

## Rare Voices Australia Endorsement Criteria

Rare Voices Australia (RVA) will prioritise the criteria outlined in this document when considering RVA endorsement. Endorsement must be formally requested and addressed to RVA's Chief Executive Officer.

## Rare Voices Australia

As the national peak body for Australians living with a rare disease, RVA's work is non-disease specific and is based on the commonalities of rare disease. Our advocacy focuses on rare disease policy, processes and systems. RVA advocates for all rare disease communities.

All endorsement requests will be reviewed to assess if they align with RVA's broader vision, mission and how we work. See RVA's website for more information. Additionally, RVA will assess how endorsement requests align with the Australian Government's National Strategic Action Plan for Rare Diseases and progress its ongoing collaborative implementation.

## **Rare Voices Australia Criteria for Endorsement**

- Resources have a systemic focus and relate to, or are transferable to, a range of rare diseases.
- It is evident that a person-centred and/or codesign approach has been undertaken that involves people living with a rare disease, including families and carers.
- Consultation with RVA and other key stakeholders and relevant experts has been undertaken, with evidence that feedback provided by RVA has been appropriately considered and incorporated.
- Equity of access and participation have been prioritised, acknowledging the diversity in the rare disease sector.
- Partnerships have been sought, established and are being maintained as part of the development of
  resources. Partners are actively working together to reduce duplication, while addressing existing
  gaps and continuing work to collectively build capacity within the rare disease sector.
- A demonstrated understanding of systems and processes is evident, with resources having a clear value and purpose to the intended audience(s). Resources should clearly articulate how the intended audience can use the material in practice to equip and empower the rare disease sector.
- Resources are credible, evidence-based and of high quality from a communication perspective. Credibility is vital to achieving long-term sustainable change at scale.
- Resources are solutions and results oriented.

## **Rare Voices Australia Endorsement Process**

Email your endorsement request and all necessary background information to <a href="mailto:nicole.millis@rarevoices.org.au">nicole.millis@rarevoices.org.au</a>, with the subject line, 'RVA Endorsement Request'. Your request will be reviewed by RVA's Chief Executive Officer, our Education and Advocacy Manager and other relevant RVA staff depending on the nature of the request. RVA will be in touch as soon as possible regarding the outcome of your request, or with any questions we may have.