate Professor Alison Parr, Clinical Lead, Palliative Care • North Metropolitan Health Service <ul style="list-style-type: none"> ○ Anthony Dolan, Chief Executive ○ Paola Morellini, Director, Clinical Planning

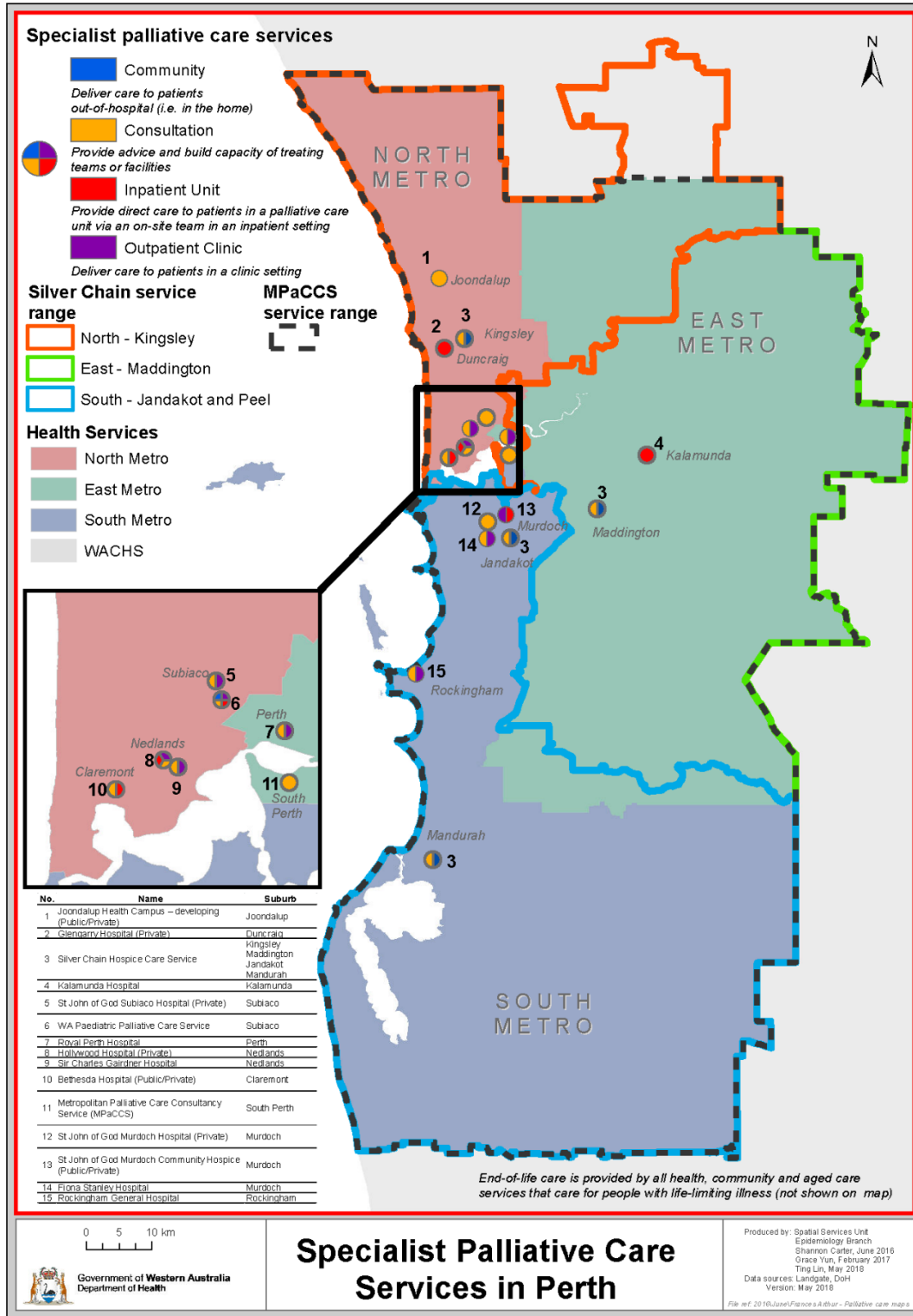
APPENDIX 2

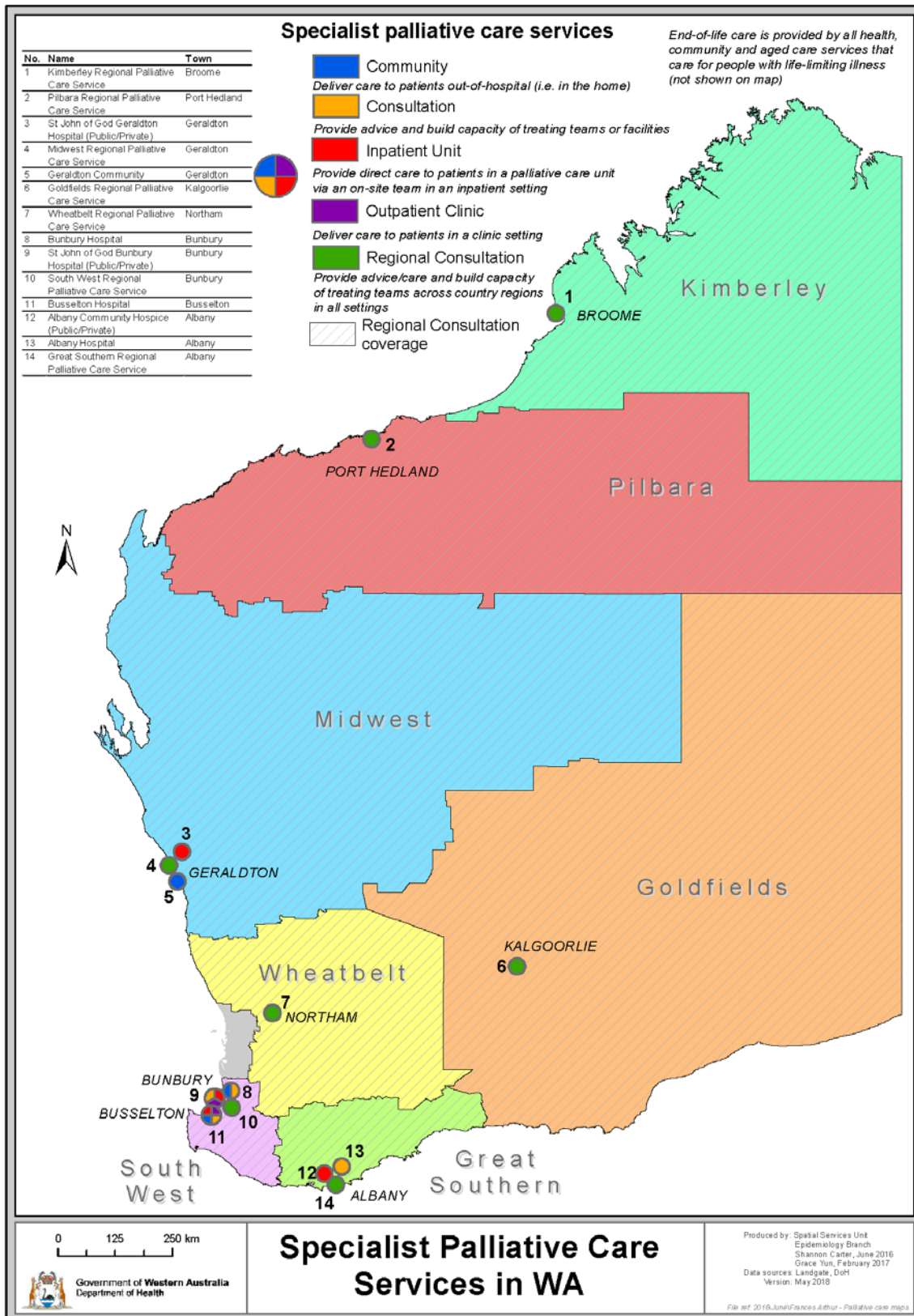
GOVERNANCE STRUCTURE OF WA HEALTH



APPENDIX 3

MAPS OF SPECIALIST PALLIATIVE CARE SERVICES





APPENDIX 4

THE END OF LIFE FRAMEWORK

Stages*		Triggers	Action	
1	<i>Would you be surprised if the patient died in the next 6-12 months?</i>	Advancing disease	<ul style="list-style-type: none"> Known advanced cancer or chronic disease Evidence of disease progression and/or symptoms Patient/family expresses concern about the future Would you be surprised if the patient died in the next 6-12 months? 	Consider: <ul style="list-style-type: none"> Advance Care Planning Palliative Care consultation
2	<i>Would you be surprised if the patient died this admission or in the next month?</i>	Increasing decline	As for Stage 1 plus: <ul style="list-style-type: none"> Increasing frailty Increasing symptom burden Increasing psychosocial support needs Not responding to treatment or non-adherence with treatment For hospital inpatients, would you be surprised if the patient died this admission? 	Consider: <ul style="list-style-type: none"> Referral to palliative care for ongoing care or palliative care consultation and/or shared care partnerships with palliative care
3	<i>Irreversible clinical deterioration, life expectancy one week or less</i>	Last days of life	<ul style="list-style-type: none"> Irreversible clinical deterioration Team decision of diagnosis of dying. 	Commence: <ul style="list-style-type: none"> Best practice care of the dying, e.g. <i>Care Plan for the Dying Person</i>
4		Death and bereavement	<ul style="list-style-type: none"> Death of patient 	Consider: <ul style="list-style-type: none"> Bereavement follow-up needs

* The stages are provided as a guide and are not intended to be prescriptive – each patient's circumstances will be different and care should be provided accordingly.

