RACGP submission - Epilepsy in Australia

Senate Affairs References Committee

May 2026

RACGP

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1. Executive Summary

General practitioners (GPs) are central to epilepsy care in Australia, given the chronic, lifelong nature of the disease. GPs are typically the first point of contact for most people with a suspected first seizure, or with unexplained collapse, loss of awareness or episodic behavioural change. GPs are often relied on by epilepsy patients to provide ongoing care and management, with limited specialist support due to long wait times.

The RACGP's submission responds in detail to each area of focus identified by the Inquiry's Terms of Reference. It identifies limited access to neurologists in rural and remote areas, long wait times for public and private neurology services, inconsistency in the availability of diagnostic services such as electroencephalography (EEG) in public settings, and fragmented coordination and lack of care integration across sectors—including general practice, emergency departments, ambulance services and neurology, cultural and language factors, and cost as key barriers to diagnosis and access to appropriate treatment options.

Our submission also identifies the limited community awareness and understanding of epilepsy. Ongoing stigma associated with the condition affects how individuals experience and disclose their diagnosis. It notes that there is a lack of understanding of the different types of epilepsy and that stigma contributes to exclusion from key areas of life, including sport, employment and education. This stigma affects help-seeking behaviours, particularly in culturally diverse communities, where epilepsy may be hidden due to fear of discrimination.

Among other recommendations the RACGP's submission calls for increased research into conditions such as non-epileptic seizures, which represent a significant proportion of presentations to epilepsy services but are poorly understood and inadequately managed. In relation to Aboriginal and Torres Strait Islander peoples, research should include ethnicity data and prioritise Indigenous-led approaches to epilepsy management. Strengthening the evidence base in this area is essential to addressing inequities in outcomes and care.

Finally, our submission notes that the current system places a significant administrative burden on patients and GPs, particularly in accessing transport assistance and specialist service and calls for simplification of processes for patients and GPs to enhance access to care, particularly for transport assistance and access to specialist services.

2. Summary of Recommendations

The RACGP makes 11 recommendations for consideration by the Committee. These are:

1. Increase patient Medicare rebates, in particular, the rebates for longer consultations (C and D items) by 40%. This will help all patients with complex, chronic conditions to access affordable primary health care.
2. Support GPs to have updated lists of approved and effective equipment for people with epilepsy (such as monitors, devices, safety aids) and where they can be purchased. PHNs could help to build these relationships with places that have this equipment at lower prices.
3. Increase investment nationwide in patient transport schemes to support people with epilepsy (and also people with other chronic conditions) in rural and remote areas access appropriate care.
4. Invest in culturally appropriate education and engagement to ensure equitable care.
5. Invest in culturally safe care, support Aboriginal Community Controlled Health Organisations (ACCHOs), and improve access to culturally appropriate diagnostic and treatment services for Aboriginal and Torres Strait Islander patients with epilepsy.
6. Fund research into pathways and treatment options for people with non-epileptic seizures so they can be appropriately treated and well-supported.
7. Support workplaces by funding education and training to support employees with epilepsy.

8. Fund state-based organisations to produce epilepsy resources in other languages for patients and their families to help address the needs of CALD communities, particularly where there may be stigma or epilepsy is poorly understood.
9. Increase funding for epilepsy research relevant to primary care, including non-epileptic seizures, and support Indigenous-led approaches to improve outcomes for Aboriginal and Torres Strait Islander peoples.
10. Provide funding for the development of nationally consistent, multidisciplinary, evidence-based epilepsy guidelines that can be used across all services.
11. Simplify processes for patients and GPs to enhance access to care, particularly for transport assistance and access to specialist services.

The rationale for each of these recommendations is outlined in section 4 of this submission.

3. Introduction

About the Royal Australian College of General Practitioners (RACGP)

The RACGP is the voice of general practitioners (GPs) across our nation, representing more than 50,000 members in our growing cities and throughout rural and remote Australia. For more than 60 years, the RACGP has supported the backbone of Australia's health system by setting the standards for general practice education, practice and continuous professional development. Every year, more than 22 million Australians choose to visit a specialist GP for their healthcare needs[1], making GPs the most accessed health professional in the country and general practice the cornerstone of Australia's primary care system.

The RACGP thanks the Community Affairs References Committee for the opportunity to provide comment on this Inquiry.

The role of GPs in epilepsy and neurological care

General practice is central to epilepsy care in Australia, given the chronic, lifelong nature of the disease. GPs are typically the first point of contact for most people with a suspected first seizure, or with unexplained collapse, loss of awareness or episodic behavioural change. GPs are often relied on by epilepsy patients to provide ongoing care and management, with limited specialist support due to long wait times.

