



rare voices
A U S T R A L I A[®]

DEVELOPING THE 'RARE DISEASE RESOURCES FOR THE REGIONAL, RURAL, AND REMOTE COMMUNITIES' COLLECTION



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Introduction

Australians living with a rare disease in regional, rural, and remote areas face many barriers to accessible and equitable health care.

The Australian Government's National Strategic Action Plan for Rare Diseases (the Action Plan) states:

"Where people live can have a significant impact on their ability to access services. The lack of disease expertise nationally is accentuated by Australia's vast size. Most rare disease expert centres are located in capital cities, thus travel creates a financial barrier for regional, rural, and remote Australians living with a rare disease and their families. Australians living in rural and remote areas experience poorer health and welfare outcomes, including higher rates of chronic disease, disease burden, and mortality (death) compared to those living in metropolitan areas. This inequity is likely exacerbated when people living in regional, rural, and remote areas are also living with a rare disease as they have lower access to health services, and are more likely to present to hospital with conditions that could have been treated by a primary health care practitioner."¹

Regional, rural, and remote rare disease community members may face barriers such as:

- Less access to health care near them. Rural areas have up to 50% less health providers per capita compared to capital cities, and waiting times can be excessive, which can lead to increases in potentially preventable hospitalisations.
- The time and costs associated with obtaining health care when living regionally, rurally, or remotely can be prohibitive. People living with a rare disease may need to arrange and pay for transport, accommodation, child care arrangements, and time off work in order to obtain treatment in a major city. Medicare constraints also add further financial stress, as they allow rebates for one specialist or allied health visit per day.
- English, digital, and health literacy rates are lower for people living in regional, rural, and remote areas compared to people living in major Australian cities. This can often mean people living in country Australia may not have access to health education resources that are appropriate and accessible. People living in regional, rural, and remote areas may also not have the appropriate infrastructure for digital learning (e.g. internet access), reducing their options further.²

The National Strategic Action Plan for Rare Diseases and Priority Population Resource Collections



Developing the 'Rare Disease Resources for the Regional, Rural, and Remote Communities' collection addresses the following actions and implementation steps in the Action Plan:



Action 1.1.1

"Develop and conduct national awareness and education activities for rare diseases."

This project specifically addresses Action 1.1.1.4., "Collaborate with targeted stakeholders to maximise the reach and appropriateness of materials to Aboriginal and Torres Strait Islander people, those with CALD backgrounds, and other priority populations."



Action 1.2.1

"Raise awareness among people living with a rare disease, and their families and carers, about the care and support services available to them."

Collating and presenting this collection of resources makes it easier for the rare disease community living in country Australia to find resources and supports that address their unique needs.



Implementation 2.1.2.1

"Develop an accessible multi-purpose digital repository, incorporating elements targeted at the workforce that supports people living with a rare disease..."

Providing a digital repository like RVA's Online Education Portal means that health professionals supporting people living with a rare disease in regional, rural, and remote communities may be better equipped to assist with service navigation and access to health, disability, and other systemic care.



Action 2.5.3

"Develop the capacity of rare disease organisations to provide wellbeing and mental health support."

Promoting the resource collection to the rare disease community and RVA Partners will allow rare disease organisations to spread the word further, allowing for ongoing collaboration and development of supports for those living with a rare disease in regional, rural, and remote communities.

Priority Population Resource Development Process

"Investment in the prevention and management of rare diseases should be implemented collaboratively."



A key principle of the the Action Plan is a person-centred perspective and collaboration in all projects undertaken. The development of the 'Rare Disease Resources for Regional, Rural, and Remote Communities' collection reflects this.

