rare voices
AUSTRALIA®

# DEVELOPING THE ‘RARE DISEASE RESOURCES FOR THE MULTICULTURAL COMMUNITY’ COLLECTION

# Table of Contents

# Introduction

## Multicultural Australians living with rare diseases face many barriers to accessible and equitable health care.

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

> *"Both language barriers and cultural differences can have negative impacts on the way people from CALD backgrounds experience health care and support services. Information is often not available in all languages, and cultural norms around health and support, including mental health, can vary significantly. Furthermore, some rare diseases are more prevalent in people from certain CALD backgrounds, such as thalassaemia in Australians of Mediterranean origin."*[1]

Multicultural Australians living with rare diseases may face barriers such as:

- Lower English, digital, and health literacy rates compared to other Australians, especially for people who migrated at an older age, are recent immigrants, and those with low education levels. This can often mean multicultural Australians face challenges understanding their health and wellness, seeking information, and navigating the Australian health care system.
- Cultural attitudes and stigma around health and sickness that conflicts with standard Australian health care approaches, which can lead to a lack of community engagement with the health care system.
- Language and communication problems when multicultural Australians engage with the health care system. Lower English comprehension levels and a lack of easily accessible translation services or health education material in a primary language can result in a lack of engagement and understanding.
- Poor cultural competency of health care providers can result in lower access and engagement with the multicultural community.
- Existing disadvantages and discrimination “increase stigma, embarrassment, fear, racism, and discriminatory practices, poor knowledge and understanding of the health system, and difficulties in navigating the systems”.[2]

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

Developing the 'Rare Disease Resources for the Multicultural Community' 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 far easier for the multicultural rare disease community 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.

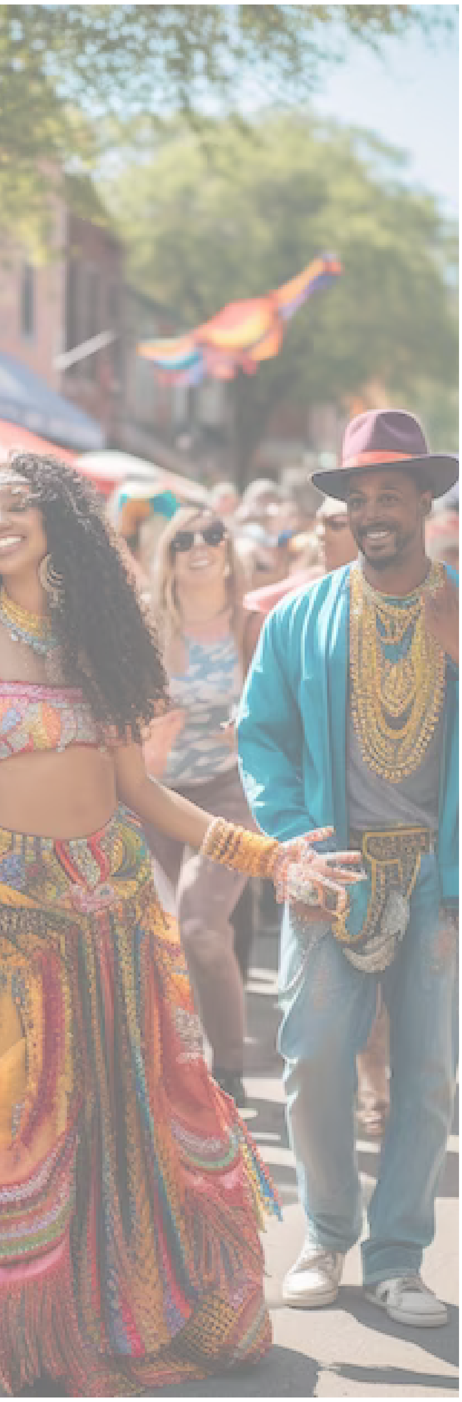
### Action 2.5.3

*"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 the multicultural community living with rare diseases.

# Priority Population Resource Development Process

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



A key principle of the Action Plan is a person-centred perspective and collaboration in all projects undertaken. The development of the 'Rare Disease Resources for the Multicultural Community' 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 actions 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 multicultural community using the set of inclusion criteria provided in this report.

# Collaboration with Stakeholders

1

**Project Brief**

A report explaining the barriers and solutions RVA wanted to develop written to accompany the resource.

PROJECT BRIEF

2

**Resource Scoping**

Research into resources, recorded in a spreadsheet tracking information.

SCOPING PROCESS

3

**Stakeholder Contact**

Project brief and resource spreadsheet sent to peak bodies and major organisations.

INITIAL CONTACT

4

**Stakeholder Feedback**

Stakeholders provide comment on project brief, suggestions for additions or removal of resources.

FEEDBACK

5

**Changes to Collection**

Changes to resources, wording, or scope made dependent upon stakeholder feedback.

CHANGES

6

**Stakeholder Contact**

Draft webpages created and sent to stakeholders for further feedback and suggestions.

SECOND CONTACT

7

**Final Changes**

Final changes to resources made after feedback on webpages were made.

FINAL CHANGES

8

**Resource Launch**

Webpages made live on RVA Online Education Portal, stakeholders informed.

LAUNCH

# 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 multicultural 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 Resources for the Multicultural Community' 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 multicultural Australians living with rare diseases.

☐ **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 multicultural people living with rare diseases in Australia aligns with the Action Plan and provides more support to identified priority populations.

## Multicultural Australians

Multicultural people living with rare diseases in Australia:

- Often face more barriers to access health care.
- Have less services and supports to address these barriers.

## Developing the Collection

Developing and releasing a resource collection for multicultural Australians living with rare diseases 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 multicultural people living with rare diseases in Australia have access to the health care and support they need.**

## REFERENCES

1. Department of Health Australia. National Strategic Action Plan for Rare Diseases [Internet]. 2020 p. 1–64. Available from: https://rarevoices.org.au/wp-content/uploads/2020/08/NationalStrategicAPRD.pdf
2. Khatri RB, Assefa Y. Access to health services among culturally and linguistically diverse populations in the Australian universal health care system: Issues and challenges. BMC Public Health [Internet]. 2022 May 3;22(1). Available from: https://bmcpublichealth.biomedcentral.com/articles/10.1186/s12889-022-13256-z

Report released September 2023.

## DISCLAIMER

This report and the 'Rare Disease Resources for the Multicultural Community' collection are all subject to Rare Voices Australia's Education Terms of Use.

## ACKNOWLEDGMENTS

**We would like to acknowledge the contributions of the organisations that worked this project:**

- The Federation of Ethnic Communities' Councils of Australia (FECCA).
- Australian Multicultural Health Collaborative.

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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