



Rare Voices Australia

Strategic Plan 2024-2027

RVA's Vision

RVA is dedicated to working with all key stakeholders to drive the best outcomes for Australians living with a rare disease.

This vision maps out the transformation Rare Voices Australia (RVA) wants to see in Australia: From a country where rare disease is not well understood or prioritised, to one that has the funding, policies and systems in place that will ensure all Australians living with a rare disease achieve the best outcomes. The best outcomes for each person will vary according to their unique circumstances, but in all cases, outcomes will span multiple domains: physical and mental health, wellbeing, lifestyle etc. RVA is committed to achieving practical, tangible outcomes in a fair and equitable manner. Importantly, RVA defines 'Australians living with a rare disease' broadly to include not only those who have a rare disease, but also their families and carers.

RVA's Mission

RVA provides collaborative leadership for the development and implementation of rare disease policy in Australia.

Collaboration is vital to achieving RVA's vision and mission: We don't (and can't) do it all ourselves. RVA is the unifying voice for empowering key stakeholders in the rare disease sector. Our focus is to provide collaborative leadership for the development and implementation of rare disease policy in Australia. As the national peak body for Australians living with a rare disease, we focus on overall 'systems'.

Our Philosophy

We are person-centred

We want the outcomes that are best for each person. We will be driven by people's individual needs and what works best for them.

We adopt a systemic focus

We are uniquely positioned to engage in systemic advocacy. Effective reform to systems and processes must be prioritised to reduce the number of individuals and groups repeatedly facing common challenges. This is vital to achieving sustainable change at scale.

We aim for a unified voice

We recognise that without a unified voice, the rare disease sector cannot be successful in achieving the support Australians living with a rare disease need. Therefore, RVA prioritises consultation, conversation, co-design, support and education within the sector to ensure our voice to policymakers and the broader community is unified and reflects the views of key stakeholders.

We actively build and maintain partnerships

We are the voice of the sector, magnifying the voices of all stakeholders that share our goals. We recognise that achieving the transformation we want to see in Australia will require working in partnership with key stakeholders.

We work for equity of access and participation

We believe equity of access and participation is vital for all Australians living with a rare disease. We ensure equity is a key factor in the planning and design of our initiatives, and the principles of equity will be foremost in our advocacy.

We equip and empower

We aim to equip and empower groups/organisations and individuals with the skills they need to advocate for themselves and their communities.

We are solutions and results oriented

We must be strategic in addressing the multiple challenges in rare disease. We want to see results for Australians living with a rare disease. This requires progressing long-term goals and being pragmatic. It's important to maintain traction and continue celebrating easier wins and achieving results, while maintaining effective stakeholder relationships and partnerships.

We are credible and act with integrity

We acknowledge that our effectiveness is only as good as our credibility and integrity. We recognise the importance of maintaining RVA's reputation as a representative, knowledgeable, evidence-based and well-respected national peak body. We ensure that our actions and words continue building RVA's credibility.

Strategic Diagnosis

RVA has been the unified voice and national peak body for Australians living with a rare disease since 2012. Our work is non-disease specific and is based on the commonalities of rare disease. RVA's advocacy focuses on rare disease policy, processes and systems. We provide a strong, common voice and advocate for all rare disease communities.

Stakeholders look to RVA to:

- Provide policy leadership and systemic advocacy
- Build the capacity of consumer-led rare disease groups/organisations
- Effectively partner with all stakeholders, including rare disease groups/organisations, researchers, clinicians, industry and governments

This approach is critical to continuing to raise the profile and awareness of rare diseases in Australia, in addition to driving systemic change in government policy. RVA's initial key focus was to advocate for a national rare disease framework/plan, which culminated in the collaborative development and launch of the Australian Government's [National Strategic Action Plan for Rare Diseases](#) (the Action Plan) in February 2020. RVA's name is associated with the Action Plan, which is an endorsement of RVA's role as a peak body and is reflective of the strong relationship with governments, the rare disease sector and community.

Following the launch of the Action Plan, RVA's focus has shifted to leading its collaborative implementation. In collaboration with the rare disease sector, RVA has progressed activity across all three Action Plan Pillars: Awareness and Education; Care and Support; and Research and Data. As part of our stewardship of the Action Plan, RVA released a [2023 Status Report: Implementing the National Strategic Action Plan for Rare Diseases](#) (the report). The report is intended to support all stakeholders to review, reflect on, and refine their approaches to support the most accessible, effective and efficient path to implementation of sustainable systemic change across all pillars, priorities, actions and implementation steps.

