ANZSPM

The Australian & New Zealand Society of Palliative Medicine Inc. ABN 54 931 717 498

Portfolio Committee No. 2 – Health
NSW Legislative Council
Parliament House, SYDNEY NSW 2000

15 January 2021

Dear Committee,

ANZSPM Submission to the Inquiry into Health Outcomes and Access to Health and Hospital Services in Rural, Regional and Remote New South Wales

The Australian and New Zealand Society of Palliative Medicine (ANZSPM) appreciates the opportunity to provide the attached submission to the Portfolio Committee No. 2 – Health regarding its *Inquiry into Health Outcomes and Access to Health and Hospital Services in Rural, Regional and Remote New South Wales*.

ANZSPM is the specialty medical society that represents medical practitioners who provide care for people with a life limiting illness in Australia and New Zealand. We aim to improve health outcomes by working with and influencing the system and community around the person with a life-limiting illness. ANZSPM facilitates professional development, support, and advocacy for its members across Australia and New Zealand to promote best practice in palliative medicine.

Any inquiries in relation to this submission can be directed to:
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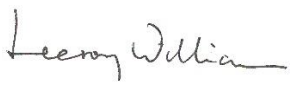
We would be happy to meet with members of the Committee to provide further information in support of this Inquiry.

Yours sincerely,



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ANZSPM Submission:

Inquiry Into Health Outcomes And Access To Hospital Services In Rural, Regional And Remote NSW

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1. Introduction

1.1 This submission is made by the Australian and New Zealand Society of Palliative Medicine (ANZSPM), the specialty medical society for medical practitioners who provide care for people with a life-limiting illness in Australia and New Zealand. ANZSPM represents practitioners of palliative medicine across Australia and New Zealand, with around 22% of our members based in New South Wales.

1.2 ANZSPM appreciates the opportunity to make this submission to the Portfolio Committee No. 2 – Health (the Committee) with respect to its *Inquiry Into Health Outcomes And Access To Hospital Services In Rural, Regional And Remote NSW* (the Inquiry).

1.3 In this submission, we firstly provide background information on ANZSPM, then comment on the Inquiry's terms of reference, in particular with respect to end-of-life and palliative care.

1.4 We would welcome the opportunity to meet with the Committee to provide additional information that may be of assistance with the Inquiry.

2. Executive Summary

2.1 The rural population is aging at a faster rate than the metropolitan population, which contributes to a higher total disease burden rate. Rural and remote patients are more likely to face barriers in accessing GPs and specialists, and lower attendance rates and participations in health screenings may also be leading to poorer health outcomes in these areas. In terms of the provision of palliative and end-of-life care, these trends can increase the burden on under-resourced residential aged care and palliative care services in rural and remote areas.

2.2 The provision of palliative care in rural and remote NSW is variable. In some areas, palliative care is mostly provided by GPs, community and palliative care nurses, and residential aged care staff. Other areas have more established specialist palliative care services, and some operate with a combination of specialist and generalist services. These varied combinations of health professionals and services create disparites in access and quality of health services for rural and remote patients. It also means that it is difficult to determine exactly who delivers palliative care in rural and remote NSW.

2.3 In areas without specialist palliative care services, access and quality of palliative care is often determined by the interest and initiative of General Practitioners. While it is clear that more specialists are needed in these areas, there still remain no substantial incentives for Staff Specialists to move to and work in rural and remote settings.

2.4 There are some positive features to palliative care provision in rural and remote settings when compared to metropolitan areas. Local hospitals and local health professionals offer a sense of familiarity and community for many patients. However, this sense of community and continuity of care is being threatened with the loss of older GPs, many of whom are being replaced with fly-in/fly-out doctors.

3. About ANZSPM

3.1 ANZSPM is a not-for-profit specialist medical society for medical practitioners who provide care for people with a life-limiting illness. ANZSPM aims to improve health outcomes by working with and influencing the system and community around the person with a life-limiting illness.

3.2 ANZSPM facilitates professional development, support and advocacy for its members across Australia and New Zealand to promote best practice in palliative medicine.

3.3 ANZSPM promotes the discipline and practice of Palliative Medicine in order to improve the quality of care for patients with palliative diagnoses and support their families.

3.4 ANZSPM is overseen by a Council of members, which includes representation from Australia and New Zealand and also from the Royal Australasian College of Physicians' Australasian Chapter of Palliative Medicine. ANZSPM's day-to-day operations are managed by a small team of staff based in Canberra ACT.

3.5 Our members include palliative medicine specialists, doctors training in the specialty of Palliative Medicine, General Practitioners and doctors who are specialists in other disciplines with an interest in palliative medicine such as oncologists, haematologists, intensivists, psychiatrists and geriatricians. ANZSPM currently has 532 members, including 115 members based in New South Wales.

