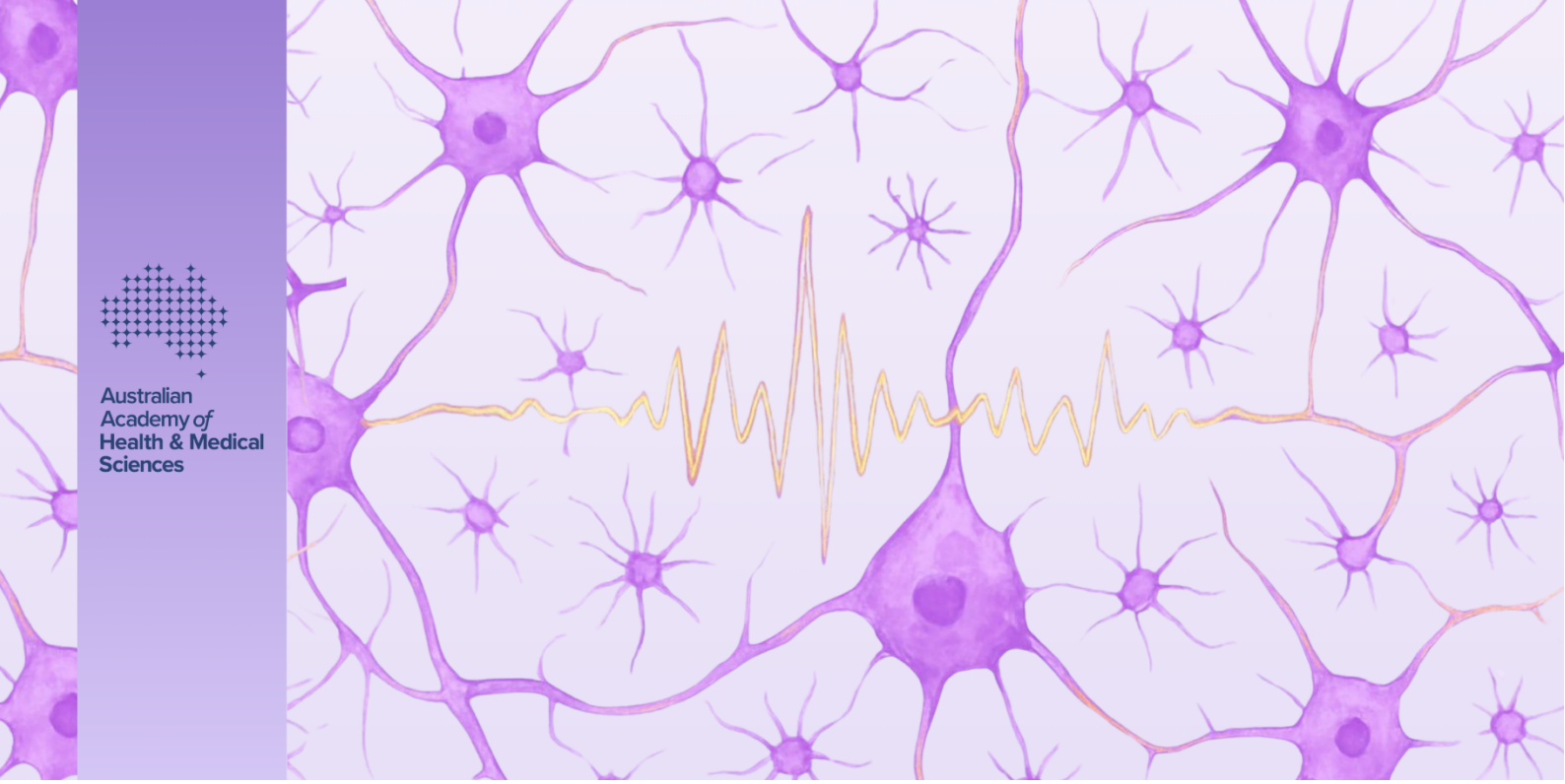

Australian Academy of Health & Medical Sciences

Submission to the inquiry into epilepsy in Australia

May 2026

Executive summary

- Australia is a global leader in epilepsy research, but this is not consistently translated into effective, timely diagnosis and clinical care for patients across the country.
- Factors contributing to delayed diagnosis include absence of a national standard for specialist review after a first seizure, inconsistent referral pathways, metropolitan concentration of services, and shortages in specialist staff.
- Factors contributing to inconsistently evidence-based epilepsy care include many patients not being managed by neurologists or epileptologists, uneven access to specialist-led services such as first seizure clinics, and patchy implementation of evidence-based multidisciplinary care across Australia.
- Mechanisms that would enable the more consistent translation of epilepsy research into excellent epilepsy diagnosis and care include national time standards for specialist review after a first seizure, hybrid telehealth models to extend specialist reach beyond metropolitan centres, research-active clinicians embedded within care settings, and sustained workforce funding to train and retain neurologists, epileptologists and specialist nurses.
- Commonwealth investment has enabled major epilepsy research initiatives, but funding for research translation remains more focused on platforms and technologies than on the specialist workforce and service infrastructure needed to embed research findings in routine care.

