A Shared Vision for the Future

Rare and Complex Epilepsies in Australia

PREPARED FOLLOWING THE DEE ROUNDTABLE
AUGUST 2026

COLLABORATION
EVIDENCE
IMPACT

Executive Summary

Developmental and Epileptic Encephalopathies (DEEs) are severe, genetically driven neurodevelopmental disorders. Epilepsy is only one feature of this complex, multi-system and lifelong condition. Treating DEEs as a subset of epilepsy understates their impact and produces the wrong system response. They require coordinated action across health, disability, education, research and social systems.

Throughout this Report, DEEs are also referred to as Rare and Complex Epilepsies, a term that reflects the severity and breadth of these conditions rather than narrowing them to a clinical label. The rationale for this shift is set out in the Introduction.

Australia does not lack expertise. It lacks the national mechanisms to align and deploy it. Strengths in clinical care, diagnostics, research, disability, education, policy and advocacy are disconnected. Families pay the price for that fragmentation through delayed diagnosis, inconsistent multidisciplinary care, disability and education systems that cannot respond to complexity, and inequitable access to emerging precision therapies. These are not isolated service gaps. They are the predictable consequences of a system without national leadership.

The current Senate Inquiry and heightened political attention create a time-limited window for reform. That window must be used to secure national recognition, investment and accountability for Rare and Complex Epilepsies. Other rare disease communities have shown that a unified national voice can convert fragmented effort into policy change.

The DEE Roundtable 2026 brought together patient advocates, clinicians, researchers, policymakers, industry and other sector leaders to determine what must happen next. A clear mandate emerged: Australia must establish a national organisation with the authority, representation and capability to lead the sector.

The National Rare and Complex Epilepsies Collaborative is the sector's chosen mechanism for national coordination. It will bring stakeholders together to align Australia's fragmented ecosystem, agree shared priorities, inform policy and system reform, accelerate research translation, improve care and strengthen advocacy for equitable access to emerging therapies. Its task is not simply to convene. It is to enable expertise and consensus to inform coordinated national action across health, research, disability and education.