APPENDIX 5

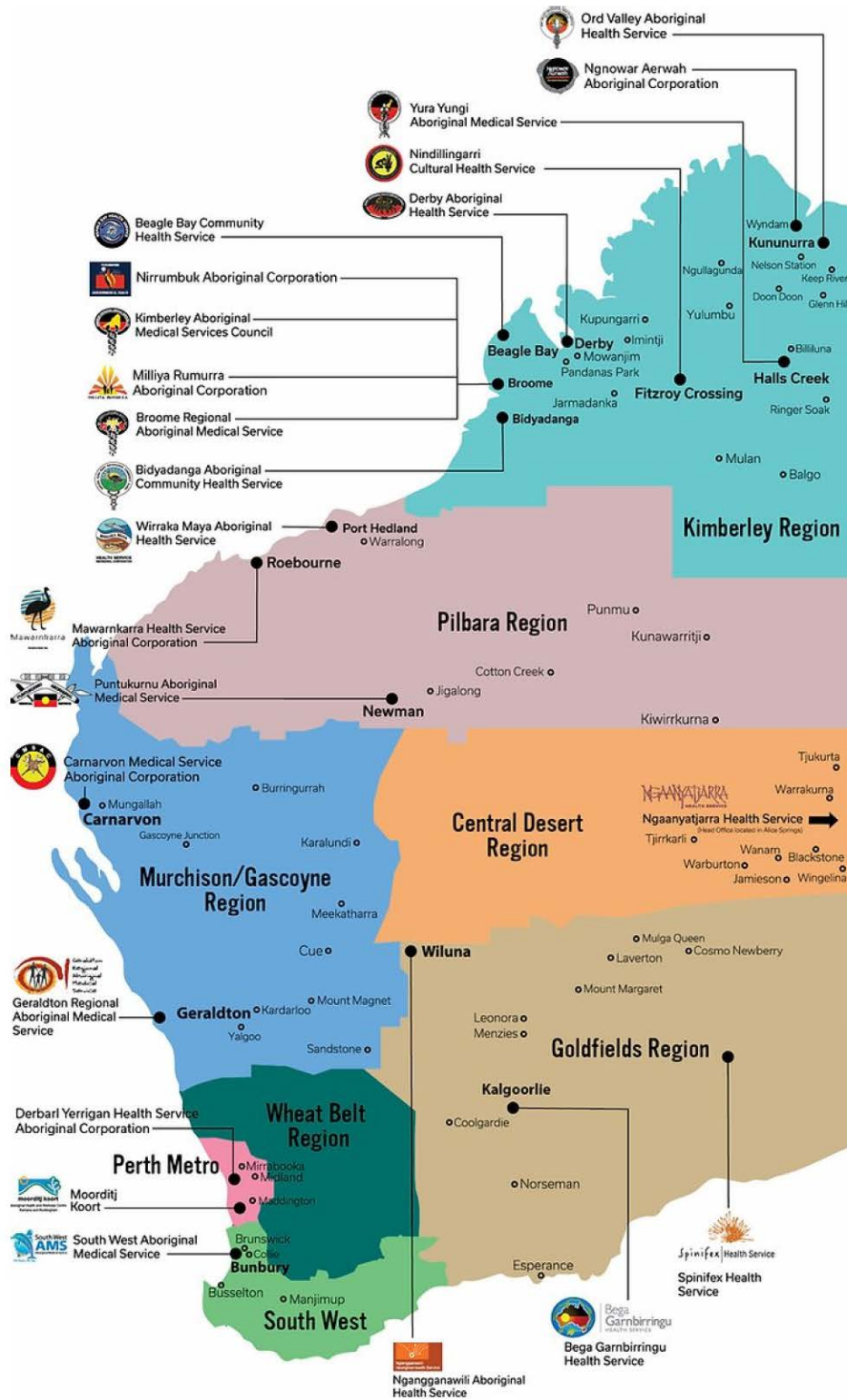
STRATEGIC ALIGNMENT TABLE FROM IMPLEMENTATION PLAN ONE

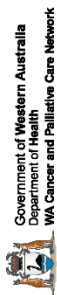
Strategic alignment of the priorities to the end-of-life and palliative care recommendations of the *My Life, My Choice* Report of the Joint Select Committee on End of Life choices

Priority	Strategic alignment to the <i>My Life, My Choice</i> Report recommendations
 Priority One: Care is accessible to everyone, everywhere	7, 8, 9, 10, 12, 13, 14
 Priority Two: Care is person-centred	9, 11.1, 11.2, 11.3, 11.4, 15, 16, 17.1, 17.2, 18
 Priority Three: Care is coordinated	7, 8, 10, 11.1, 11.2, 11.3, 11.4, 12, 13, 14, 15, 16, 17, 18
 Priority Four: Families and carers are supported	9, 11.1, 11.2, 11.4, 17
 Priority Five: All staff are prepared to care	11.1, 11.2, 11.3, 11.4, 15, 16, 17, 18
 Priority Five: The community is aware and able to care	9, 11.1, 11.2, 11.4, 17

APPENDIX 6

AHCWA MAP OF MEMBER LOCATIONS





Guide to Specialist Palliative Care Services

Admission criteria by service type			
Outpatient Clinic	Community	Consultation – Facilities*	Consultation – Hospital
Specialist advice required	Specialist advice and/or care at home required	Specialist advice required	Specialist care required
Patient is within catchment (for public services only)	Patient is within catchment	Patient is within catchment	Patient cannot be optimally managed in current environment
Able to attend clinic	Patient and carer have consented to care at home		
Patient has consented to referral	Patient and carer aware of referral and have understanding of palliative care	Patient and carer aware of referral and have understanding of palliative care	Patient and carer aware of referral and understanding of palliative care
