

IMPACT REPORT

We are on a mission to change the lives of people living with epilepsy.

About the Australian Epilepsy Project

Over 250,000 Australians currently live with epilepsy. One in ten Australians will have a seizure at some point in their lives. But epilepsy is not just seizures. It is associated with increased injury risk, cognitive deficits, mental illness and suicide as well as lower educational and occupational attainment reduced independence, reduced quality of life and stigma. Epilepsy leads to over 300 Australian deaths each year, of which two-thirds are preventable with optimal care.

In 2021, the Australian Epilepsy Project received a grant of \$30 million from the Medical Research Future Fund's Frontier program - the largest ever single government investment into epilepsy research in Australia - to develop a solution to three key problems in the treatment of epilepsy in the Australian healthcare system:



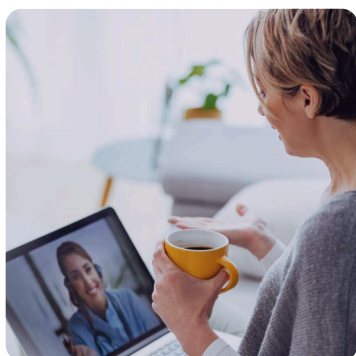
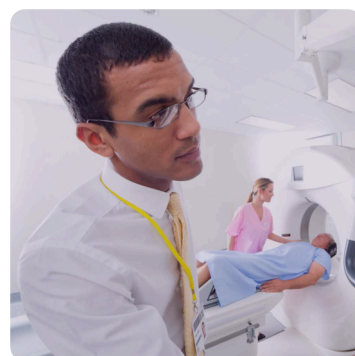
Uncertainty

The treatment of epilepsy is full of uncertainty at every stage. Doctors cannot accurately predict whether a subsequent seizure will occur after initial presentation, leading to delays in starting medication. **Selection of medication is commonly a trial-and-error process**, with up to 20 years passing before seizures are controlled. And doubt about the origin or cause of seizures prevents timely referral for brain surgery.



Access

Many epilepsy patients who need advanced diagnostics and treatments can't access them. Access to medical care traditionally depends on where you live – the notorious 'postcode lottery' – and epilepsy expertise is concentrated in metropolitan centres. In some parts of Australia, epilepsy patients may never even be seen by a neurologist.



Cost

The financial burden of epilepsy for both individuals and the Australian economy is substantial. **Those living with epilepsy see a 26% loss in Productivity Adjusted Life Years (PALYs)**, which significantly impacts their livelihoods and careers. This loss of productivity, combined with the direct healthcare costs of treating and managing epilepsy, costs the Australian economy \$12.3 billion every year¹, making epilepsy the second most burdensome neurological disease after dementia.

The AEP has developed a bold and novel solution to these problems, which is already delivering tangible healthcare outcomes for Australian epilepsy patients, while also building the foundation for future scientific breakthroughs in the understanding and treatment of epilepsy.

As we approach the latter phase of the project and plan our transition to a sustainable delivery model, we are proud to share this report, providing a snapshot of our achievements and impacts to date.

[1] Deloitte Access Economics, 2019

Providing access for epilepsy patients across Australia

The AEP has built a network of MRI scanning sites across Australia to provide epilepsy patients with access to advanced diagnostic testing that is otherwise only accessible to a small number of patients each year.

AEP participants undergo a comprehensive advanced MRI protocol designed to detect epilepsy-related changes in brain anatomy and cognitive functions such as language and memory. Expert radiological evaluation is used to pinpoint the specific area of the brain responsible for seizures to assist in surgical planning for people with severe epilepsy. Additionally, participants receive a mailed genetic self-testing kit to screen for chromosomal abnormalities and complete a guided online cognitive assessment using our proprietary Telehealth Enabled Neuropsychology Testing (TENT) tool.

To date, over 1,500 patients have been referred to the AEP by one of 160 neurologists registered with our project. Our national network has ensured that epilepsy patients across regional and remote Australia – from Albury and Mildura to Eight Mile Creek and Humpty Doo – have access to gold standard care that is usually only available in specialist epilepsy clinics in major metropolitan hospitals, breaking down the bricks and mortar barriers of traditional postcode-based healthcare.