Executive Summary

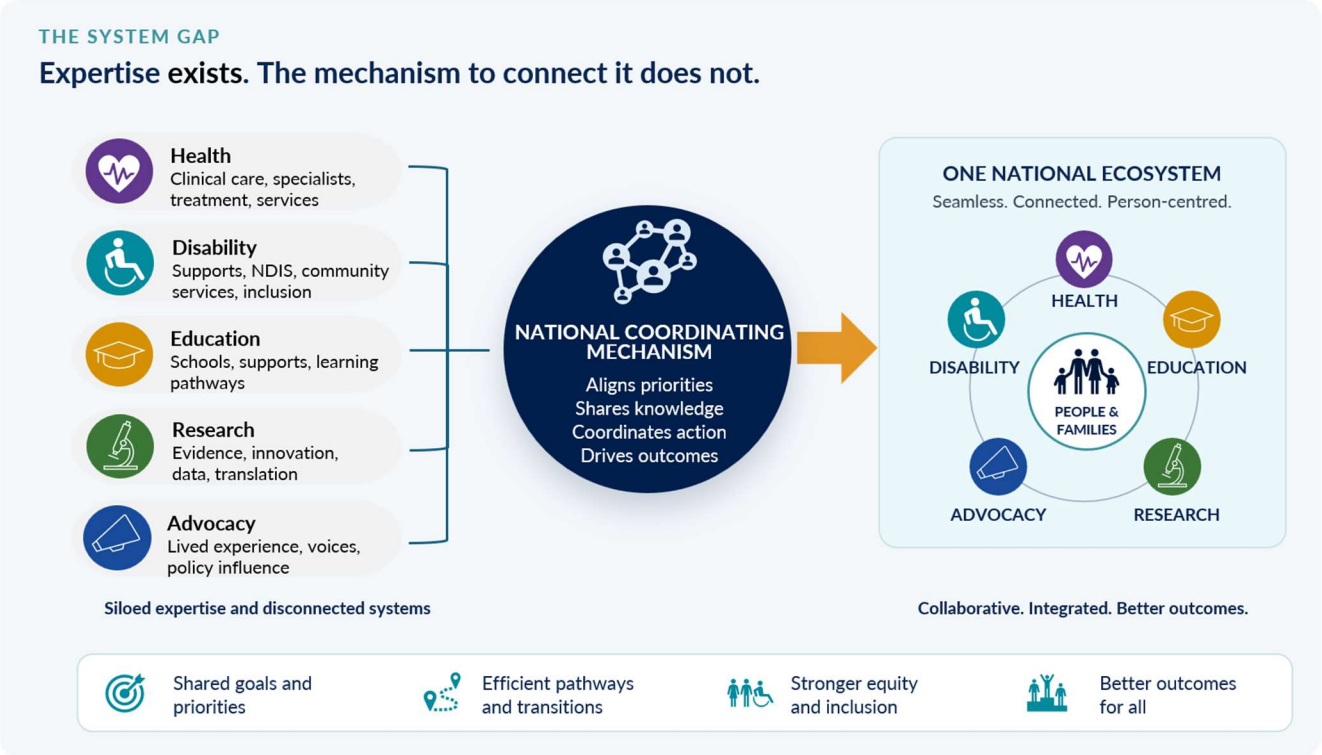


Figure 1. Australia's Rare and Complex Epilepsies systems today, and the same systems coordinated through the Collaborative.

The legitimacy of the Roundtable process, bringing together stakeholders from across the Rare and Complex Epilepsies landscape to collaboratively design the sector's future, is central to the strength of the Roundtable consensus and a critical enabler of the reforms it calls for.

This Report is not a record of discussion. It captures the sector consensus to move from fragmented goodwill to coordinated national delivery.

Purpose

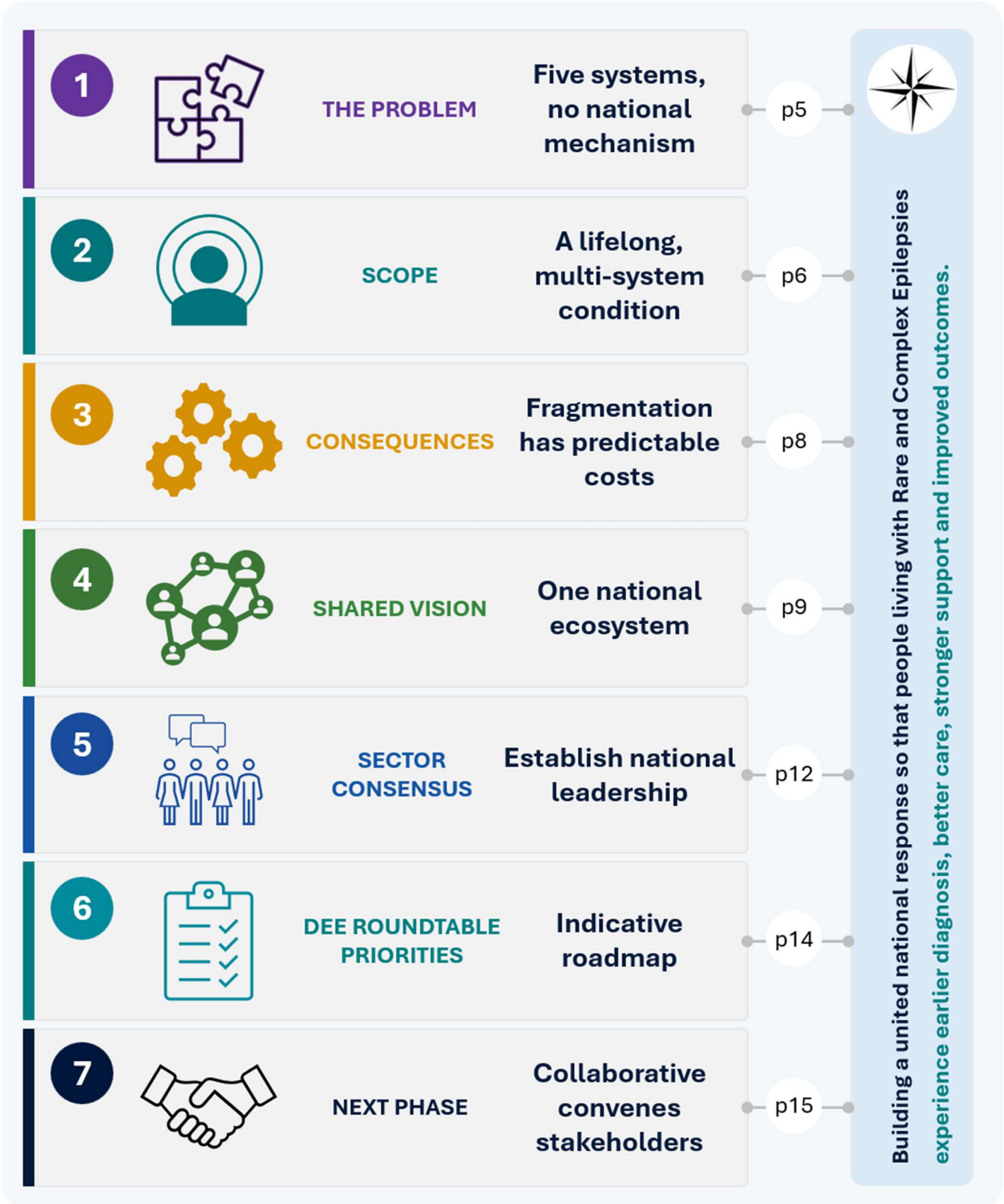
This Report establishes the basis for coordinated national action, recording the sector consensus reached by stakeholders in the Rare and Complex Epilepsies sector during the Roundtable. It sets a direction for the Steering Committee, and the broader sector, to develop the mechanisms for national coordination, and provides the evidence base underpinning the Roundtable's recommendations: the foundation for advocacy and funding proposals to further develop the collaboration model.