Background: Epilepsy in Australia

This submission from the Australian Academy of Health and Medical Sciences responds to Terms of Reference (a), examining barriers to the diagnosis and treatment of epilepsy in Australia and (e), addressing the adequacy of Commonwealth funding for epilepsy research of the Senate inquiry into epilepsy in Australia. Specifically, this submission focuses on several major gaps in diagnosis, care and research translation, and on the health and medical sciences infrastructure needed to bridge them.

Epilepsy is one of the most common chronic brain conditions across the lifespan, and can affect cognition, mental health, behaviour, independence, education and employment. In more severe presentations, it can be associated with wider multi-morbidity and significant demands on families and carers. It is also a substantial public health issue: during 2024-2033, epilepsy in Australian adults is projected to be associated with 15,227 deaths and approximately A$19.9 billion in total healthcare costs if current models of diagnosis and care are not reformed.[1]

Australia has an outstanding national record when it comes to epilepsy research. In 1995, Australian researchers identified the first epilepsy gene in a large Australian family, paving the way for precision diagnosis through genetic testing, thereby transforming epilepsy care worldwide.[2] Australia's global leadership today is broad across epilepsy, spanning from improved understanding of underlying mechanisms to more effective diagnostic approaches and treatment. For example, Australian researchers are developing AI-assisted magnetic resonance imaging (MRI) tools that can detect subtle brain lesions missed on routine review – helping guide earlier diagnosis, surgery and targeted interventions, while also testing new treatments through cutting-edge clinical trials and advancing understanding of the genetic basis of common and rare epilepsies.[3,4] Research through long-running registers such as the Australian Pregnancy Register is also improving understanding of antiseizure medication safety during pregnancy.[5] Australia's epilepsy research capability has also been translated into evidence-based service design, including the development of first seizure clinics. These clinics facilitate early specialist assessment of patients who have experienced a first suspected seizure, expediting access to targeted investigations, and referral to appropriate treatment and ongoing care. [i]

Despite Australia's global epilepsy research leadership, Australian patients often experience delayed diagnosis and specialist review, and do not have equal access to coordinated epilepsy services – with barriers including geographic location, socioeconomic status, language barriers, transport availability, and caring responsibilities continuing to impact timely access to evidence-based epilepsy diagnosis and care. For Australia to maximise the returns on its investments in epilepsy research, it must strengthen mechanisms for consistently translating this research into clinical practice.

[i] A first suspected seizure is a first event that may have been a seizure but requires specialist review to determine whether it was epileptic or caused by another condition with similar features.

Barriers to timely diagnosis

Evidence shows that earlier access to specialist epilepsy care is associated with better outcomes, including better seizure control, fewer hospital presentations and lower mortality.[6] Being seen in a first seizure clinic within 14 days of a suspected first seizure is associated with fewer hospitalisations, fewer seizure-related emergency presentations and lower mortality than attending more than 14 days after the event.[7] Despite this, Australia does not have a national standard for timely access to specialist care following a suspected first seizure. There are some good international models for timely access. For example, the model used in England includes National Institute for Health and Care Excellence (NICE) guidance recommending specialist assessment within two weeks of a first suspected seizure.[8]

For most people, the diagnosis pathway often begins in a primary care or emergency department setting, and is ideally followed by referral to a neurologist or epileptologist.[ii] However, Australian referral pathways vary across states, health services and individual providers – meaning that in practice, many people living with epilepsy either receive a referral late or not at all.[9]

Following referral, patients across Australia commonly experience subsequent service delays. Access to first seizure care is concentrated in metropolitan areas, and typical wait times for a first appointment in a dedicated first seizure clinic are around 2 months, often longer.[10] Epilepsy clinics are not sufficiently resourced to provide timely, evidence-based diagnosis and care for all patients; many services lack a clinical nurse or care coordinator, and delays in accessing electroencephalogram (EEG) and MRI, often several months long, are more common and more severe for patients in regional, rural and remote areas.[10]

These gaps result in a leaky diagnostic pipeline, with many Australians facing delays in accessing evidence-based care and therefore experiencing poorer outcomes.

Access to evidence-based care

Epilepsy management demands an evidence-based, multidisciplinary approach. Many people who live with epilepsy will require access to specialist nursing, neuropsychology, and mental and allied health services.

Uneven access to specialist epilepsy care, particularly for people in rural, regional and remote areas, requires targeted solutions. Telehealth offers a practical mechanism to reduce this gap but is not a wholesale substitute for the initial clinical encounter. First assessments require physical examination, access to investigations such as EEG and MRI, and clinical observation that cannot be fully replicated remotely. A hybrid model that combines an initial in-person review to establish diagnosis and baseline care, followed by telehealth for ongoing management where clinically appropriate, is the most practical approach for patients outside metropolitan centres, and is consistent with the National Health and

[ii] An epileptologist is a neurologist with specialised training in epilepsy and seizures. They are usually involved when diagnosis is unclear, seizures are hard to control, or treatment decisions are more complex.