Referral by doctor, nurse practitioner or palliative care service	Referral by doctor, nurse practitioner or palliative care service	Referral by doctor, nurse practitioner or nurse in consultation with GP	Referral by doctor, nurse practitioner or palliative care service
Services provided by admission type			
All services have links with and can refer to other Specialist Palliative Care Services			
Comprehensive assessment	Comprehensive assessment	Comprehensive assessment	Comprehensive assessment
Care planning and co-ordination	Care planning and co-ordination	Care planning and co-ordination	Care planning and co-ordination
Symptom management	Symptom management	Symptom management	Symptom management
Access to multidisciplinary team	Access to multidisciplinary team	Access to multidisciplinary team	Access to multidisciplinary team
Psychosocial support for patient and family	Psychosocial support for patient and family	Psychosocial support for patient and family	Psychosocial support for patient and family
Shared care with other care providers	Shared care with other care providers	Shared care with other care providers	Shared care with other care providers
	Access to equipment and resources		Care in specialised facility
	Practical support	Advisory/educational support to doctors, nursing and allied health care workers	Advisory/educational support to doctors, nursing and allied health care workers
	Terminal care	Terminal care	Terminal care
	Bereavement support	Bereavement support	Bereavement support

* Residential Care Facilities, Secondary Hospitals, Disability Service Facilities, Mental Health Services and Correctional Services.

APPENDIX 8

RECOMMENDATIONS 7–18 OF THE JOINT SELECT COMMITTEE ON END OF LIFE CHOICES

Chapter 3 'Palliative Care'

Recommendation 7 Page 67

The Minister for Health should facilitate the establishment of an inpatient specialist palliative care hospice providing publicly funded beds in the northern suburbs of Perth.