The purpose is practical: to turn consensus into decisions, decisions into funded work, and funded work into measurable improvements for people and families.

A companion Methodology Report sets out the full design, facilitation approach and data collection methods behind this Report's findings.

Report-at-a-Glance

From system gaps to a connected response



1 The Problem

Across health, disability, education and social systems, Rare and Complex Epilepsies are typically folded into the broader category of epilepsy. Neither the evidence nor the lived experience of families supports this. Families are not falling through gaps in one system; they are falling through gaps in every system, and none of these systems can meet their needs in isolation. Only coordinated national leadership can address the cross-system fragmentation currently experienced by people living with Rare and Complex Epilepsies (Pierce et al. 2025).

The insights in this report, drawn from the Roundtable and the consultation process that preceded it, set out why.

National Coordination

No single system can meet the needs of people living with Rare and Complex Epilepsies in isolation. The sector is fragmented, with duplication of effort across organisations and gene groups, missed opportunities for shared leadership, and no mechanism to convene or coordinate stakeholders. Progress is fragile and uneven, dependent on individual champions rather than system design.

National Voice

The Rare and Complex Epilepsies landscape currently lacks a recognised, authoritative voice to represent all stakeholders, and particularly families. Advocacy is fragmented, government engagement is inconsistent, and policy settings do not reflect the complexity of these conditions. Establishing a national coordinated organisation is essential to influence policy, secure funding and drive systemic reform.

Figure 2. Five systems impacting patients and families with no formal coordination between them

2 Scope of the Challenge

DEEs are the most severe group of epilepsies. The International League Against Epilepsy (ILAE) formally recognised DEEs as a distinct category in its 2017 classification, recognising "developmental consequences arising directly from the effect of the genetic mutation, in addition to the effect of the frequent epileptic activity on development" (Scheffer et al. 2017).

Individuals with DEE experience a wide range of multi-morbidities, in addition to early-onset, usually drug-resistant, epilepsy. These include intellectual disability, autism, psychiatric and behavioural consequences, movement and musculoskeletal disorders, feeding and gastrointestinal problems, sleep disturbances, and an elevated risk of sudden unexpected death in epilepsy (SUDEP). DEEs are lifelong conditions, consistently associated with developmental slowing or regression (Scheffer et al. 2024). Most are genetically driven, each individually rare but collectively common; management depends on the underlying cause.

Population-based data estimate that DEEs collectively affect approximately 1 in 590 Australian children (Poke et al., 2023)

