

## **RVA Guidelines for Research Partnerships**

Rare Voices Australia (RVA) is Australia's peak body for rare diseases, advocating for the best outcomes for Australians living with a rare disease.

RVA led the collaborative development of the [National Strategic Action Plan for Rare Diseases](#) (the Action Plan), which was launched in February 2020 by the Federal Government. 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 groups planning or undertaking research of all types that broadly aligns with one or more of the research priorities detailed in the Action Plan. These research priorities are outlined below.

### ***RVA Research Priorities***

- 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
- 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 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
- Opportunity to work with the peak body for rare diseases in Australia on both a specific research project and as an ongoing RVA Partner.

### ***What can your group bring to RVA?***

- A genuine partnership to ensure the best outcomes for the rare disease community
- Opportunity to contribute to state-of-the-art research to improve the lives of those living with a rare disease
- Opportunity to provide a patient voice to rare disease research in Australia

### ***How to contact RVA with your Research Partnership Proposal***

- Provide a brief summary (1 page maximum, or a short PowerPoint presentation if you prefer) of your research plan, including predicted impacts on the lives of Australians living with a rare disease, and a statement on what you envisage the role of RVA will be in both the planning and execution stages of the project
- Provide a brief (½ page) bio for chief investigators, including links to any relevant publications
- If you have a funding scheme in mind, provide details of the scheme and any relevant deadlines (please contact RVA at least 1 month prior to the submission deadline)
- Provide a list of other consumer organisations (if any) you envisage may also be involved

Please submit the above information to [nicole.millis@rarevoices.com.au](mailto:nicole.millis@rarevoices.com.au) with the heading: Proposal for Research Partnership - [your surname]. Your request will be reviewed by the CEO, other relevant RVA staff and/or members of the RVA 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 feel free to contact Nicole Millis, RVA CEO on [nicole.millis@rarevoices.com.au](mailto:nicole.millis@rarevoices.com.au) or +61 (0)459 021 204.