Key Strategic Goal:

To ensure RVA continues building on its existing sustainability, reputation and influence to enable the organisation's successful leadership of the collaborative implementation of the Action Plan. This in turn ensures tangible and practical outcomes for Australians living with a rare disease, now and in the future.

Organisational Strategic Priorities: May 2023

Advocacy Focus: Centres of Expertise

Rare Disease Centres of Expertise* (CoE) are recognised in the Action Plan as international best practice exemplars of implementation mechanisms. At the 2023 RVA Strategy Planning meeting, it was agreed that prioritising advocacy for the further development of CoE will strategically accelerate and underpin the implementation of several aspects of the Action Plan. This focus aligns with the understanding that a coordinated approach across all pillars of the Action Plan is integral to successful implementation and achieving the best health and wellbeing outcomes for Australians living with a rare disease.

*For the Australian context, we have adopted the term 'Centres of Expertise' rather than the internationally used 'Centres of Excellence' so as not to cause confusion with Centres of Excellence research funding schemes.

Strategic actions:

- Work with experts to develop a working definition of CoE in the Australian context, and create standards and expectations suitable for future CoE accreditation/designation
- Advocate to governments for investment
- Advocate to and with key stakeholders (especially rare disease groups/organisations, clinicians and clinical centres) for active participation and collaboration in promoting and developing CoE

Other Key Focus Areas

Peak Body Role

Why Is This Strategic?

Policymakers have repeatedly communicated their preference to easily engage with the rare disease sector via a credible and informed national peak body such as RVA, with a strong understanding of policy, systems and the sector. For the best outcomes in rare disease, we need to engage multiple stakeholders, drive systemic change and advocate with a unified voice that is representative of the sector.

Stewardship of the Action Plan

Why Is This Strategic?

The Action Plan was "developed by the rare disease sector, for the rare disease sector". Its vision ("the best possible health and wellbeing outcomes") aligns with RVA's vision ("the best outcomes for Australians living with a rare disease"). As an Australian Government policy framework, the Action Plan has the potential to influence and drive policy outcomes relevant to Australians living with a rare

disease. The collaborative implementation of the Action Plan is the responsibility of all stakeholders in the rare disease sector.

Progressing the Awareness and Education Action Plan Pillar

In partnership with a range of stakeholders, RVA is leading work on progressing implementation of the Awareness and Education Pillar. Key projects and examples include the ongoing development of the [Rare Awareness Rare Education \(RARE\) Portal](#); [RVA's Online Education Portal](#); and our Mentorship and Education Program which focuses on building the advocacy capacity of rare disease groups/organisations.

Progressing the Care and Support Action Plan Pillar

In partnership with a range of stakeholders, RVA is leading work on progressing implementation of the Care and Support Pillar. Key projects and examples include The Navigator Project; the Rare Disease Awareness, Education, Support and TraininG (RAREST) Project (which concluded on 30 June 2024); the RARE Portal; NBS advocacy; the Refreshed National Medicines Policy; ongoing health technology assessment advocacy; and disability advocacy.

Progressing the Research and Data Action Plan Pillar

In partnership with a range of stakeholders, RVA is leading work on progressing implementation of the Research and Data Pillar. Key projects and examples include measuring implementation of the Action Plan; the RARE Portal; RVA's Research and Project Partnerships; progressing work on guidelines for Australian CoE; and *Recommendations for a National Approach to Rare Disease Data*.

Funding and Sustainability

RVA's financial sustainability is key to achieving the best outcomes for Australians living with a rare disease. RVA's current funding model is based primarily on a combination of industry contributions, government grants (generally 3-year duration cycles), and to a lesser extent, partnership fees and small-scale fundraising and donations. All of the industry and government funding RVA receives is connected to projects/activities with specific deliverables.

Measures of Success

RVA will continue using metrics to measure organisational impact. Acknowledging this is potentially complex in the not-for-profit sector, RVA is exploring more fit for purpose models. We have developed and implemented a tailored approach to metrics best suited to RVA. RVA will routinely collect and analyse data relevant to each Action Plan Pillar; monitor progress and review it on a yearly basis; and make select data readily available to stakeholders. We are also exploring the Most Significant Change Methodology, so that we can adopt aspects of storytelling most relevant to the rare disease context.