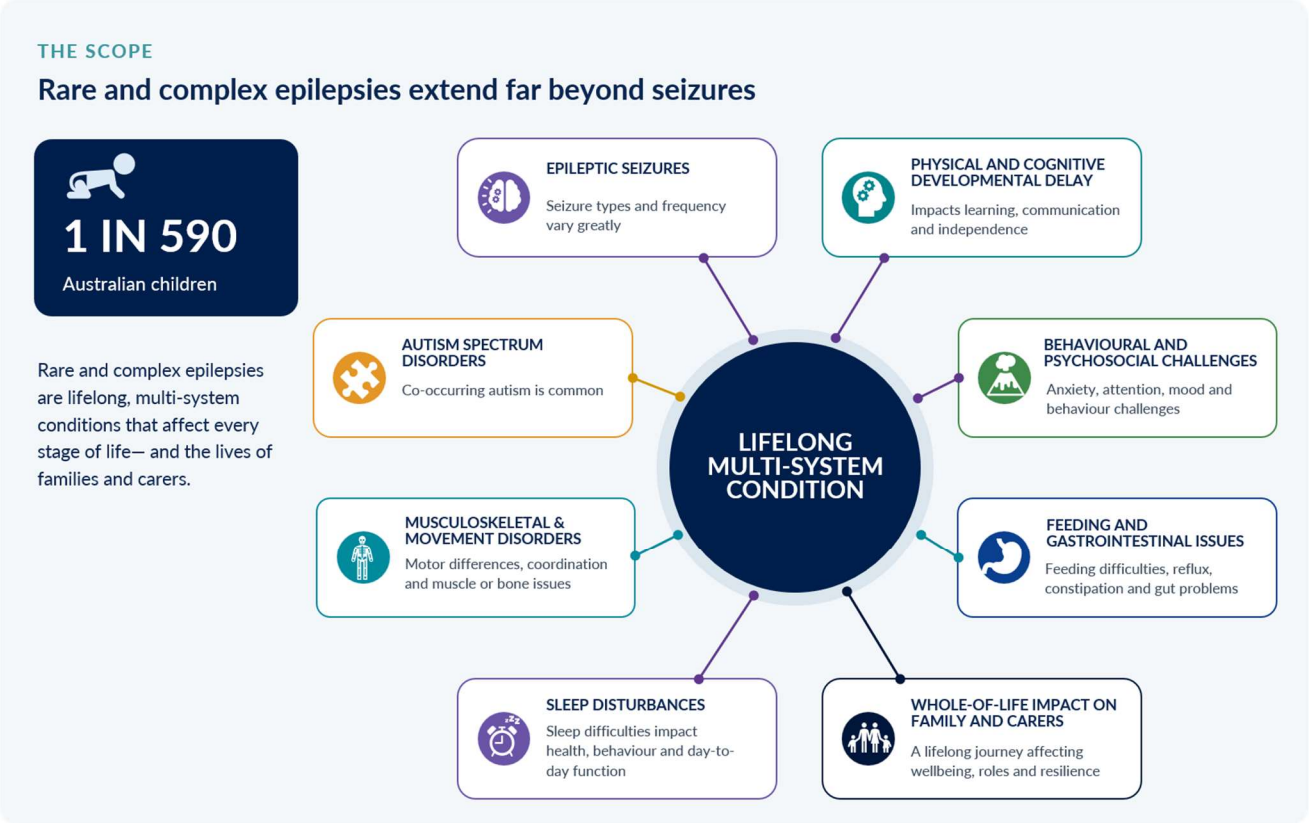


Figure 3. Persons born with a rare and complex epilepsy face a broad range of co-morbidities that have a lifelong impact on them and their families

2 Scope of the Challenge

A life-long, multi-system condition

This classification matters because it makes clear that DEEs impose a lifelong burden on affected individuals, families and society, and because it defines what good care looks like: managing a DEE well is not the same task as managing epilepsy well. The complexity and multi-system nature of DEEs requires lifelong, holistic and coordinated multidisciplinary management that extends beyond seizure control (Scheffer et al. 2024).

Throughout this Report, Developmental and Epileptic Encephalopathies (DEEs) remain the clinical classification. However, the Report also adopts the broader term Rare and Complex Epilepsies in recognition of a key area of consensus from the DEE Roundtable: that the term DEE, while clinically important, is not well understood outside specialist settings and does not readily convey the severity, complexity or whole-of-life impact of these conditions.

The use of Rare and Complex Epilepsies is therefore a deliberate public and policy-facing framing. It is intended to improve recognition among governments, funders, service systems and the broader community, without altering or replacing the clinical classification of DEE.

This distinction matters because the way these conditions are framed influences how needs are recognised and responded to. When they are understood primarily through the lens of epilepsy or seizures, the broader developmental, cognitive, behavioural, communication, movement, health and disability impacts can be overlooked, contributing to the fragmentation described throughout this Report.

3 Consequences of Fragmentation

Fragmentation has predictable costs

Recognition Beyond Epilepsy

Rare and Complex Epilepsies cannot be effectively addressed within an epilepsy-only framework. The current framing narrows care to seizure control and obscures the developmental, behavioural, cognitive, psychosocial and disability needs that define these conditions. This misalignment shapes every part of the system: clinical pathways focus on seizures rather than whole-condition management; policy settings fail to reflect multi-system impact; and adults fall out of paediatric-centric structures entirely. Establishing Rare and Complex Epilepsies as a distinct category is foundational to any coordinated national response.

