



RARE

Rare Disease Awareness,
Education, Support, and Training

Taking Action Together Toolkit Improving Health and Wellbeing Outcomes for Australians Living with a Rare Disease

Companion document: How the Toolkit was developed

18 June 2024

How the Toolkit was Developed

This Toolkit was developed as part of the Rare Disease Awareness, Education, Support and Training (RAREST) Project, a partnership between UNSW Sydney, Rare Voices Australia (RVA), Macquarie University, and the University of Western Australia.

Input into the Toolkit was sought from people living with a rare disease, including the RAREST Stakeholder Reference Group comprising 12 people with lived experience of rare disease; members of Australian rare disease organisations; academics; and clinicians.

The toolkit co-design process

Several stakeholders were part of almost every iteration of the Toolkit, including:

- defining the purpose and scope of the Toolkit
- informing and refining sections to reflect lived experience
- identifying useful content

Consultation with 11 rare disease groups/organisations helped identify a gap in capacity for rare disease groups and organisations, and a need to share resources and learnings among the sector. From this discussion, a scoping tool (below) was produced, which helped identify potential resources to be added to the Toolkit.

Several iterations of the Toolkit were developed, and the RAREST Stakeholder Reference Group, RAREST Australian Rare Diseases Organisations Community of Practice (ARDO-CoP) and RAREST Steering Committee were all part of refining the structure, focus and content during each iteration.

Resources in this Toolkit

During the development of this Toolkit, a scoping review was conducted to find tools that aligned with the themes discussed in the Toolkit. These resources were then assessed against the criteria in Table 1.

Table 1. Criteria for assessing potential resources for inclusion in the Toolkit.

Themes	Traits	Resource type
<ul style="list-style-type: none"> • Support for effective advocacy • Multi-stakeholder engagement • Priority populations • Recognising and valuing lived experience of people living with a rare disease • Person-centred approaches and co-design 	<ul style="list-style-type: none"> • Accuracy, recency and legitimacy • Accessible and navigable • Clearly defined purpose and reach • Relevant to the Australian context, or easily adapted to the Australian context • Succinct but comprehensive • Solution-focused 	<ul style="list-style-type: none"> • Informative <ul style="list-style-type: none"> ○ e-learning resources ○ factsheets ○ infographics ○ case studies • Practical <ul style="list-style-type: none"> ○ frameworks ○ guides ○ checklists ○ reflections ○ videos