Rare Voices Australia Guidelines for Project 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.

RVA supports the need for high-quality, person-centred project partnerships that are collaborative and positively impact Australians living with a rare disease. RVA welcomes genuine project partnerships that broadly align with one or more of the priorities in the Action Plan.

RVA Project Partnership Priorities

RVA partners on projects that:

- Relate to, or are transferable to, a range of rare diseases and are person-centred;
- Respond to unmet need in rare disease and/or address existing gaps; and
- Are collaborative and lead to better outcomes for Australians living with a rare disease.

What can RVA bring to your project?

- A person-centred approach to project co-design and implementation
- A conduit to rare disease organisations relevant to your project
- Assistance facilitating 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 projects/initiatives
- The opportunity to work with the national peak body for Australians living with a rare disease on a specific project.

RVA's project roles and experience include formal participation in project advisory groups or steering committees, ad hoc consumer and policy advice, as well as facilitating the involvement of relevant rare disease organisations and their members.

Please contact RVA to discuss how RVA's contribution will be acknowledged and/or remunerated. Capacity limitations mean we cannot offer in-kind support in every case. 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 Project 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 all people involved;
- 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 project summary to nicole.millis@rarevoices.org.au with the email subject line: **Proposal for Project Partnership – [your surname].** Proposals considered in alignment with RVA's 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 Nicole Millis, RVA's Chief Executive Officer, at nicole.millis@rarevoices.org.au or +61 (0)459 021 204.