> ***"I feel like I'm constantly having to explain that it's not just epilepsy, it's intellectual disability, it's language delay, it's behavioural challenges."***
>
> **— parent, DEE Roundtable family consultation**

Coordinated Lifelong Support

Families described overwhelming complexity and a lack of coordinated support across every stage of the journey: trauma from first seizures, repeated crises, years of being dismissed or disbelieved, exhaustion, burnout, post-traumatic stress disorder (PTSD), financial strain, and the toll of retelling their story to professionals who do not communicate with each other. The consequences are profound: inequity driven by geography, socioeconomic status, cultural background and health literacy; delayed access to supports; and avoidable distress.

> ***"The biggest challenge on a day-to-day basis is that our child needs full supervision all day, every day."***
>
> **— parent, DEE Roundtable family consultation**

Diagnosis, Treatment and Research

Access to diagnosis and treatment varies significantly across Australia. Families often rely on their own advocacy to drive investigations, secure genomic testing, or obtain specialist appointments. Diagnostic pathways differ between states, adults and late-onset presentations are particularly disadvantaged, and comorbidities such as sleep, gut, mental health, behaviour and cognition are frequently overlooked. Limited access to multidisciplinary teams and centres of excellence slows trial readiness and restricts participation in emerging therapies.

Integrated Systems

NDIS pathways are slow, unpredictable and not tailored to the complexity of Rare and Complex Epilepsies; schools lack condition-specific knowledge; and community providers often misunderstand the condition entirely. Families from Culturally and Linguistically Diverse (CALD) backgrounds, First Nations communities, and rural and remote areas face additional barriers, and siloed data systems prevent coordinated care.

Research Translation

Australia has world-class research capability, particularly in genomics, natural history studies and early-phase drug development, but research efforts are fragmented, with duplication across gene groups, inconsistent coding and classification, and limited visibility of who is doing what. Regulatory frameworks are not suited to rare and ultra-rare diseases, and biobank and brain bank infrastructure is inadequate.

4 Shared Vision

The Roundtable gave key stakeholders from across the Rare and Complex Epilepsies landscape the opportunity to unite around a shared vision for the future. The strength of consensus among attendees as to what that future looks like underpins the shared direction set out in this Report.

Central to this vision is the National Rare and Complex Epilepsies Collaborative, a national organisation that addresses the System Gap described above, providing leadership and multi-stakeholder representation for the sector.

> ***The Collaborative will bring together patient groups, clinicians, researchers, governments and advocacy organisations within a nationally coordinated, equitable and person-centred Rare and Complex Epilepsies ecosystem. Through an integrated ecosystem model that shares knowledge and expertise, shares leadership, and mobilises champions across clinical care, research, policy, and advocacy, it will enable stakeholders to align fragmented efforts and support progress toward consistently high-quality care, world-class research and development, education and awareness, and lasting system reform. The proposed Collaborative will seek government support to advance equity for people and families affected by Rare and Complex Epilepsies, including recognition, investment and access to support on par with other lifelong conditions***

Figure 4. The Australian Rare and Complex Epilepsies ecosystem: one national collaborative connecting people, evidence and action.

4 Shared Vision

People & Families - People living with Rare and Complex Epilepsies and their families experience a system that is coordinated, navigable and centred on their needs across the lifespan. They have access to specialist nursing, care coordination and navigation that supports seamless pathways across diagnosis, treatment, disability, education and social services.

People and families can draw on a single, trusted source of information about Rare and Complex Epilepsies, from understanding conditions and care pathways to accessing emerging and precision therapies. Digital tools improve access and provide practical resources, including a Rare and Complex Epilepsies toolkit designed with and for people and families.

Clinicians - Clinicians work within connected specialist networks and a nationally consistent, co-designed model of care, supported by multidisciplinary teams and aligned with international standards. Timely genomic diagnostics are available nationally, enabling earlier and more accurate diagnosis of Rare and Complex Epilepsies and supporting appropriate care, research participation and access to emerging therapies.

Clinicians have access to best-practice guidance and clear pathways across health, disability and community services. Geography, institutional setting and local resourcing no longer determine whether people and families can access coordinated, high-quality care.

Researchers - Researchers work within a connected, data-enabled national research ecosystem with shared priorities and infrastructure. Shared datasets, meaningful measures of real-world impact and quality of life, and improved disease classification and coding enable deeper understanding of Rare and Complex Epilepsies and more targeted research.

Researchers can collaborate across institutions, disciplines and jurisdictions, with stronger pathways from discovery to clinical translation. Australia is internationally recognised for aligned research priorities, trial readiness, genomics capability and meaningful involvement of people and families in research.