The GP's role in epilepsy patient care includes:

- recognising diverse seizure types
- differentiating epilepsy from other causes (such as syncope, panic attacks, functional seizures)
- initiating investigations and appropriate referral pathways
- medication review and monitoring
- managing adverse effects
- providing medical certification (such as driving eligibility)
- supporting patients navigate systems such as Centrelink and the NDIS, and employer requirements
- coordinating care across multiple providers and settings. Many patients, particularly those on low incomes or living rurally, cannot afford or access mental health care, increasing reliance on GPs to manage complex needs including management of anxiety, depression, stigma and social isolation.

Current Medicare settings often do not reflect the complexity and time required to care for people with epilepsy and suspected epilepsy. Epilepsy care commonly involves long consultations, addressing multiple complex issues per visit (medical, mental health, social, administrative) and coordination with multiple services. These issues align with longstanding RACGP concerns regarding inadequate funding for longer consultations for patients with complex, chronic conditions.[2]

We provide comments on the Terms of Reference as outlined below.

4. RACGP's response to Committee Terms of Reference

The Committee Terms of Reference for its inquiry into Epilepsy in Australia identifies the following areas of particular focus:

- 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;*
- b) *drug-resistant epilepsy and its psychosocial and economic impacts on patients and the community;*
- c) *the level of community awareness and understanding of epilepsy and treatment options;*
- d) *barriers to access support services after diagnosis, including the National Disability and Insurance Scheme;*
- e) *the adequacy of Commonwealth funding for research into epilepsy; and*
- f) *any other related matters.*

This section of our submission addresses each of these focus areas in turn.

a. Barriers to diagnosis and access to appropriate treatment options

Access to care

Limited access to neurologists in rural and remote areas significantly impacts diagnosis and treatment for patients living with epilepsy. Many patients travel long distances, including interstate, to receive specialist care, leading to missing school for paediatric patients, and adult patients missing work, adding to overall treatment costs.

Wait times

Long wait times for public and private neurology services, often extending into years, further limits access. High out-of-pocket costs for private neurologists particularly affect and limits accessibility for patients on low-incomes. Paediatric neurology services often face public waitlists ranging from one to three years, impacting child health and wellbeing and increasing reliance on hospital emergency departments for care.

Limitations of diagnostic services

Diagnostic services such as electroencephalography (EEG) are not consistently available in public settings, and although a Magnetic Resonance Imaging (MRI) scan for unexplained seizures is now rebatable under the Medicare Benefits Schedule (MBS), gap payments remain prohibitive for many patients. Similarly, accessibility to private EEG services with GP referral has increasingly long wait times for neurologist review and diagnostic testing. The RACGP can provide more detail on this for the Inquiry if required.

Fragmentation of care

Fragmented coordination and lack of care integration across sectors—including general practice, emergency departments, ambulance services and neurology can lead to inconsistent management pathways and outcomes. There is also inconsistent transition of care between paediatric and adult epilepsy services. GPs provide regular review via Chronic Condition Management Plans, deliver preventive care as per RACGP Guidelines for preventive activities in general practice, including immunisations, and provide support for prescribing and referrals to specialists and allied health professionals. They also provide Mental Health Plans and refer to clinical psychologists. However, access to appropriately funded MBS items is not appropriate and time-based billings do not adequately resource long consultations for patients with chronic conditions.

Financial barriers

Cost remains a significant barrier to accessing diagnosis and ongoing care. High specialist fees, gap payments for imaging, and the expense of private care contribute to inequitable access. Many participants who responded to the Australian Epilepsy Longitudinal Survey indicated they did not have access to equipment they needed, such as seizure monitors and alarms, and nearly half the participants could not afford the equipment.[3] It has also been reported that people with epilepsy, particularly those on low incomes were unable to attend medical appointments, afford anti-seizure medication and had to economise to buy food and pay bills.[4]

Patients are frequently unable to access psychological services due to cost or limited availability, and travel to metropolitan centres for specialist care imposes additional financial burdens for those in rural and remote areas. The Australian Epilepsy Longitudinal Survey found that 44.5% of participants reported epilepsy affected their ability to drive, and 35.5% reported this impacted their ability to undertake paid work.[3] The Survey also found that participants needed more support with transport, attending and making appointments, social activities and domestic duties.[3] Patient transport schemes offer limited reimbursement but do not adequately cover travel, accommodation, or other incidental costs. For example, the current reimbursement for accommodation in the Victorian Patient Transport Assistance Scheme (VPTAS) is $45, which does not cover the cost of a hotel room close to a city hospital. Increased investment in these and similar schemes nationwide will support patients with epilepsy and other chronic conditions in rural and remote areas access appropriate care.