Medical Research Strategy 2026–2036 – which emphasises expanding telehealth-enabled models in regional, rural and remote settings (Focus Area 3.4).[11]

The implementation of Australia's first National Health and Medical Research Strategy is a once-in-a-generation opportunity to build a nationally coordinated workforce of specialist, research-active epilepsy nurses able to support evidence translation in clinical settings, including clinicians with expertise in complex epilepsies such as the developmental and epileptic encephalopathies (DEEs) (Box 1).[iii] A nationally consistent approach to strengthening this element of the health and medical research workforce would strengthen the delivery and translation of epilepsy research in clinical settings, ensuring that all Australian communities can access effective care.[iv] For example, specialist epilepsy nurses can support research and its translation by educating patients and families, helping identify eligible patients for trials, supporting follow-up, and contributing to the implementation and evaluation of new models of care.

Box 1: In focus: Developmental and epileptic encephalopathies (DEEs)[14]

DEEs are a group of severe childhood-onset epilepsy syndromes in which recurrent seizures and the underlying brain disorder both contribute to developmental impairment. Most are genetic, with more than 970 genes implicated as contributing to DEEs. DEEs begin in early childhood, with about 500 children diagnosed each year in Australia and an estimated 8,500 Australians currently living with a DEE. For comparison, approximately 750 children are diagnosed with cancer annually in Australia, yet DEEs have far lower awareness and no coordinated care pathway. DEEs commonly involve one or more complications such as intellectual disability, developmental delay, behavioural and psychiatric symptoms, sleep and feeding difficulties, movement disorders, and repeated hospital admissions. In short, they bring about significant multimorbidity.

Diagnosing DEEs is often challenging because it can require highly specific genetic testing, prolonged EEG or video EEG monitoring, and assessment of associated developmental and functional needs. Barriers to support adequate care are often intensified in DEEs, including delays in diagnosis, uneven access to specialist treatment, and fragmented support, especially during transition from paediatric to adult care, where existing gaps in epilepsy care are often magnified.

[iii] This approach is consistent with Focus Area 3.2 of the National Health and Medical Research Strategy, which calls for the formal recognition and resourcing of nurses and clinical research coordinators as part of the clinical research workforce - as well as Focus Area 3.1, which identifies embedding research translation into clinical settings as a national priority.[11]

[iv] Evidence from comparable federally funded nurse-led programmes in Australia - the McGrath Breast Care Nurse initiative - has shown improved quality of life, reduced emergency department presentations and health service use, more efficient consultations through reduced clinician time, and cost savings to the health system.[13]

Research and translation funding

Commonwealth funding has enabled major epilepsy research in Australia, including the Australian Epilepsy Project (AEP).[10] Funded through the Medical Research Future Fund (MRFF) Frontier Health and Medical Research Program, the AEP is one of the world's largest and most detailed epilepsy research initiatives, enabling advances across genetics, imaging, AI-supported diagnosis and new therapies. On 22 May 2026, the Federal Government announced a further $30 million in MRFF funding for the AEP, bringing total Commonwealth investment to $60 million.[12] The direction of this funding – towards embedding the AEP platform in the health system, scaling its reach, and preparing it for commercialisation of AI innovations in epilepsy care and its uptake by health systems in other countries – is a valuable step towards meaningful impact.

Funding for research translation has to date been weighted towards platform and technology scaling – such as building and expanding the AEP's AI-enabled digital diagnostic platform – rather than the workforce and system infrastructure needed to embed research findings in routine care, including regional service capacity, specialist nursing roles and clinician-researcher pipelines for the next generation of epilepsy researchers and subspecialty trainees.

Resourcing of the epilepsy component of the health and medical research workforce remains a major constraint. Closing the translational gap requires sustained investment in the people and infrastructure needed to deliver AEP-enabled care at scale, including strengthening regional workforce capacity, tele-trials, and hub-and-spoke models that extend trial and care access beyond major metropolitan centres. [v] [vi]

The workforce and funding enablers of the National Health and Medical Research Strategy provide a foundation for strengthening epilepsy diagnosis and care, but realising their full benefits will depend on targeted support for the broader epilepsy care workforce– including research-active neurologists, epileptologists, specialist epilepsy nurses and early-career researchers entering the epilepsy field.[11]

[v] Tele-trials connect a primary trial site with regional and remote satellite sites using telehealth, allowing patients to enrol and be followed up closer to home while the primary site retains overall trial oversight.
[vi] Hub-and-spoke models centralise specialist functions in a primary 'hub' site while connected 'spoke' sites deliver care and support trial participation closer to patients' homes.

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