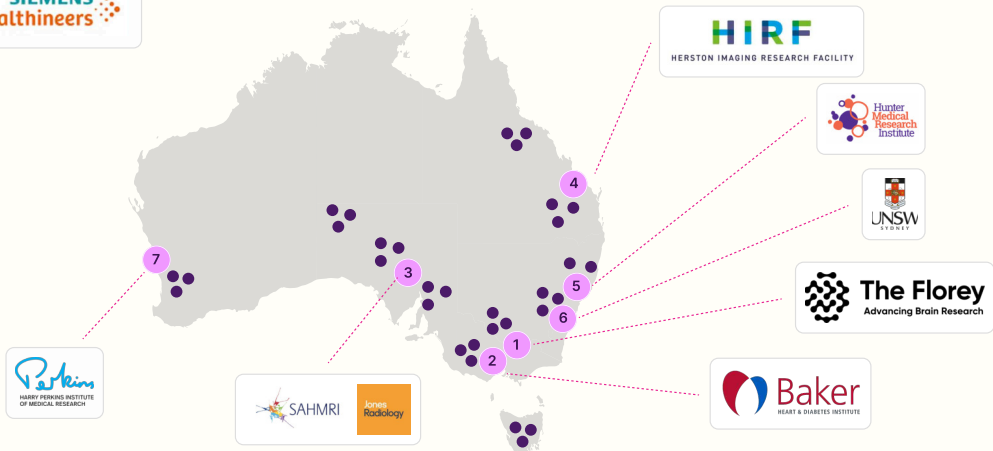
National Network Partners:



7 scanning sites across 5 states

160 clinicians registered to refer to the AEP

- Scanning site
- Patients & clinicians



1,500+

patients referred to participate in the AEP

49%

with drug-resistant epilepsy

34%

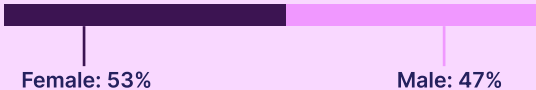
newly diagnosed with epilepsy

17%

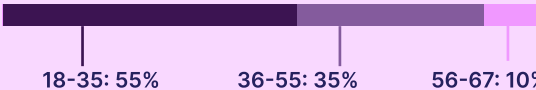
have had a first seizure but don't yet have a diagnosis



Participants' gender



Participants' age



Feedback from participants and clinicians:

77*

Participant NPS

75*

Clinician NPS

★★★★★

"I've honestly found the AEP life changing. Very thankful!"

Rural/remote participant

★★★★★

"The types of opportunities offered as part of the AEP study give me hope I may find an answer."

Rural/remote participant

★★★★★

"[With the AEP], it seems like every avenue is being investigated as to the cause of my seizures."

Rural/remote participant

★★★★★

"You gain better access to more in depth testing."

Regional participant

★★★★★

"[The AEP has given me] the opportunity to take part in a thorough process to establish causation and diagnosis."

Rural/remote participant

* NPS of 70-100 is considered 'Excellent' and is far above the industry standard. The Australian Healthcare Index 2021 reports the average NPS for GPs as 50, and advises that healthcare providers should aim for an average NPS of 30 (30-69 being 'Great').

Life-changing benefits for epilepsy patients

The AEP was designed to deliver tangible outcomes to participants from day one. First and foremost, this comes in the form of the AEP Report – a detailed report with results of the AEP testing sent to the participant’s referring neurologist. The report serves as a decision support tool, to guide optimal treatment selection for patients.

950 AEP Reports have been delivered to neurologists to date. As a direct result of these reports, neurologists have been able to identify or rule out brain lesions that are causing their patients’ epilepsy. In some cases, patients have been referred for surgery – which has potential to provide them with freedom from seizures – within two years of their epilepsy diagnosis. This is in stark distinction to the typical journey for epilepsy patients, which can see a period of up to 20 years elapse between first seizure and surgery.

AEP testing is also picking up genetic abnormalities that could be causing or contributing to patients’ epilepsy but would otherwise have remained undetected. In addition, AEP Reports are providing doctors with an insight into their patients’ mental health status and cognitive profile, which may influence their choice of anti-seizure medication or help them to better understand patients’ concerns about issues such as memory loss or mood changes. Based on the 6, 12 and 24 month follow-up data we collect from project participants, we are also starting to see significant downstream impacts on patients’ longer term health outcomes and quality of life.