RACGP recommendations:

- Increase patient Medicare rebates, in particular, the rebates for longer consultations (C and D items) by 40%. This will help all patients with complex, chronic conditions to access affordable primary health care.[2]
- Support GPs to have updated lists of approved and effective equipment for people with epilepsy (such as monitors, devices, safety aids) and where they can be purchased. PHNs could help to build these relationships with places that have this equipment at lower prices.
- Increase investment nationwide in patient transport schemes to support people with epilepsy (and also people with other chronic conditions) in rural and remote areas access appropriate care.

Cultural and language barriers

Cultural and language factors can significantly affect access to diagnosis and care. Within culturally and linguistically diverse communities, epilepsy may be associated with stigma and secrecy, leading to delays in seeking care or concealment of the condition to fear or misunderstanding. The need for investment in culturally appropriate education and engagement is required to ensure equitable care.

For Aboriginal and Torres Strait Islander peoples, disparities in prevalence, hospitalisation, and mortality rates indicate systemic inequities in access to care. These inequities are influenced by broader social determinants of health, including socioeconomic disadvantage and remoteness. Culturally safe care, support for Aboriginal Community Controlled Health Organisations (ACCHOs), and improved access to culturally appropriate diagnostic and treatment services would assist Aboriginal and Torres Strait Islander patients with epilepsy. Integrated Team Care arrangements can be used to access gap payments for specialists, but access to neurologists remains limited.

RACGP recommendations:

- Invest in culturally appropriate education and engagement to ensure equitable care.
- Invest in culturally safe care, support Aboriginal Community Controlled Health Organisations (ACCHOs), and improve access to culturally appropriate diagnostic and treatment services for Aboriginal and Torres Strait Islander patients with epilepsy.

Regulatory requirements

Regulatory requirements, such as the need for neurologist sign-off for driving, create additional access barriers where specialist appointments are difficult to obtain or unaffordable. Commercial licence holders require privately billed general practice appointments as this cannot be billed to the MBS.

Other access barriers

While not in scope, it is worth noting that people with non-epileptic seizures also require support. These patients may require investigations and review by neurologists to consider epilepsy as a diagnosis. They typically follow epilepsy treatment pathways, until they are advised that their seizures are non-epileptic. As a result, they fall through the cracks in the system and frequently do not receive the required specialist treatment. Better research into the pathways and treatment options for this group could help epilepsy care more generally, not only to gain more understanding of how to treat such people appropriately, but to free up epilepsy investigations for those most likely to benefit from it.

RACGP recommendation:

- Fund research into pathways and treatment options for people with non-epileptic seizures so they can be appropriately treated and well-supported.

b. Drug-resistant epilepsy and its psychosocial and economic impacts

While approximately 70% of people with epilepsy achieve seizure control with medication, a significant proportion of these people experience ongoing seizures, including drug-resistant epilepsy.

The psychosocial impacts are substantial and include:

- reduced participation in education, employment, and community life;
- social isolation and loss of independence;
- ongoing mental health challenges.
- stigma, which is prevalent in the community as a result of lack of education and understanding on the condition (for example, people with epilepsy may be unnecessarily excluded from participating in sport).

People with drug-resistant epilepsy may lose their driver’s licence or be unable to gain one. This has particularly profound impacts on employment and their social life, especially for people in rural and remote areas where public transport options are limited.

Economic impacts extend beyond individuals to the broader community through healthcare utilisation, including emergency department presentations and hospital admissions. Patients with poorly controlled seizures may require repeated acute care, reflecting gaps in effective long-term management. From a general practice perspective, these patients usually require longer appointments due to their complex condition.

RACGP recommendation:

- Increase patient Medicare rebates, in particular, the rebates for longer consultations (C and D items) by 40%. This will help all patients with complex, chronic conditions to access affordable primary health care.[2]

c. The level of community awareness and understanding of epilepsy and treatment options

There is limited community awareness and understanding of epilepsy. Ongoing stigma associated with the condition affects how individuals experience and disclose their diagnosis. State-based organisations provide education and training to schools which have children who have epilepsy. Funding could be extended to workplaces with employees with epilepsy.

In particular, there is a lack of understanding of the different types of epilepsy. For example, some forms, such as absence seizures, may present with behaviours that are not recognised as seizures, leading to misunderstanding.

