

Rare Voices Australia Guidelines for Research Partnerships

Rare Voices Australia (RVA) is the national peak body for Australians living with a rare disease. RVA is dedicated to working with all key stakeholders to drive the best outcomes for Australians living with a rare disease through collaborative leadership for the development and implementation of rare disease policy in Australia. Key stakeholders include people living with a rare disease, governments, key peak bodies, researchers, clinicians and industry.

In 2018, the Australian Government commissioned RVA to lead the collaborative development of the [National Strategic Action Plan for Rare Diseases](#) (the Action Plan). The Action Plan is the first nationally coordinated effort to address rare diseases in Australia and was informed by an extensive multi-stakeholder consultation process. The Minister for Health launched the Action Plan in February 2020, with bipartisan support. The Action Plan has three interrelated Pillars: Awareness and Education; Care and Support; and Research and Data. RVA is now leading the collaborative implementation of the Action Plan.

In line with the Research and Data Pillar, RVA supports the need for high-quality collaborative research that positively impacts the lives of Australians living with a rare disease. RVA welcomes genuine partnerships with experienced research groups planning or undertaking research of all types that broadly aligns with one or more of the research priorities detailed in the Action Plan.

RVA Research Priorities

RVA partners in research that:

- Aligns with the Action Plan;
- Relates to, or is transferable to, a range of rare diseases and is collaborative and person-centred;
- Responds to unmet need in rare disease and/or addresses existing gaps;
- Involves coordinated and collaborative data collection that facilitates increased knowledge of rare diseases; and
- Can ultimately be translated into clinical care—clinical care informs research, innovation and policy.

What RVA can bring to your research

RVA is highly experienced in providing consultancy to researchers with a focus on linking and translating research into policy. RVA consultancy includes:

- Provision of broad rare disease stakeholder knowledge and expertise as Australia's national peak body for Australians living with a rare disease, including a strong track record in effective rare disease advocacy and policy influence;
- Support to align your research with priorities in the Action Plan;
- Support to identify opportunities for translation of research outcomes into measurable impact, including rare disease policy reform for the best possible health and wellbeing outcomes for Australians living with a rare disease;
- Provision of rare disease consumer expertise;
- Guidance on a person-centred approach to research co-design and implementation;
- Links to a network of over 100 rare disease patient groups and other rare disease stakeholders;
- Assistance convening focus groups to facilitate meaningful consumer engagement; and
- Support leveraging external grant funding for rare disease research.

Letters of Support (LoS): RVA will generally only provide LoS for grant proposals when given ample opportunity to participate in research co-design and provide rare disease policy and consumer expertise. If you require a LoS, please contact RVA as early as possible and not fewer than 10 business days prior to the submission deadline. Where possible, please provide a template/draft LoS.

RVA's previous roles and experience in research include associate investigator and project officer roles, formal participation in project advisory groups or steering committees, ad hoc policy and consumer advice, as well as facilitating the involvement of relevant patient groups and their members in surveys, questionnaires and focus groups.

As a non-profit charitable organisation, RVA may not always have the capacity to meet demand for in-kind contributions. Some contributions may need to be appropriately costed as a separate line item in the grant budget.

In-kind support is more likely to be considered where the proposed research activities align with existing or already planned RVA activities. In-kind and budgeted contributions are discussed with researchers, individually. Formal acknowledgement for RVA's contributions may be requested.

RVA's interactions with all stakeholders are guided by the values and ethical principles prescribed by the Australian Ethical Health Alliance's Australian Consensus Framework for Ethical Collaboration in the Healthcare Sector.

How to contact RVA with your Research Partnership Proposal

Provide a project synopsis as early as possible and **not fewer than 10 business days** prior to grant submission deadline. Your project synopsis should include:

- Predicted impacts on the lives of Australians living with a rare disease;
- A list of investigators;
- Research funding body, grant program name and any relevant deadlines;
- Potential roles/commitments for RVA in the co-design and execution stages of your project; and
- A list of other consumer organisations/expertise involved in the project.

Please email your synopsis and the information outlined above to research@rarevoices.org.au, with the email subject line: Proposal for Research Partnership – [your surname]. Your request will be reviewed by RVA's Chief Executive Officer, Research and Evaluation Manager and members of RVA's Scientific and Medical Advisory Committee. Proposals considered in alignment with RVA's research priorities, and the Action Plan will be progressed in collaboration.

If you would like to discuss any aspect of this process in more detail, please contact Dr Falak Helwani, RVA's Research and Evaluation Manager, at research@rarevoices.org.au or +61 (0)448505184.