Genomics and precision medicine in epilepsy care

InGeNA response to the Senate inquiry report

22 September 2026

InGeNA welcomes the Senate Community Affairs References Committee's report *Epilepsy in Australia*, tabled on 17 September 2026. Its findings strengthen the case for earlier genetic diagnosis and better integration of genomics into routine epilepsy care. The next step is to translate that direction into services people can access and use to improve their care. [1]

Our submission to the inquiry called for a nationally coordinated epilepsy genomics and precision medicine pathway. We thank the people with epilepsy, families, carers, clinicians and organisations whose evidence informed the inquiry. Genomics belongs within the report's broader agenda for better treatment, support, workforce capability and equitable access. [1, 2]

How genomics can inform care

Epilepsy has many causes and affects people differently. For some people, genomic testing can identify a genetic cause, guide medication choice or avoidance, inform specialist referrals and help identify suitable clinical trials. Precision medicine uses this information alongside other clinical evidence to tailor care. Testing does not always provide a diagnosis, and a genetic diagnosis does not necessarily identify an available targeted treatment. [1, 2]

The report cites InGeNA's evidence on delayed diagnosis and the clinical value of precision medicine, including "reducing prolonged trial-and-error treatment where a more targeted approach is available". It also cites our concerns about assessment and reimbursement for rare genetic epilepsies. These passages reflect important elements of our submission. [1, paragraphs 3.53, 4.68 and 4.102]

What the Senate recommends

Several findings are directly relevant to InGeNA's priorities:

- **Earlier testing and access for adults.** Recommendation 7 asks government and stakeholders to investigate opportunities to improve access to genetic testing early in diagnosis and offer it to adults with longstanding epilepsy.
- **National care pathways.** Recommendations 1 and 4 call for a National Epilepsy Action Plan and optimal care pathways. The committee also explicitly encourages Genomics Australia to include epilepsy in its work integrating genomics into routine healthcare.
- **Clinical trials and precision treatments.** Recommendation 14 calls for reviewing clinical-trial regulation and funding, including N-of-1 trials involving an individual patient. The committee separately supports implementing the Health Technology Assessment Policy and Methods Review findings in full.
- **Better data and research.** Recommendations 15 and 16 propose a national epilepsy registry and a targeted research call. The committee's discussion includes genomic testing, personalised treatment and links between patients and trials.
- **Services and workforce.** Recommendations 3 and 8–10 address epilepsy workforce planning, comprehensive epilepsy centres and national standards. These are important foundations for accessible specialist care. [1]

Turning recommendations into routine care

The report supports the direction of reform. Funding, eligibility, workforce and delivery arrangements still need to be settled before its recommendations can become accessible services. [1]

InGeNA calls on the Australian Government, working with states and territories and the epilepsy community, to develop a nationally coordinated genomics and precision medicine pathway. Building on our submission, that pathway should include:

- **Funding for the complete care pathway.** Cover clinically indicated testing, interpretation, counselling and appropriate follow-up, including reanalysis as knowledge evolves and links to treatment, trials and support.
- **Clear and consistent testing access.** Establish a funded National Genomic Test Directory setting out indications, eligibility, ordering and funding arrangements, including for people who missed earlier opportunities for diagnosis.
- **Workforce and data capability.** Support genetic counselling, pathology, bioinformatics and clinical decision support, with secure, interoperable data that can connect diagnosis, treatment and outcomes under appropriate consent and governance.
- **Assessment suited to precision medicine.** Develop assessment and reimbursement approaches that can evaluate genomic tests and therapies for small patient populations, alongside evidence on medication response and safety. [2]

The Test Directory, routine reanalysis and detailed genomic data infrastructure remain InGeNA proposals rather than measures specified in the report. The proposed registry offers an opportunity to consider connections between clinical and genomic data.

Access must be designed around people's circumstances, including rural and remote communities, First Nations people and culturally diverse communities. Genomic information should support care planning and must not become a requirement for disability or social support. Progress should be measured through timeliness, access to appropriate care and patient and family outcomes. [2]

Working together on implementation

InGeNA's members bring expertise across diagnostics, technology, data and therapeutics. Collaboration with clinicians, researchers, governments and people with lived experience can help identify practical delivery options. Members can contribute evidence on access barriers, workforce needs and approaches that improve care.

Dame Professor Sue Hill's visit to Australia, hosted by InGeNA from 12 to 16 October 2026, offers a timely opportunity to learn from England's experience of making genomic medicine a routine health service. Epilepsy provides a concrete example for discussing how those lessons could inform delivery in Australia. [3]

We call for sustainable, equitable services that connect genomic testing with appropriate care and support, wherever a person lives.

Sources and further reading

1. Senate Community Affairs References Committee, Epilepsy in Australia, September 2026. See paragraphs 3.53, 4.68, 4.102, 7.47–7.51, 7.79 and 7.85–7.93, and Recommendations 1, 3, 4, 7–10 and 14–16. Quoted text © Commonwealth of Australia, CC BY-NC-ND 4.0.

2. InGeNA submission to the Senate Inquiry into Epilepsy in Australia, Submission 135, 15 May 2026, especially pages 1–2, 4–5 and 8–11.

3. Dame Professor Sue Hill to visit Australia in October 2026, InGeNA, 30 July 2026.