Recommendation 8 Page 68

The Minister for Health should ensure that community palliative care providers, such as Silver Chain, are adequately funded to provide for growing demand.

Recommendation 9 Page 74

WA Health should conduct an independent review, from a patient's perspective, of the three models of palliative care in Western Australia: inpatient, consultative and community. The review should examine the benefits and risks of each model and the accessibility of each across the state as well as the admission criteria for hospice care (see Finding 18).

Recommendation 10 Page 78

WA Health should implement a process to determine the unmet demand for palliative care and establish an ongoing process to measure the delivery of palliative care services with the aim of making those services available to more Western Australians.

Recommendation 11 Page 79

To improve understanding of palliative care in Western Australia, WA Health should:

- establish a consistent definition of palliative care to be adopted by all health professionals;
- provide comprehensive, accessible and practical information and education services about palliative care to health professionals and the community;
- encourage knowledge sharing by palliative care specialists with their generalist colleagues; and
- establish a palliative care information and community hotline.

Recommendation 12 Page 83

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 Page 83

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

Recommendation 14 Page 91

Once a consistent definition of palliative care has been established by WA Health in accordance with Recommendation 11, the Minister for Health should appoint an independent reviewer to audit:

- The level of palliative care activity actually provided in Western Australia's hospitals and compare it against the level of recorded palliative care activity.
- The actual spend by WA Health on palliative care on a year-by-year and like-for-like basis, across all aspects of palliative care provision, including community service providers, area health services (including WA Country Health Services) and delineating between inpatient, consultancy and community care.

Chapter 4 'Lawful options at end of life'

Recommendation 15 Page 113

WA Health should provide ongoing professional development for all health professionals – beyond undergraduate training – about the right of a patient to refuse medical treatment. WA Health should also specifically amend the Consent to Treatment Policy to provide comprehensive information in relation to a competent patient's absolute right to refuse medical treatment.

Recommendation 16 Page 119

WA Health should provide ongoing professional development – beyond undergraduate training – for all health professionals regarding the absolute right of a competent patient to refuse food and water. Training should also include those working in aged care.

Recommendation 17 Page 122

WA Health should provide ongoing professional development – beyond undergraduate training – for health professionals about the transition from curative to non-curative end of life care and effective discussions with patients and families about futile treatments. WA Health should consider how it might effectively educate the community about end of life decision-making, and implement appropriate health promotion in this area.

Recommendation 18 Page 130

WA Health should provide specific guidelines on the use of terminal sedation by health professionals for patients at the end of life. These guidelines should include an agreed name and definition of the treatment.

As per any other medical treatment, the requirement for informed consent must be clear.

The treatment must be specifically noted in the medical record as 'terminal sedation'.

GLOSSARY

Term	Definition
ACCHS	Aboriginal community-controlled health service
ACFI	Aged Care Funding Instrument
ACP	Advance care planning
ACSA	Aged and Community Services Australia
AHCWA	Aboriginal Health Council of Western Australia
AHD	Advance health directive as defined in section 3 of the <i>Guardianship and Administration Act 1990</i>
AIHW	Australian Institute of Health and Welfare
AMA(WA)	Australian Medical Association (WA)
ANZSPM	Australian and New Zealand Society of Palliative Medicine
Bethesda	Bethesda Healthcare
BHCI	Busselton Hospice Care Inc.
CAHS	Child and Adolescent Health Service
Committee	Joint Select Committee on Palliative Care
Current State Report	Department of Health, <i>WA Health End-of-Life and Palliative Care – Current state of WA palliative care service provision and key findings: Working paper, June 2020</i>
Department of Health	Western Australian Department of Health
End-of-life	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 approaching end-of-life will be considered likely to die during the next 12 months
End-of-life care	End-of-life care is care needed for people who are likely to die in the next 12 months due to progressive, advanced or incurable illness, frailty or old age
End-of-Life Framework	Department of Health, <i>The End-of-Life Framework, 2015</i> , see Appendix 4
End-of-Life Framework document	Department of Health, <i>The End-of-Life Framework: A statewide model for the provision of comprehensive, coordinated care at end-of-life in Western Australia, 2015</i>
EMHS	East Metropolitan Health Service