 **950**

AEP Reports delivered to referring neurologists

How the AEP Report is helping patients

Neurologists have told us about some of the ways the AEP Report has helped them with diagnosis and treatment plans for their patients:

- “Since definitely MRI-negative, we will pursue advanced non-invasive investigations prior to considering SEEG (a surgical solution)”
- “Confirmed structural abnormality strongly associated with epilepsy (polymicrogyria)”
- “[Patient] has a structural abnormality that was not identified on previous MRI”
- “Genetics identified previously unknown issue”
- “High anxiety scores useful to flag to psychiatry team”

 **10%**


of AEP MRI scans have identified previously undetected epileptogenic lesions

 **1 in 30**

participants have been identified as having abnormal genetic results contributing to their epilepsy

 **1 in 2**

participants have been identified as being of high risk of depression or anxiety disorder

 Neither advanced MRI, genetic testing nor cognitive screening are common early in the epilepsy patient journey. When undertaken at the point of diagnosis or first seizure, these tests can have a significant impact on patients' trajectory.

Our early analysis of patient follow-up data is suggesting that AEP participants are experiencing, on average, the following benefits over 2 years:

 **8%**

improvement in quality of life

 **6%**

decrease in levels of depression/ anxiety

 **8%**

reduction in seizure frequency

 **9%**

improvement in work productivity (for those reporting impairment)

The above figures are unpublished findings based on internal analysis and modelling of baseline and 24-month follow up data available at the time of writing (manuscripts pending).

Participant stories



William Campbell

William had been having episodes described as 'dissociative events' since the age of 12 or 13. Prior to his diagnosis, these events had intensified and he was experiencing up to three per day. He had also recently had his first tonic clonic seizure. However MRI scans ordered by William's doctors had returned with normal results. In February 2023, the AEP testing protocol revealed an abnormality – a right hippocampal sclerosis. This result opened up the option for surgery for William and a possible cure for his epilepsy. In November 2024, less than 2 years since his diagnosis, William underwent brain surgery – a right temporal lobectomy. He has been seizure free since then.

"Access to the resources at the AEP changed my life," says William. "To finally know what was going on with my epilepsy shouldn't have taken 10 years. It is my hope that the work at the AEP will lead to better outcomes for people like me, both in the long-term from the research conducted, and immediately by providing proper diagnoses of epilepsy."

Wendy Randall

Wendy was working as a nurse in a regional private hospital when she had her first seizure at the age of 42. Over the next 11 years, she experienced frequent seizures, often daily. She was prescribed numerous medications, but none of them worked. In 2017, four years after her first seizure, she was admitted to hospital for video EEG monitoring. She had a seizure while being monitored, but still no reason for her epilepsy could be found. In 2024, Wendy came across the AEP on Facebook and filled in an expression of interest. The AEP team contacted her neurologist, Dr Elizabeth Reyneke, who referred her into the project. The AEP's unique sequence of MRI scans revealed a number of temporal encephaloceles in her brain – a potentially curable cause of her seizures.

"Everybody else gave up on me especially my doctors. But I was going to fight this time because I had a grandson and I couldn't hold him, I couldn't look after him and I was devastated. One day I found the AEP I didn't know anything about it, but it's been a magical experience. [They] found things that could be the true cause of my seizures. I'm so glad I reached out to them."

Wendy is currently undergoing further monitoring and investigations for possible surgery.



A 34-year-old male was referred to the AEP as part of the drug-resistant cohort. He had been experiencing seizures for nearly 20 years, with no clear cause identified from previous EEG and MRI tests. Within two months after referral, AEP testing revealed sclerosis in the right hippocampus. At the time of his 12-month follow-up, he was being evaluated for surgery, which could potentially cure his epilepsy.

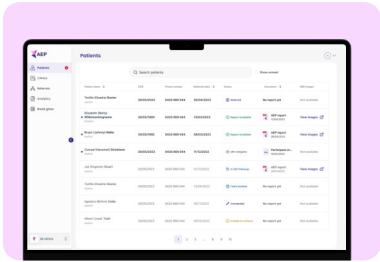
A 19-year-old female was referred to the drug-resistant cohort of AEP after experiencing seizures for 13 years. While her seizures had been stable for a time, they had recently worsened in frequency and severity, impacting her quality of life. Previous tests had shown no cause for her seizures. AEP's specialised epilepsy MRIs revealed focal cortical dysplasia, a disorganisation of brain cells. She was subsequently referred for video EEG monitoring in preparation for surgery.