4 Shared Vision

Policymakers - Policymakers have a clear national understanding of Rare and Complex Epilepsies, supported by consistent definitions, evidence and lived experience that inform policy, funding, service design and health and disability pathways.

They have established mechanisms for engaging with the Collaborative and accessing coordinated sector expertise. Stronger connections across Commonwealth, state and territory governments, the NDIS and other relevant systems support more coherent policy and reduce fragmentation. Champions within government help translate evidence and identified priorities into sustained reform.

Advocates - Advocates work across organisations, communities and jurisdictions around shared priorities for Rare and Complex Epilepsies. Alignment on core messages and policy priorities strengthens their ability to engage decision-makers while preserving the distinct voices, expertise and identities of individual organisations and communities.

Advocates have clear mechanisms for bringing lived experience and community priorities into the Collaborative and for taking shared evidence and messages back to their own communities. Together, they strengthen the national voice for Rare and Complex Epilepsies and increase its influence across local, state and Commonwealth policy.

Industry Partners - Industry partners see Australia as an attractive environment for responsible research, clinical development and investment in Rare and Complex Epilepsies. Connected clinical and research networks, appropriate access to research cohorts, national data capability and trial-ready infrastructure provide a strong environment for developing and evaluating new therapies.
Industry partners engage transparently and responsibly with researchers, clinicians, people and families, with clear principles governing collaboration and conflicts of interest. Strong partnerships support investment in Australian research and clinical trials and increase opportunities for Australians to participate in the development of emerging therapies.

5 Sector Consensus

THE SECTOR CONSENSUS

The minimum platform for reform

01 ESTABLISH NATIONAL LEADERSHIP
A permanent mechanism across organisations and jurisdictions

02 CONTRIBUTE TO NATIONAL ACTION PLANNING
A broader epilepsy plan with a dedicated rare and complex plan

03 AGREE PRIORITIES THROUGH THE COLLABORATIVE
Relevant stakeholders determine how priorities are taken forward

The Roundtable reached alignment across lived experience, clinical care, research, policy, advocacy and industry.

The recommendations below are not a menu of options. Together, they form the minimum platform for reform.

THE INTEGRATED ECOSYSTEM MODEL

A national hub that aggregates expertise and coordinates action

A Rare and Complex Epilepsies coordinating organisation will play a system integrator role. It will work with a network of partner organisations to collaboratively set national priorities, provide a single voice to all stakeholders, coordinate action and align funding to projects addressing the greatest needs.

Figure 5. The integrated ecosystem model: The Rare and Complex Epilepsies coordinating organisation convenes the Collaborative and works with partner organisations to establish priorities and then provides a consistent voice to all parties and coordinates action and funding across the sector.

5 Sector Consensus

National Collaboration Model

Australia requires a permanent mechanism that can provide leadership across organisational and jurisdictional boundaries. The Collaborative will bring together the existing strengths, support partner organisations to agree shared priorities, contribute to consistent standards and hold the national agenda together when individual projects, leaders or funding cycles change.

Contributing to National Epilepsy Action Planning

The Collaborative will contribute to the development of a broader National Epilepsy Action Plan, with a dedicated Rare and Complex Epilepsies Action Plan sitting within it. Through the Collaborative, relevant stakeholders would determine how the priorities identified by the DEE Roundtable should inform action planning across health, disability, education, research and community systems. This could establish a shared understanding of national standards of care, diagnostic pathways, and models of practice; support equitable access to genomic testing, multidisciplinary teams, and centres of excellence; and inform priorities for investment, workforce development, and data infrastructure. It would help reduce the “postcode lottery” currently experienced by people living with Rare and Complex Epilepsies and embed lived experience insights into system design and evaluation.

National Organisation

From the collective voices of the Rare and Complex Epilepsies community, strong sector-wide agreement has emerged: to establish a national organisation that provides leadership and multi-stakeholder representation for the sector. A Rare and Complex Epilepsies coordinating organisation will convene the Collaborative with partner organisations and would serve as the unified voice for Rare and Complex Epilepsies, providing authoritative advice to governments, coordinating stakeholder input across systems, and supporting the sector to contribute to the broader National Epilepsy Action Plan and the dedicated Rare and Complex Epilepsies Action Plan within it.

The Collaborative would not duplicate existing strengths; it would build on them, operating through the integrated ecosystem model described. It would ensure that undiagnosed families, adults, and those from diverse backgrounds, including CALD, First Nations, and rural and remote communities, are included in national coordination.

