

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:

- 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 can RVA bring to your research project?

- A person-centred approach to research co-design and implementation
- A conduit to rare disease patient groups relevant to your research
- Assistance with convening focus groups to facilitate meaningful consumer engagement
- Access to a wealth of experience in rare disease advocacy and policy influence
- Support for leveraging external grant funding for rare disease research
- The opportunity to work with the national peak body for Australians living with a rare disease on a specific research project.

Letters of Support (LoS): *RVA will generally only provide LoS for research projects in which there has been ample opportunity for RVA to participate in co-design and provide rare disease policy and consumer expertise. If you require a LoS, please provide a template/draft.*

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

RVA will request payment for our contributions to research projects. RVA will consider providing some in-kind support to researchers; however, our capacity to do this will depend on other commitments. RVA may also request formal acknowledgement for our contributions to your research. 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 brief summary of the project, including:

- Predicted impacts on the lives of Australians living with a rare disease;
- A list of investigators;
- Grant round and any relevant deadlines (please contact RVA at least 2 weeks prior to the submission deadline);
- The potential role/commitment for RVA (related to rare disease policy and consumer expertise) in the co-design and execution stages of your project; and
- A list of other consumer organisations/expertise involved in the project.

Please submit your summary 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, our Research and Evaluation Officer 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 Falak Helwani, RVA's Research and Evaluation Officer, at research@rarevoices.org.au or +61 (0)448505184.