Stigma contributes to exclusion from key areas of life, including sport, employment and education. It also affects help-seeking behaviours, particularly in culturally diverse communities, where epilepsy may be hidden due to fear of discrimination. A national awareness campaign would be helpful. State-based organisations should also be funded to produce resources in other languages to help address the needs of those communities, particularly where there may be stigma or epilepsy is poorly understood.

RACGP recommendations:

- Support workplaces by funding education and training to support employees with epilepsy.
- Fund state-based organisations to produce epilepsy resources in other languages for patients and their families to help address the needs of CALD communities, particularly where there may be stigma or epilepsy is poorly understood.

d. Barriers to access support services after diagnosis, including the National Disability Insurance Scheme (NDIS)

GPs play a central role in coordinating the healthcare of patients with epilepsy and in supporting patients to navigate access to services, including applications for the NDIS, Disability Support Pension, and aged care. However, system complexity and resource constraints can limit timely access. For patients with epilepsy, access to post-diagnostic support services is inconsistent. While some individuals receive support through the NDIS or aged care systems, there are gaps in the provision of necessary supports, including assistive technologies, such as monitoring devices.

Financial barriers also affect access to allied health and psychological services through the NDIS, which are critical to ongoing management and quality of life. It also impacts access to necessary equipment. As described in Terms of Reference a, many patients indicated they did not have access to or were unable to afford much needed equipment such as seizure monitors and alarms.[3]

e. The adequacy of Commonwealth funding for research into epilepsy

Funding for epilepsy research is limited, particularly in areas relevant to primary care. There is a lack of targeted research on how best to support people with epilepsy in general practice settings, despite GPs playing a central role in diagnosis, management, and coordination of care.

Increased research is needed into conditions such as non-epileptic seizures, which represent a significant proportion of presentations to epilepsy services but are poorly understood and inadequately managed.

In relation to Aboriginal and Torres Strait Islander peoples, research should include ethnicity data and prioritise Indigenous-led approaches to epilepsy management. Strengthening the evidence base in this area is essential to addressing inequities in outcomes and care.

RACGP recommendation:

- Increase funding for epilepsy research relevant to primary care, including non-epileptic seizures, and support Indigenous-led approaches to improve outcomes for Aboriginal and Torres Strait Islander peoples.

Need for national guidance

It is important for research to be translated into usable clinical guidelines. There is a need for nationally consistent, multidisciplinary, evidence-based guidelines that include input from general practice. Current gaps in clinical pathways, including limited engagement of neurologists in local HealthPathways, contribute to variability in care.

Improved coordination across services, enhanced triage systems to prioritise complex and treatment-resistant cases, and investment in alternative models such as asynchronous specialist advice would improve access and outcomes.

There are concerns regarding the currency of emergency response information for seizure management, highlighting the need for updated and standardised guidance across ambulance and emergency services.

RACGP recommendation:

- Provide funding for the development of nationally consistent, multidisciplinary, evidence-based epilepsy guidelines that can be used across all services.

f. Any other related matters

Health system navigation

The current system places a significant administrative burden on patients and GPs, particularly in accessing transport assistance and specialist services.

RACGP recommendation:

- Simplify processes for patients and GPs to enhance access to care, particularly for transport assistance and access to specialist services.

Thank you again for the opportunity to provide comment on the inquiry to *Epilepsy in Australia.* If you have any questions regarding our submission, please contact Mr Stephan Groombridge, National Manager, e-health, Quality Care & Standards at stephan.groombridge@racgp.org.au or 03 8699 0544.

5. References

1. The Royal Australian College of General Practitioners. General Practice: Health of the Nation 2025. East Melbourne, Vic: RACGP, 2025
2. The Royal Australian College of General Practitioners. Pre-Budget Submission 2025-27. East Melbourne, Vic: RACGP 2026. Available at: https://www.racgp.org.au/advocacy/reports-and-submissions/view-all-reports-and-submissions/2026-reports-and-submissions/pre-budget-submission-2026-27
3. Epilepsy Foundation. The Australian Epilepsy Longitudinal Study. Canterbury, Vic: Epilepsy Foundation, 2020. Available at: https://epilepsyfoundation.org.au/research-initiatives/australian-epilepsy-research-register/information-and-publications/
4. Walker C, Peterson CL. General Practitioners and the Impact of Low Income in the Lives of People With Epilepsy: Results of an Australian Survey. J Eval Clin Pract. 2026 Jun;32(4):e70470. doi: 10.1111/jep.70470.