Roles, Responsibilities and Governance

The Rare and Complex Epilepsies coordinating organisation should be established as an independent, non-government entity with multi-stakeholder governance. Its roles and responsibilities should include:

- Leadership and coordination across the Rare and Complex Epilepsies landscape
- Policy and systems engagement, including structured government liaison
- Development of national standards of care, diagnostic pathways and models of practice
- Coordination of research and data, including national registries and harmonised coding
- Workforce development, including training for clinicians, allied health, educators and disability providers
- Navigation and family support, including nurse navigators and peer system navigators
- Awareness and education, including national campaigns and co-designed toolkits
- Alignment with national and international frameworks

Governance should include lived experience, clinical experts, researchers, advocacy organisations and policy leaders, supported by advisory groups focused on specific domains such as research, clinical care, disability, education and data.

6 DEE Roundtable Priorities

The Roundtable identified priorities for a connected national response. The timeframes are indicative: sequencing, implementation and accountability will be determined collaboratively with relevant stakeholders.

An indicative roadmap to national impact

7 Next Phase

From Consensus to Action

> ***The consultation phase has established the basis for action. The next phase is to establish the Collaborative and bring stakeholders together to determine how the Roundtable priorities are taken forward.***

The Steering Committee will support the transition to an interim establishment group with the representation, authority and capabilities required to establish the Collaborative. Immediate priorities are governance, stakeholder engagement, funding and government engagement.

The Committee will use the Senate Inquiry and the lead-up to the 2027 Federal Election to seek commitments to national recognition, establishment funding and government partnership. It will formalise sector participation through the integrated ecosystem model.

Funding is an immediate strategic priority. The Committee will pursue start-up investment to establish the Collaborative and enable stakeholder engagement on the Roundtable priorities, as well as a pathway to sustainable operating funding.

We will continue to communicate with the Rare and Complex Epilepsies sector, and we welcome and encourage you to reach out to the Steering Committee, via the contact details below.

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On behalf of the Roundtable Steering Committee

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Methodology

Background to the Roundtable

The DEE Roundtable 2026 built on the inaugural Roundtable held in 2019, *Developmental and Epileptic Encephalopathies: Improving Care*, and its resultant publication, 'Fulfilling the needs of caregivers in delivering health services to children with developmental and epileptic encephalopathies' (Kelada et al. 2025). While the 2019 Roundtable brought together key opinion leaders in the Australian landscape for the first time, the momentum felt on the day was not sustained. By 2025, Steering Committee members and other key opinion leaders agreed the strategic context had evolved enough for a further Roundtable to make a lasting difference.

The DEE Roundtable 2026: From Insights to Impact brought together patient advocates, clinicians, researchers, policymakers, industry and others to co-design practical, collaborative actions to improve outcomes for families affected by Rare and Complex Epilepsies in Australia. Its objectives were:

- To identify and articulate the key challenges and priorities of families across the care journey and life-course.
- To define a set of clear, realistic and meaningful goals for advocacy across key domains.
- To agree on a practical and coordinated pathway to deliver on these goals.

This Report draws on a structured, multi-phase engagement process: analysis of the Rare and Complex Epilepsies landscape; consultation with parents and carers via questionnaire and focus group; and a full-day Roundtable held in Brisbane on 1 May 2026, attended by approximately 55 individuals from 34 organisations, guided by independent facilitator Barrie Littlefield OAM.

Attendees worked through a series of facilitated workshops examining the current situation, the desired future state, and the barriers and drivers between them, before agreeing shared goals and agreement to establish a national coordinating body.

The full design, facilitation approach, stakeholder selection process and data collection methods are set out in the companion DEE Roundtable 2026 Methodology Report.5

References

Kelada, L., Best, S., Pierce, K., Allen, M., Cobb, J., Berens, K., Goranitis, I., Palmer, E.E., Scheffer, I.E. and Howell, K.B. (2025). Fulfilling the needs of caregivers in delivering health services to children with developmental and epileptic encephalopathies. European Journal of Paediatric Neurology, 54, 147-158. https://doi.org/10.1016/j.ejpn.2025.01.007

Pierce, K., Murphy, J.B., Robertson, E.G., Khan, J.R., Bullock, S., O'Loughlin, C.B., Loden, M., McIntosh, R., Beavis, E., Roberts, N., Palmer, E.E. and Lingam, R. (2025). 'Just realising that I wasn't alone... was profound': a mixed-methods evaluation of a pilot peer-to-peer wellbeing program for carers of children with rare epilepsies. Orphanet Journal of Rare Diseases, 20, 524. https://doi.org/10.1186/s13023-025-04036-0

