17 June 2026

Senator Penny Allman-Payne
Chair, Senate Community Affairs References Committee
PO Box 6100
Parliament House
Canberra ACT 2600

By email: community.affairs.sen@aph.gov.au

Dear Chair,

ACRRM submission to the inquiry into Epilepsy in Australia

The Australian College of Rural and Remote Medicine (ACRRM) is pleased to provide this submission to the Community Affairs References Committee's current inquiry.

ACRRM's vision is for *'Healthy rural, remote and First Nations communities through excellence, social accountability, and innovation'*. Key to this is access to doctors, including Rural Generalists who are appropriately skilled and supported to provide services in rural and remote communities. ACRRM has more than 7,000 members including doctors living and working in rural, remote, and Aboriginal and Torres Strait Islander communities across Australia. Our members deliver expert frontline medical care in a diverse range of environments such as general practices, hospitals, Aboriginal Medical Services and other remote settings. ACRRM plays an important role in strong representation and advocacy for these dedicated professionals and the rural and remote communities they serve.

In this submission, ACRRM provides feedback focused on the rural and remote context, the challenges faced by people living in these areas seeking to access comprehensive health services, and the support required for Rural Generalists and rural General Practitioners. As such, this submission particularly addresses the following terms of reference:

a) barriers to diagnosis and access to appropriate treatment options, including the impact of factors such as:
   i. geographic locations,
   ii. availability of medical practitioners, including neurologists,
   iii. costs, and
   iv. cultural and language barriers;

c) the level of community awareness and understanding of epilepsy and treatment options;

e) the adequacy of Commonwealth funding for research into epilepsy.

Epilepsy in rural and remote Australia

There are approximately 270, 000 people in Australia living with epilepsy[1], which has a significant cost to the Australian health system and society. For example, in 2019-20 the estimated total annual cost of epilepsy was $12.3 billion, including $4.2 billion in direct financial costs (healthcare, lost productivity, informal care, and transportation) and $8.2 billion in lost well-being due to disability and premature mortality[2].

Those living in rural and remote areas disproportionately experience the impact of this condition, with the Australian Institute of Health and Welfare (AIHW) reporting higher rates of burden of disease (measured in Disability Adjusted Life Years or DALYs) attributed to epilepsy in areas outside of major cities. In 2018 the age-standardised rate of total disease burden attributed to epilepsy was highest for people living in Inner regional areas (2.6 DALY per 1,000 population), followed by people living in outer regional areas (2.2 DALY per 1,000 population), remote and very remote areas (1.8 DALY per 1,000 population) and then, lastly, people living in major cities (1.6 DALY per 1,000 population)[3].

The rate of health system costs for epilepsy is also higher outside of major cities and increases with increasing remoteness. That is, the rate of health spending for epilepsy was at the highest rate for people living in very remote areas at $4.3 million per 100,000 population, followed by those in remote areas at $3.5 million, people in outer regional areas at $2.92 million, those in inner regional areas at $2.82 million and people living in major cities having the lowest rate at $2.5 million per 100, 000 population.

People from rural and remote areas are also more likely to be hospitalised or present to hospital emergency departments (ED) due to epilepsy, with the AIHW reporting that as recently as 2023-24:

- Aged-standardised hospitalisation rates due to epilepsy were 2.1 times as high for people living in remote and very remote areas compared with people living in major cities (180 and 84 hospitalisations per 100,000 population, respectively); and,
- Age-standardised rates of ED presentations due to epilepsy were 1.6 times as high for people living in remote and very remote areas as for people living in major cities (160 and 99 per 100,000 population, respectively).

ACRRM notes data from the AIHW that over two-thirds of health system expenditure on epilepsy is for public hospital services, including admitted patient services and almost 20% on emergency department services. This raises some concern given that for the majority of people living with this condition it can be

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[1] Epilepsy Foundation (n.d) *What is epilepsy?* https://epilepsyfoundation.org.au/understanding-epilepsy/about-epilepsy/what-is-epilepsy/ [accessed 21 April 2026]

[2] Muthusamy, S., Phan, A. L. G., Seneviratne, U., Beare, R., Srikanth, V., Ma, H., Phan, T. G. (2025) 'Identifying hotspots of seizure-related hospital admissions in Australia' *Seizure: European Journal of Epilepsy Volume 129, July 2025,* pp.70-76, Available: https://www.sciencedirect.com/science/article/pii/S1059131125000810 [accessed 21 April 2026]

[3]Australian Institute of Health and Welfare (2025) *Neurological conditions in Australia: Epilepsy in Australia* https://www.aihw.gov.au/reports/neurological-conditions/epilepsy [accessed 21 April 2026]

well managed, with the Epilepsy Association of Australia reporting that around 70% of people successfully managing seizures through antiseizure medication, while surgical options and diet management are effective for others. Effective epilepsy management requires appropriate engagement with a healthcare team, and the higher rates of hospitalisations for rural and remote Australians outlined above indicates a particular need for improvement. ACRRM also notes that there are higher rates of epilepsy, acuity and related hospitalisations amongst Aboriginal and Torres Strait Islander Australians, a proportionately high number of whom live in rural and remote areas which requires a specific, and culturally appropriate approach that is designed and led by community[4].