A 53-year old female was referred to the AEP after filling in an expression of interest via our website. She had been experiencing seizures for 11 years which had become longer in duration and were followed by post-ictal symptoms that could last all day. Multiple brain scans had failed to identify any clear abnormalities. The AEP MRIs detected multiple temporal encephaloceles – a likely cause of seizures. At the time of the AEP's 6-month follow-up, the patient was being assessed for surgery, which could potentially see her become seizure-free.

World-class technology and AI solutions

The AEP would not be possible without the innovative technology platform we have built in-house to meet the specific requirements of the project and its users. It includes a clinician portal to enable simple and fast interactions for participating neurologists; a cloud-hosted platform that provides secure and scalable data storage and processing capabilities; interfaces between multiple systems to support complex data flows; and automations that allow us to generate the AEP Report in minutes rather than hours.

A key feature of the platform is its use of machine learning to analyse and identify empirical patterns across the vast and varied multi-modal data we collect. This capability is enabling us to develop predictive algorithms to address some of the key areas of uncertainty in the treatment of epilepsy. While our technology platform has been developed specifically for the AEP, it is being designed and built in such a way that it can be readily adapted for other neurological conditions. It has already being recognised as a leader in digital health solutions.



Clinician portal

The AEP Clinician portal is an AI-enabled, secure online portal that allows neurologists to refer patients into the AEP, track progress, receive notifications and view AEP Reports. The portal also includes a built-in MRI viewer and AI-powered Medical History Explorer which allow clinicians to review primary data to support their clinical decision making, as well as AI-generated patient summaries, document versioning and other patient data focused functions.



Automation

Manually processing of all the data is not feasible for a large-scale project like the AEP, which has thousands of participants and hundreds of thousands of data points. The AEP Technology Team has developed an automated pipeline that extracts, processes and delivers the information for the AEP Report and research datasets. It includes automated data quality checks to ensure veracity of the outputs. Machine learning and AI processes are natively incorporated into the processing pipeline.



Merging of multimodal data

The AEP Data Nexus has been developed to merge the vast and varied data we collect, so it can be analysed and processed using the latest machine learning, AI and data science techniques. The Data Nexus tracks data provenance and keeps a record of which versions of algorithms, machine learning models and training data were used in the creation of the resultant information. The system supports the chaining of sequential machine learning models, allowing for smaller and more understandable models, a requirement for the use of AI in clinical settings.



Image processing

The AEP was born out of leading brain imaging research. The techniques developed over decades by our research team have been enhanced and automated through the AEP into a standardised and repeatable process, which includes a unique MRI protocol specific to epilepsy, data collection from MRI devices and a robust processing pipeline including image filtering, analysis and quantification techniques. This complex image processing pipeline has enabled a significantly higher detection rate of clinically relevant abnormalities.



TENT

Our stand-alone Telehealth Enabled Neuropsychology Testing (TENT) product supports comprehensive cognitive assessments from the comfort of participants' homes. This examiner-led, computer-assisted videoconferencing approach gathers data that is comparable to or even better than traditional in-person, paper-based testing. By harnessing the underlying technology, it offers the added advantage of automated and immediate control-normalised scoring, access to novel data and meta-data types (e.g. mouse clicks, precise response timing) and native electronic records readily ingested into a centralised database.

Recognition for our platform



The AEP was invited to deliver a keynote presentation at the Amazon Web Services (AWS) Public Sector Symposium in Canberra in August 2024, where it was recognised as “pioneering a transformative platform” in Australian healthcare.



The TENT tool developed by the AEP is already being used by other major research studies including the Monash University SeLECT study, a Phase II clinical trial of sodium selenate in epilepsy, and the MRFF-funded Young Stroke Service. Negotiations are also underway with major research groups across Europe and the US to roll out TENT as part of large-scale projects targeting epilepsy and neurological diseases more broadly.