Poke, G., Stanley, J., Scheffer, I.E. and Sadleir, L.G. (2023). Epidemiology of developmental and epileptic encephalopathy and of intellectual disability and epilepsy in children. Neurology, 100(13), e1363-e1375. https://doi.org/10.1212/WNL.0000000000206758

Scheffer, I.E., Berkovic, S., Capovilla, G., Connolly, M.B., French, J., Guilhoto, L., Hirsch, E., Jain, S., Mathern, G.W., Moshé, S.L., Nordli, D.R., Perucca, E., Tomson, T., Wiebe, S., Zhang, Y.H. and Zuberi, S.M. (2017). ILAE classification of the epilepsies: Position paper of the ILAE Commission for Classification and Terminology. Epilepsia, 58(4), 512-521. https://doi.org/10.1111/epi.13709

Scheffer, I.E., Zuberi, S., Mefford, H.C., Guerrini, R. and McTague, A. (2024). Developmental and epileptic encephalopathies. Nature Reviews Disease Primers, 10, 61. https://doi.org/10.1038/s41572-024-00546-6

Appendix 1: Acknowledgements

Acknowledgement of Country

The Steering Committee acknowledges Aboriginal and Torres Strait Islander peoples as the First Australians. We recognise their cultures, histories and diversity and their deep connection to the lands, waters and seas.

Roundtable Steering Committee

This project was led by a dedicated Steering Committee, responsible for guiding the project's strategic direction, ensuring integrity in decision-making, and maintaining accountability throughout.

The DEE Roundtable 2026 Steering Committee.

- **Kris Pierce** — Project Chair and Co-Lead — Director, SCN2A Australia and Strategic Lead, Rare Diseases NSW, UNSW
- **Associate Professor Katherine Howell** — Neurologist and Neurology Research Lead, Royal Children's Hospital; Clinician-Scientist Fellow, Neuroscience Group Leader and Epilepsy Team Leader, Murdoch Children's Research Institute
- **Kathryn Milne** — Project Lead — Rare Insight Advisory
- **Associate Professor Elizabeth Palmer** — UNSW Sydney, Clinical Geneticist at Sydney Children's Hospitals Network
- **Dr Neil Deacon** — Founder, Health Advance Connect
- **Meagan Cross** — Co-Founder and CEO, FAST Australia — Foundation for Angelman Syndrome Therapeutics
- **Leah Duffy** — Genetic Epilepsy Team Australia

Parents and Carers of People Living with DEEs

The Steering Committee sincerely thanks the parents and carers of people living with DEEs for generously sharing their time and lived experiences at each stage of the project.

Sponsors

The Roundtable Steering Committee also thanks Lundbeck Australia Pty Ltd, SCN2A Australia and UCB Australia Pty Ltd for their financial support towards the project as a whole, including the Roundtable and the preparation of this Report.

The findings, sector consensus and recommendations in this Report reflect the consensus reached by Roundtable attendees and the broader consultation process. Sponsors provided financial support for the Roundtable and the preparation of this Report but had no role in determining its content, findings or recommendations.

Appendix 2: Organisations Represented at the DEE Roundtable 2026

Thirty-four organisations from across the country were represented at the Roundtable, noting that additional organisations, and families with lived experience, were involved in the consultation process but did not attend the Roundtable.

(Alphabetical order — 34 of 34 shown)

Alexion Pharmaceuticals	Queensland Children's Hospital
Austin Health	Queensland University of Technology
Autism Queensland Limited	Rare Diseases NSW
Carers Queensland	Rare Voices Australia
Epilepsy Action Australia	SCN2A Australia
Epilepsy Queensland	Syngap Research Fund Australia
Epilepsy Tasmania	Sydney Children's Hospitals Network
Foundation for Angelman Syndrome Therapeutics	The Children's Hospital at Westmead
Genetic Epilepsy Team Australia (GETA)	The Florey Institute of Neuroscience and Mental Health
Genomics Australia	The Kids Research Institute Australia
Health Advance Connect	The Pip.ilepsy Foundation
InGeNA	The Royal Children's Hospital
Jazz Pharmaceuticals	The University of Melbourne
Lundbeck Australia Pty Ltd	The University of Queensland
Murdoch Children's Research Institute	UCB Australia Pty Ltd
Nabu.ai	UNSW Sydney
Patient Voice Initiative	Victorian Clinical Genetics Service