Term	Definition
ePalCIS	The Department of Health's Electronic Palliative Care Information System
EPIS	East Pilbara Independence Support Incorporated
FTE	Full-time equivalent
GP	General practitioner
Hall & Prior	Hall & Prior Health & Aged Care Group
HCC	Health Consumers' Council (WA)
HSP	Health Service Provider
Implementation Plan One	Department of Health, WA Cancer and Palliative Care Network, <i>WA End-of-Life and Palliative Care Strategy 2018–2028 Implementation Plan One 2020–2022</i> , 2020
JSCEOLC	Joint Select Committee on End of Life Choices
JSCEOLC Minority Report	Minority Report by Hon NP Goiran MLC for the Joint Select Committee on End of Life Choices submitted under Legislative Assembly Standing Order 274, <i>The safe approach to End of Life Choices: Licence to Care not Licence to Kill</i> , August 2018
JSCEOLC Report	Joint Select Committee on End of Life Choices, report 1, <i>My Life, My Choice</i> , 23 August 2018
Life-limiting illness	An illness or condition that can be reasonably expected to cause the death of a person within the foreseeable future, inclusive of both malignant and non-malignant illness
MBS	Medicare Benefits Schedule
MND Association	Motor Neurone Disease Association of WA Inc
MPaCCS	Metropolitan Palliative Care Consultancy Service
National Partnership Agreement	Commonwealth of Australia & Government of Western Australia, <i>Project Agreement for Comprehensive Palliative Care in Aged Care</i> , October 2019
National Standards	Palliative Care Australia, <i>National Palliative Care Standards</i> , 5 th edition, 2018
National Strategy	Australian Department of Health, <i>National Palliative Care Strategy 2018</i> , December 2018
NMHS	North Metropolitan Health Service
Palliative Care	An approach that improves the quality of life of individuals, including their family/carer, facing problems associated with life-threatening illness/condition, through the prevention and relief of suffering
PaSCE	Palliative and Supportive Care Education

Term	Definition
PCOC	Palliative Care Outcomes Collaboration
PCWA	Palliative Care Western Australia
Primary care	The care a person receives at first contact with the healthcare system, usually involving coordination and continuity of care over time
RACF	Residential aged care facility
RACGP	Royal Australian College of General Practitioners
Secondary care	Care provided by a specialist or facility upon referral by a primary care physician
Service Development Guidelines	Palliative Care Australia, <i>Service Development Guidelines</i> , January 2018
Silver Chain	Silver Chain Group
SMHS	South Metropolitan Health Service
Specialist Palliative Care	Care undertaken by a professional palliative care team or service with recognised qualifications or accredited training in palliative care
Sustainable Health Review	Department of Health, <i>Sustainable Health Review: Final Report to the Western Australian Government</i> , 2019
Terminal care	Care of the dying in the last days or hours of life
Tertiary care	Care provided by a facility that includes highly-trained specialists and often advanced technology
WA Health	Collectively the Department of Health, NMHS, SMHS, EMHS, WACHS, Health Support Services, PathWest and the Quadriplegic Centre
WA Strategy	Department of Health, WA Cancer and Palliative Care Network, <i>WA End-of-Life and Palliative Care Strategy 2018–2028</i> , 2018
WACHS	WA Country Health Service
WAPHA	WA Primary Health Alliance
webPAS	The Department of Health's web-based Patient Administration System
WHO	World Health Organization


Joint Select Committee on Palliative Care in Western Australia

Date first appointed:

28 May 2020

Terms of Reference:

On Thursday 28 May 2020, the Legislative Council ordered that:

- (1) A joint select committee of the Legislative Assembly and Legislative Council into palliative care in Western Australia be established
 - (2) That the joint select committee inquire into and report on —
 - a) the progress in relation to palliative care, in particular implementation of recommendations of the Joint Select Committee into End of Life Choices;
 - b) the delivery of the 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 services between metropolitan and regional areas.
 - (3) That the joint select committee consist of six members, of whom —
 - a) three will be members of the Assembly; and
 - b) three will be members of the Council.
 - (4) That the standing orders of the Legislative Council relating to standing and select committees will be followed as far as they can be applied.
 - (5) That the joint select committee report to both houses by 19 November 2020.
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