Rich dataset for research and precision medicine

Precision medicine has for some time been recognised as one of the most transformative trends in healthcare, with the potential to offer patients more accurate and personalised diagnosis, prediction and treatment. Advances in precision medicine are dependent on the availability of high quality, well-curated data across multiple modalities, combined with the analytical power now available thanks to advances in machine learning and artificial intelligence.

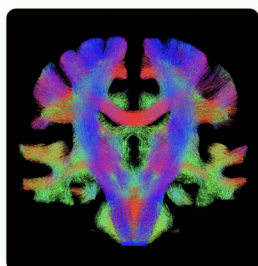
The creation of such a dataset is a key objective of the AEP. Through the integrated analysis of our multi-modal testing data, combined with longitudinal outcomes data, we are seeking answers to the most pressing research and clinical questions for people living with epilepsy: Why did I have a seizure? Will I have another one? Will medication work for me? Am I a good candidate for surgery? In addition, our unparalleled dataset will provide the global research community with a rich resource for addressing many traditional scientific and mechanistic questions in epilepsy.

AEP researchers have already published important new scientific findings based on early analysis of AEP data, while our data scientists are generating predictive insights for clinicians based on statistical similarity of first seizure patients to a comparable cohort.

Advancing the understanding of epilepsy through collaborative research

The Australian Epilepsy Project (AEP) welcomes external researchers to leverage our comprehensive dataset to drive innovative studies and insights that can improve epilepsy care and outcomes.

Request data access 



Scan the QR code to request access to AEP data.



Researchers around the world can request access to AEP data for 500 epilepsy participants and 300 healthy controls aged 18-67.

Data includes:

- ✓ Genetics - molecular karyotype and copy number variant
- ✓ Cognitive assessments
- ✓ High resolution MRI images
- ✓ Self report questionnaires including QoLiE-31, EQ5D, WPAI, Healthcare service Utilisation, Big Five Inventory and Sleep Condition Indicators

Selected research findings from the AEP:

We developed an imaging protocol for dual research-clinical use, targeting detection of subtle epileptogenic lesions, and assessing feasibility within the patient group. Using data from our pilot study, we demonstrated that the protocol was feasible for a clinical group of people with seizures, and sensitive for epileptogenic lesions, with detection rates in a first-seizure cohort either comparable or exceeding previous studies.

Vaughan et al (2022), American Epilepsy Society Annual Meeting

Our work using a telehealth neuropsychology approach has demonstrated that cognitive issues are present before a formal diagnosis of epilepsy, suggesting that they are caused by the same underlying brain disturbance that is causing the seizures, rather than secondary effects. This finding also provides evidence for cognitive screening of all new epilepsy cases to promote early management of cognitive problems.

Pugh, et al (2024), *Epilepsia Open*

Our analysis of the AEP pilot dataset found that iron and related mineral deposition in the brain appears to be stable over the course of focal epilepsy. These findings contribute to current research in epilepsy that seeks to determine how the brain is affected by ongoing seizures.

Vaughan et al (2023), publication under review

We have developed statistical methods for combining MRI data acquired from multiple imaging centres. These methods include both human imaging data and the use of MRI 'phantoms' – devices that are designed to mimic properties of human brain tissue and can be used to calibrate MRI scanners.

Pierre et al (2023), ISMRM annual meeting

AEP data has been used to incorporate temporal lobe encephalocles as a common data element in the National Institute of Health (NIH) form for brain MRI in epilepsy. These are compiled by the NIH to facilitate standardised data collection and to allow for comparison and harmonisation of datasets across studies.

<https://www.commondataelements.ninds.nih.gov/epilepsy>

Our health economics team has used AEP data to develop novel models demonstrating the economic burden of epilepsy for Australia. Investigating quality of life, employment and related healthcare requirements for participants in our pilot study, the team found that long-term drug-resistant epilepsy is associated with reduced quality of life and participation in the workforce. This work may be used to inform government and healthcare policies to deliver care for people with epilepsy.

Marquina et al (2024), *Epilepsia Open*

66

AEP academic publications to date

Scan the QR code to view a selection of AEP publications.



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Scan the QR code to visit our
website and learn more about
the AEP.

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The Australian Epilepsy Project (AEP) acknowledges the Traditional Owners of the land on which we work,
the Wurundjeri people of the Kulin Nation. We pay our respects to their Elders past, present and emerging.



The Florey
Advancing Brain Research