3.6 Given the above, ANZSPM is well placed to comment on health outcomes related to palliative care in rural, regional, and remote NSW.

4. ANZSPM Comments on the Terms of Reference

4.1 We address in this part each of the terms of reference, insofar as it is relevant to ANZSPM's role as the peak body representing practitioners of palliative medicine in Australia and New Zealand.

A. Health outcomes for people living in rural, regional and remote NSW

4.2 The rural population is aging at a faster rate than the metropolitan population due to young people moving to cities and older people moving to rural and remote areas post-retirement. The requirement for palliative care in any particular area reflects the burden of disease of the population. In 2015, the total disease burden rate in remote and very remote areas was 1.4 times higher than in major cities[1].

4.3 In 2016, people in remote areas were more likely to report barriers to accessing GPs and specialists[2]. These barriers may contribute to lower participation rates in health screening and higher rates of potentially avoidable deaths. In 2015-2017, life expectancy for both males and

[1] Australian Institute of Health and Welfare 2019. Rural & remote health. Cat. no. PHE 255. Canberra: AIHW. Viewed 21 December 2020 2020, https://www.aihw.gov.au/reports/rural-remote-australians/rural-remote-health
[2] Ibid.

females decreased as remoteness increased[3]. These demographic trends can increase the burden on under-resourced residential aged care and palliative care services in rural and remote areas.

4.4 Infants, children, and adolescents are similarly affected to adults in rural and remote settings, and impoving palliative care services and support in these areas will similarly improve the situation of this population.

4.5 The Aboriginal population is often higher in rural and remote locations. The cultural needs of Aboriginal patients and their families need to be considered by those providing palliative care and bereavement care services. These considerations can include providing care on country, supporting dying on country, involving Aboriginal Liaison Officers, and facilitating Sorry Business and Smoking Ceremonies. It is important that palliative care services in rural and remote locations have the ability to fulfil these cultural wishes.

B. A comparison of outcomes for patients living in rural, regional and remote NSW compared to other local health districts across metropolitan NSW

4.6 A health outcome for patients living in rural, regional and remote NSW includes that of a "good death" or "safe death"[4]. This could describe a death in the home (including residential aged care), in a regional or district palliative care bed (hospice), in a regional or district public hospital, or in a regional private hospital.

4.7 Dying in one's preferred place of death has been used as a quality marker, with an in-hospital death often seen as a poor outcome. While rural and remote residents may initially indicate that home is their preferred place of death, this is often unachievable for those living out of town. Unlike large metropolitan tertiary hospitals however, the local rural hospital is often seen as a safe and familiar place, and providing that residents die within their community, a hospital death is often not seen as a 'bad' outcome.

4.8 The view of rural hospitals as safe, familiar places unfortunately may change as older GPs are replaced with fly-in/fly-out GPs (see response to term J). The Inquiry needs to be careful in determining how they will measure the quality of palliative care in rural, regional, and remote areas. Place of death is not the only outcome measure and is also not necessarily a reliable outcome measure.

C. Access to health and hospital services in rural, regional and remote NSW including service availability, barriers to access and quality of services

4.9 Australian Institute of Health and Welfare (AIHW) data indicate that people living in remote and very remote areas generally have poorer access to health services, including medical imaging, than people in regional areas and major cities[5]. They may need to travel longer distances to access health services. They also may have poorer health literacy and educational levels, which can also become barriers to service access.

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[3] Australian Institute of Health and Welfare 2019. Rural & remote health. Cat. no. PHE 255. Canberra: AIHW. Viewed 21 December 2020 2020, https://www.aihw.gov.au/reports/rural-remote-australians/rural-remote-health

[4] Rainsford S, Phillips CB, Glasgow NJ, MacLeod RD, Wiles RB. The 'safe death': An ethnographic study exploring the perspectives of rural palliative care patients and family caregivers. *Palliative Medicine* 2018; 32(10):1575-1583. DOI: 10.1177/0269216318800613

[5] Australian Institute of Health and Welfare 2019. Rural & remote health. Cat. no. PHE 255. Canberra: AIHW. Viewed 21 December 2020 2020, https://www.aihw.gov.au/reports/rural-remote-australians/rural-remote-health

4.10 In rural and remote areas, provision of 24/7 on-call palliative care is challenging. Where available, palliative care nurses are either supported by local specialists (who are often sole practitioners), local non-specialists, or remote clinicians via an afterhours number. Remote clinicians do not know the patient and often lack an understanding of their location.

4.11 Patients in rural and remote settings will generally have reduced access to GPs, nurses, palliative care beds, home equipment, and allied health professionals such as counsellors and psychologists.

4.12 GPs and private specialists are not generally provided reimbursement for travel to home visits, which makes home visits far less accessible for rural and remote patients.