Inadequate access to health services in rural and remote areas

People in rural and remote areas of Australia with epilepsy and/or experiencing seizures face significant challenges accessing necessary services for diagnosis and management. It has been shown that there are more frequent 'hot spots' of seizure-related hospitalisations in rural and remote areas, particularly throughout central and northern Australia, however there is limited access to specialised seizure services that are concentrated in major cities[5].

Accessing neurology services, critical in the diagnosis and management of epilepsy, can be particularly difficult for rural and remote Australians, with research finding that the 31% of the Australian population that lives outside major cities is served by only 4.1% of neurologists[6]. It was shown that this particularly limited capacity meant that, as recently as 2020, the deficits in supply against demand outside major cities reached 35, 549 for initial encounters and 646, 805 for review encounters, and that this would increase in 2034 to 44, 404 and 811, 024 respectively based on these workforce trends. The same simulation showed that even with the addition of up to 100 extra neurologists (10 per year) to rural and remote areas over the period 2022–2031- which would be a significant increase on the 25 practicing in these areas in 2020 - the deficit in review encounters would be reduced by 17.2%, remaining at 658, 092.

Accessing support services following an epilepsy diagnosis can also be highly challenging in rural and remote areas, with allied health and other specialist epilepsy support services often in short supply, if available at all. This contributes significantly to the experience of people with epilepsy and their quality of life. This is shown through a longitudinal study of people in Australia living with epilepsy, with participants

[4] Australian Institute of Health and Welfare (2025), *Epilepsy in Australia*, Available: https://www.aihw.gov.au/reports/chronic-disease/epilepsy-in-australia/contents/summary [accessed 21 April 2026]

[5](2)Muthusamy, S., Phan, A. L. G., Seneviratne, U., Beare, R., Srikanth, V., Ma, H., Phan, T. G. (2025) 'Identifying hotspots of seizure-related hospital admissions in Australia' *Seizure: European Journal of Epilepsy Volume 129, July 2025,* pp.70-76, Available: https://www.sciencedirect.com/science/article/pii/S1059131125000810 [accessed 21 April 2026]

[6] Simpson- Yap S., Frascoli F., Harrison L., Malpas C., Burrell J., Child N., Giles L.P., Luek C., Needham M., Tsang B. & Kalincik T. (2023), 'Modelling accessibility of adult neurology care in Australia, 2020–2034', *BMJ Neurology Open*, doi:10.1136 Available: https://neurologyopen.bmj.com/content/5/1/e000407 [accessed 22 April 2026]

particularly valuing emotional, informational and social supports[7]. These supports may come from psychologists and counsellors, however participants reported such services being hard to access, and when such services were withdrawn, this was experienced as a significant loss for those living with epilepsy. It was noted in this study that state-based epilepsy associations went some way to fill these gaps, often providing telephone support and printed services, as well as opportunities for social supports and interactions.

Action required

Ensuring adequate diagnosis, ongoing management and support services for people living with epilepsy in rural and remote areas requires locally-appropriate solutions that, through robust research identifies service gaps and builds on available service infrastructure. Rural Generalists (RGs) and General Practitioners (GPs) in rural and remote areas play an important role in the referral pathway for diagnosis and ongoing management and support for people living with epilepsy in these areas. GPs and RGs are often the first interaction an individual has with the health system, and in rural areas have a further unique role in their community as one of only a few people available to provide medical care. This is often without the extensive range of support services available to practitioners in urban settings, as outlined above, which both heightens and broadens their responsibilities.

ACRRM supports calls for more efficient referral pathways to diagnose and manage cases of epilepsy in rural and remote areas and enhanced training for RGs and GPs in rural and remote areas [8], ensuring that this additional training is appropriately funded as paid time for professional development and upskilling. It is noted that opportunities and incentives for professional development and upskilling is often lacking in rural practice as compared to metropolitan practice, and without dedicated funding for the paid time of clinicians, such upskilling is unlikely to succeed on the scale required to affect change in treatment and care pathways. It is critical that RGs, GPs and other health professionals practicing in rural and remote areas are adequately supported and appropriately equipped to respond to patients and families impacted by serious conditions such as epilepsy that are both more common and more acute in rural and remote areas. Training, professional development and supports that are relevant to the challenges and unique role of rural practitioners must be prioritised in distinctive approaches.

In considering workforce modelling for neurologists, it has been shown that just building the workforce will not be adequate to meet the current and projected capacity shortfall for services[6]. Models of care for referral pathways, medication and symptom management that ensure efficiency and quality of care in areas of workforce shortage are required. This may include enhancements of a neurology support workforce such as neurology-trained or specialists nurses and telehealth services. Additionally, those living with epilepsy in these areas have voiced the importance of further informational, emotional and social support services, taking a more holistic approach to managing and living with the condition which

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7 Walker, C., Peterson, C.L., (2024) 'A longitudinal study over 9 years of the role of social support for people with epilepsy' *Explor Neurosci, 2024,Volume 3,* pp. 352-361 Available: https://www.explorationpub.com/Journals/en/Article/100654 [accessed 22 April 2026]

[8]RACGP (2022) 'New epilepsy supports for patients and GPs' *newsGP,* Available: https://www1.racgp.org.au/newsgp/clinical/new-epilepsy-supports-for-patients-and-gps [accessed 22 April 2026]

requires ongoing efforts to ensure an adequate, sustainable and comprehensive health workforce in rural and remote communities.

We appreciate the opportunity to contribute to this important inquiry. If you have any queries relating to this feedback, please contact ACRRM at policy@acrrm.org.au .

Yours sincerely,

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