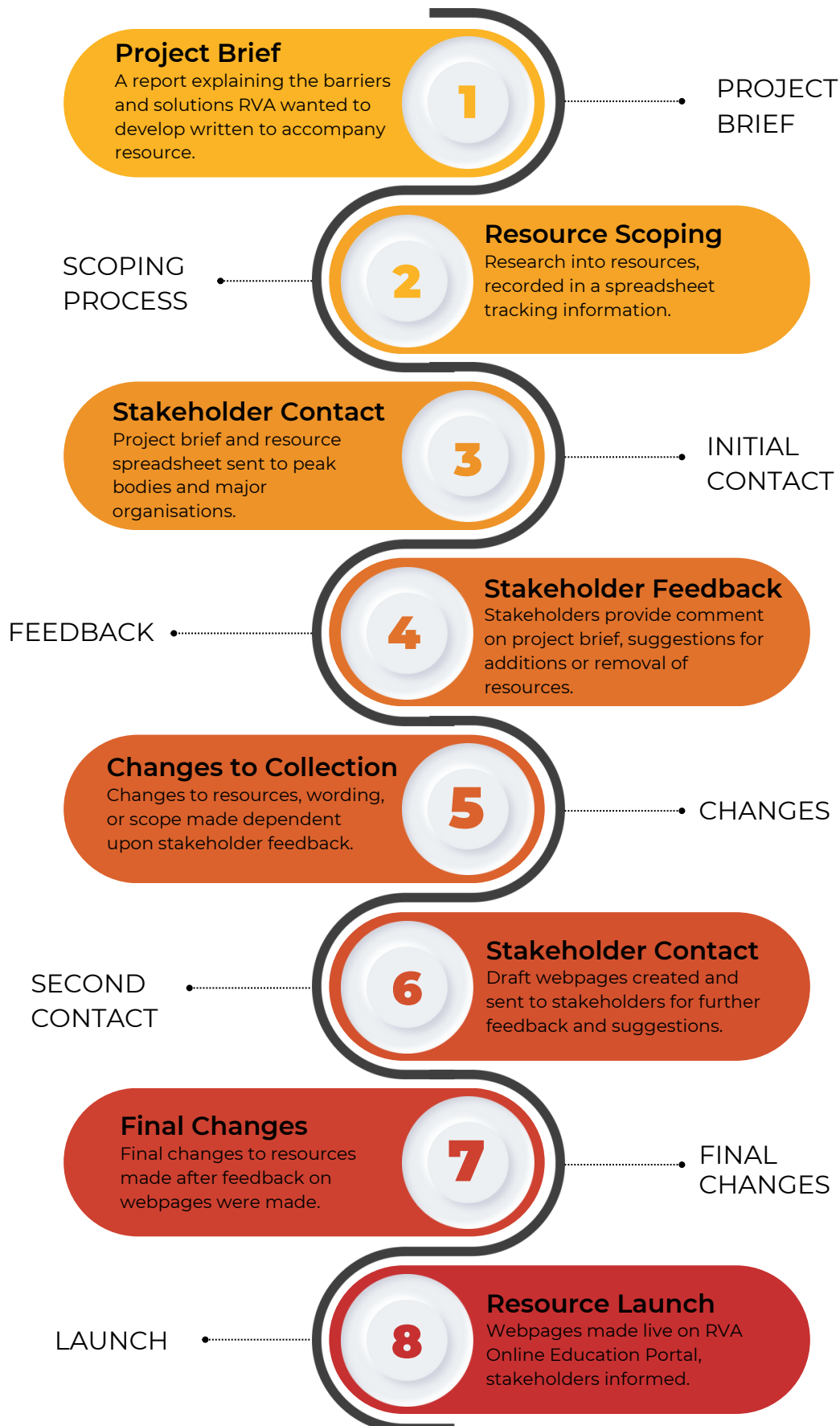
Using the Action Plan, RVA identified key Action Plan actions and implementation steps that the resource collection could address.

Guided by these action plan points and implementation steps, a list of relevant topics were developed:

- ***Preconception and Pregnancy***
- ***National Disability Insurance Scheme and Disability***
- ***Aged Care***
- ***Life Transitions***
- ***Advocacy and Self-Advocacy***
- ***Chronic Disease Management***
- ***Mental Health and Wellbeing***
- ***Carer Resources***
- ***Government Services***
- ***Genetics and Genomics***
- ***Research***
- ***Clinical Trials***
- ***Data Sovereignty/Data Ownership***

RVA then completed a wide scoping review of all online resources specific to the regional, rural, and remote community using the set of inclusion criteria provided in this report.

Collaboration with Stakeholders



Priority Population Resource Inclusion Criteria

When considering what is required for resources to be relevant and appropriate, RVA assessed them against the following criteria:

Resource Inclusion Criteria:

Applicability to Rare Disease:

Resources must align with topics that impact upon the rare disease community.

Recency:

Resources must have been created or updated within the past 10 years to ensure currency with policy, data, emerging health knowledge and technologies.