4.13 Reliable Wi-Fi is essential for both health care professionals and patients. Poor internet access can therefore become a further barrier to access and quality of services.

4.14 Contrary to all other NSW Health disciplines and other rural doctors, Staff Specialists are offered no incentives to live and work in rural and remote locations. This means that incentives such as rural loading, additional annual leave, and the GP Rural Incentive Payment (GPRIP Payment) are unavailable. In addition, Staff Specialist Training Education and Study Leave (TESL) features no additional weighting in budget allocation or leave allowance to factor in the additional costs and travel time associated with rural and remote locations.

D. Patient experience, wait-times and quality of care in rural, regional and remote NSW and how it compares to metropolitan NSW

4.15 In relation to palliative care provision, there is a need for data that compares patient experience and quality of care between rural, regional and remote NSW and metropolitan NSW.

E. An analysis of the planning systems and projections that are used by NSW Health in determining the provision of health services that are to be made available to meet the needs of residents living in rural, regional and remote NSW

4.16 ANZSPM is not in a position to contribute to this term of reference but considers the analysis to be an important one for policy and planning purposes.

F. An analysis of the capital and recurrent health expenditure in rural, regional and remote NSW in comparison to population growth and relative to metropolitan NSW

4.17 ANZSPM is not in a position to contribute to this term of reference but considers the analysis to be an important one for policy and planning purposes.

G. An examination of the staffing challenges and allocations that exist in rural, regional and remote NSW hospitals and the current strategies and initiatives that NSW Health is undertaking to address them

4.18 In relation to palliative medicine in rural and remote communities, it is not clear who is providing palliative medicine, or what qualifications they possess. Whilst this knowledge about staffing likely exists at the local level, having access to this information at a health systems level is needed to facilitate effective workforce planning.

4.19 ANZSPM understands that there are a number of unfilled palliative medicine positions across NSW and the rest of Australia.

4.20 The national quota for FTE palliative medicine specialists/100,000 population may need to be higher in rural and remote areas as more time is needed for travelling between patients.

4.21 To address the vacancies, some Local Health Districts have contracted metropolitan services to provide monthly face-to-face consults, with telehealth consults between visits. More data should be collected from patients and families to explore their satisfaction with these services.

H. The current and future provision of ambulance services in rural, regional and remote NSW

4.22 Whilst the NSW Ambulance Authorised Palliative Care Plan is a strong concept, there remain practical issues with rollout. It has been reported that not all ambulance officers are able to access and make reference to the individual patient's Plan when attending on callout. The familiarity of Paramedic staff with the ambulance care plans is also highly variable.

4.23 There are often substantial delays in having completed plans 'authorised' (i.e. with a TRIM number) by NSW ambulance. Months of delays mean that some patients die before having their plan authorised. This magnitude of delay has not been unusual through 2020, and the consequences of this are problematic. In some cases, ambulance officers have refused to follow a plan due to pending authorisation, even when a copy has been left in the house with the patient. In at least one case, this has led to the patient being subject to inappropriate resuscitative efforts. There have also been several instances of paramedics refusing to administer medications prescribed on the plan.

4.24 ANZSPM understands that NSW Ambulance is working on processes for ambulance officers to access a patient's MyHealthRecord.

4.25 More work is required to encourage GPs to complete an Authorised Palliative Care Plan with their patients, however the issues noted above would need to be resolved as a priority.

I. The access and availability of oncology treatment in rural, regional and remote NSW

4.26 ANZSPM does not have any comment on this term of reference.

J. The access and availability of palliative care and palliative care services in rural, regional and remote NSW

4.27 The provision of palliative care in rural and remote NSW is variable[6]. In some areas, it is mostly nurse-led and provided by GPs, community and palliative care nurses, and residential aged care staff. In some LHDs, there are well established specialist palliative care services that provide 24/7 care across their hospital and community. Other areas have a combination of services provided by generalist and specialist services[7].

4.28 Due to geography and patient numbers, local medical services will need to continue to provide care for paediatric palliative care patients with support from specialist paediatric palliative care services currently based at Sydney Children's Hospitals Network and John Hunter Children's Hospital. These multidisciplinary teams should continue to be appropriately funded to provide remote support and education for any health professional caring for an infant, child, or adolescent in NSW. It should also be noted that some areas of NSW obtain their specialist paediatric palliative care support from South Australia, Queensland, or Victoria, depending on location and paediatric referral pattern.

4.29 The quality of primary palliative medicine in rural and remote NSW largely depends on the experience and interest of individual GPs. The number and distribution of GPs who have a special interest in palliative care is not known.

4.30 There are no data available from the Royal Australian College of Physicians (RACP) of the number and location of GPs who have completed the RACP Palliative Medicine Diploma. The RACGP and Australian College of Rural and Remote Medicine (ACRRM) advanced skills training pathways enable Rural Generalists to develop an advanced skill, which may include palliative care. The location of those GPs with this pallative care advanced skill set is also not published, and it is hoped that the RACGP and ACRRM will contribute to the Inquiry to provide more information.

4.31 The provision of Specialist Palliative Care Services is inconsistent across rural and remote areas. For example, Southern NSW LHD has a contracted visiting specialist from Sydney that provides face-to-face consultations every 2 months and telehealth consultations in the intervening time. There is also a private palliative medicine specialist available for regular face-to-face palliative medicine support within the boundaries of one small district in the LHD. While full-time Staff Specialists are employed by and reside in some LHDs, other LHDs have fractional FTE staff specialist positions filled by fly-in/fly out specialists. For example, palliative medicine support in Murrumbidgee Local Health District is provided by fly-in fly-out specialists (0.4 FTE covering a population of around 250,000 people) and is mainly limited to Wagga Wagga.

4.32 Other adjacent services for palliative patients can also be difficult to access in rural and remote settings. This includes access to allied health professionals such as social workers, occupational therapists, psychologists and bereavement counselors.

4.33 One positive feature of traditional rural and remote general practice has been the 'cradle to the grave' relationships established often over generations, with continuity of care across rooms, hospitals, home, and residential aged care. However, with the loss of older GPs through

[6] Wenham S, Cumming M, Saruman E. Improving palliative and end-of-life care for rural and remote Australians. Public Health Research & Practice March 2020; Vol. 30(1):e3012001 https://doi.org/10.17061/phrp3012001

[7] Saurman E, Lyle D, Wenham S, Cumming M. A mapping study to guide a palliative approach to care. Rural and Remote Health 2019; 19: 4625. https://doi.org/10.22605/RRH4625

retirement and worsening GP shortages, more GP practices and hospitals are being staffed by fly-in/fly-out doctors. This may have a negative impact on continuity and cause a loss of trust in the local hospital.

4.34 After-hours services are limited, especially for those living out of town. Travelling at night can be dangerous, and it is not always possible to have enough GPs on-call every night with so few in the area. Even if travel costs were reimbursed, GPs are also unlikely to be available at night (or even in the day) to travel many kilometres to outliers.

4.35 There are many clinicians (specialists and non-specialists) that are continuing to live and work in the same community. Whilst this is often seen as a privilege by clinicians, there is also a need to acknowledge the emotional burden of caring for their community, acquaintances, colleagues, friends and sometimes even family.

4.36 Telehealth is being used more widely both in LHDs to provide specialist support, and within LHDs to assist with efficiency and timeliness of review. Reliable internet is not always available, and not all residents have the technological literacy to utilise videoconferencing. Telephone consultations are not always satisfactory in terms of patient experience.

K. An examination of the impact of health and hospital services in rural, regional and remote NSW on indigenous and culturally and linguistically diverse (CALD) communities

4.37 Nationally, around 10% of palliative care patients have a preferred language other than English[8]. In rural communities, recent increases in refugees and migrants have changed language demographics. Non-English speaking patients often rely on family or community members to act as interpreters, which raises issues of confidentiality and privacy. Telephone interpreters are not always available, which creates further access issues for these patients.

L. Any other related matters

4.38 There are many innovations occurring to improve the provision of palliative care in regional, rural and remote areas. Palliative care research is being conducted by Mid North Coast LHD, Far West LHD and Broken Hill University Department of Rural Health. Western NSW Primary Health Network, in partnership with Far West LHD, has also developed a palliative approach web resource.

5. Conclusion

5.1 We commend the Committee for considering the important issues around health outcomes and access to hospital services in rural, regional and remote NSW.

5.2 This Inquiry presents an important opportunity to facilitate greater quality and consistency in the delivery of palliative care services across rural, regional and remote areas in NSW.

[8] Blanchard M, Burns S, Clapham S, Daveson B, Eagar K and PCOC (2020) *Patient Outcomes in Palliative Care in Australia: National report for January – June 2020.* Palliative Care Outcomes Collaboration, Australian Health Services Research Institute, University of Wollongong

5.3 An ongoing challenge is that rural, regional and remote settings are faced with high palliative care needs that must be met in an environment where the provision of quality and accessible services require more resources than are often available.

5.4 The current state of palliative care across rural, regional and remote NSW is varied. Some patients in these areas benefit from dedicated specialist services, while others rely on a combination of generalists and other health professionals for their palliative care needs. More data about how palliative care is provided and variation of patient experience will be essential for understanding the true state of palliative care in these areas.

5.5 ANZSPM supports a stronger focus on these issues in palliative care within rural and remote settings, and thanks the Committee for contributing to this process.

This document was prepared by ANZSPM in consultation with the ANZSPM Rural and Remote Special Interest Group.