Organisation Type:

Resources must have been created by either:

- A government department
- A government funded service
- An established hospital, university, or research unit
- A registered NGO or charity

Relevant Knowledge and Expertise:

Originating group must be led, supported, or endorsed by credible experts from relevant backgrounds.

Priority Population Involvement:

All resources must originate from, or have significant collaboration with, the priority population community.

Consumer Availability:

Resources must be freely available to consumers without payment.

Health Literacy Level:

Resources must be easily accessible to consumers that may not have a well developed understanding of health science, technology, or rare disease.

National Significance:

Resources must be applicable to all people across Australia, and not focus on a particular region. If the resource is regional, adaptability must be considered.

Adaptability:

Regional resources will be considered if they are easily adaptable to the national context. If a resource is not adaptable, it will not be included.

Priority Population Resource Webpage Key Considerations

Population Demographics

- Less likely to have completed a Year 12 or non-school qualification.
- More likely to receive lower income and pay higher prices for goods and services.
- Lower rates of health and technological literacy.
- Less access to technology and the internet.

Impact On Website Features:

- Language and vocabulary pitched at a year 5-6 reading level.
- Jargon and acronyms replaced with plain language.
- Information for regional, rural, and remote community provided alongside important 'all audiences' material to reduce searching.
- Design elements consistent throughout all priority populations webpages.
- Menu hierarchies minimised and linear navigation used.
- Visual clutter minimised and information categorised by topic.
- Font size and colour assessed against Web Content Accessibility Guidelines (WCAG).
- Screen-reader friendly PDF transcript of entire webpage available for visually impaired people.
- PDF available to ensure offline usage available for people with minimal access to the internet.

Feedback and Updates

The 'Rare Disease Resource for Regional, Rural, and Remote Communities' collection is a continuous work in progress.

This section outlines how you can help to make sure the collection meets the needs of the community.

Multi-stakeholder involvement and partnerships are key to evolving this resource to ensure it is person-centred, current, comprehensive and useful.

We invite you to contribute to the ongoing development of this resource by:

01

Accessing our resource collection

Make yourself familiar with the resource collection, what it contains, and how it can help your networks or clients.

02

Sharing the resource collection with your networks

By regularly sharing the collection in your newsletters, on social media, or in your online support groups, we will be able to reach more regional, rural, and remote Australians living with a rare disease.

03

Providing feedback

RVA has developed and launched a [Suggestions and Feedback Form](#) that allows you to provide us with information directly.

Feedback will be reviewed on a quarterly basis.

04

Encouraging others to collaborate!

If you believe others may have information, updates, or new resources for RVA to add, please encourage them to get in touch.

Summary

The development of a resource collection for people living with rare disease in regional, rural, and remote areas of Australia aligns with the Action Plan and provides more support to identified priority populations.



Regional, Rural, and Remote Australians

People living with rare disease in regional, rural, and remote Australia:

- Often face more barriers to access than those in urban areas.
- Have less services and supports to address these barriers.



Developing the Collection

Developing and releasing a resource collection for people living with rare disease in country Australia aims to address barrier issues.

- Development of this collection has been collaborative and rigorous.



Share and Collaborate

By sharing the resource collections with your network and working with us, more of the community will benefit.

- Share news on social media.
- Suggest additions or changes via our [Suggestions and Feedback Form](#).

Together, we can ensure that all people living with a rare disease in regional, rural, or remote Australia have access to the health care and support they need.

REFERENCES

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2. Consumers Health Form of Australia, National Rural Health Alliance. Rural, regional and remote roundtable on health service access report [Internet]. 2022 Feb [cited 2022 Dec 9] p. 1–23. Available from: https://chf.org.au/sites/default/files/220222_rural_regional_remote_roundtable_report_final.pdf

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DISCLAIMER

This report and the 'Rare Disease Resources for the Regional, Rural, and Remote Communities' collection are all subject to Rare Voices Australia's Education [Terms of Use](#).

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We would like to acknowledge the contribution of The National Rural Health Alliance in producing this resource.

Rare Voices Australia acknowledges Aboriginal and Torres Strait Islander people as the Traditional Owners of Country throughout Australia and as a priority population of the rare disease sector. We pay our respects to Elders—past, present and emerging.

RVA thanks you for your continued support in our efforts to assist the rare disease community.

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