Resources for People from Priority Populations Living with a Rare Disease
Lessons Learned and Gaps Identified

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Background

The Australian Government's National Strategic Action Plan for Rare Diseases (the Action Plan) highlights the need for action and policy to recognise all Australians living with a rare disease.[1] The Action Plan identifies and emphasises the importance of access and equity for particular populations facing additional barriers and unique challenges in accessing rare disease information, care and support and research opportunities. These priority populations include Aboriginal and Torres Strait Islander people, culturally and linguistically diverse communities, and those living in regional, rural and remote communities. One way to overcome these barriers and challenges is to enable equitable access to information by centralising existing rare disease information and resources customised for these priority populations. Rare Voices Australia (RVA), the national peak body for Australians living with a rare disease, worked collaboratively with key peak body experts to co-design a collection of resources tailored for the aforementioned priority groups. A consultative and collaborative approach was critical in ensuring the development of suitable and appropriate resource collections for these groups. Through this process, several key information and resource gaps across these priority populations were identified, which should be prioritised for future work.

Aim

To identify, collate and make accessible collections of suitable, appropriate and relevant rare disease health information and education resources for Aboriginal and Torres Strait Islander people, culturally and linguistically diverse communities, and those living in regional, rural and remote communities.

Methods

A desktop web search was conducted in late 2022 and early 2023 to identify available online information and resources relevant to rare disease. The resources were categorised across 12 key areas.

12 Key Areas in Rare Disease

- Preconception and Pregnancy
- Life Transitions
- Disability
- Aged Care
- Advocacy
- Chronic Disease Management
- Mental Health and Wellbeing
- Carers Resources
- Government Services
- Genetics and Genomics
- Research and Clinical Trials
- Data Sovereignty (Ownership)

Collation of the final resource collections was done through a consultative process, with experts from key peak bodies that have established relationships with each priority population. These peak bodies included the National Aboriginal Community Controlled Health Organisation (NACCHO); the Australian Alliance for Indigenous Genomics; the Federation of Ethnic Communities' Councils of Australia (FECCA); the Australian Multicultural Health Collaborative; and the National Rural Health Alliance (NRHA).

Co-development of the resource collections involved:

- consultations and iterative review by relevant peak body experts
- methodical assessment to ensure the credibility of information and links included in each resource collection

Results

1. Development of Online Resource Collections for Priority Populations

Customised resource collections were developed for each priority population, which serve as a centralised place for care and support information relevant to individuals in these communities living with a rare disease. Webinars were also developed to complement these resource collections. Access to these online resource collections is free via RVA's Online Education Portal.

2. Key Considerations

The following key considerations were identified through the consultation process with key peak bodies as important criteria for deciding which resources should be included in each resource collection:

- **Website accessibility** – adapted for people living with a visual-impairment and other disabilities that may impact access to online content
- **Health literacy** – use of simple English and avoidance of jargon and abbreviations to ensure easy understanding and allow for accurate translation
- **Presentation of resources** – use of consistent and minimal design elements to present the material in a clear manner that isn't overwhelming

3. A Collaborative and Iterative Co-design Process Is Essential

Collaboration with key peak bodies through an iterative approach was essential for ensuring the suitability and appropriateness of each resource collection. This iterative process for collaboration with stakeholders has proven highly effective for co-design.

4. Limitations of the Research

It is important to note the following:

- existing resources developed for the general community have also been included in the collections to fill information gaps
- inclusion of offline resources was outside the scope of this work
- translation of these resource collections into languages other than English was also outside the scope of this work

5. Gaps in Resource Collections

Overall, there are limited rare disease resources and information customised for priority populations and there are many gaps. Figure 1 below highlights several key gaps for each priority population.

Figure 1: Key resource gaps identified where there are insufficient resources customised for each priority population's unique needs

Aboriginal and Torres Strait Islander communities

- resources to help build health literacy and empower the community to be active participants in their rare disease journey
- information on genetics and genomics, research and clinical trials, and data sovereignty
- culturally safe information on transition from paediatric to adult care

Culturally and linguistically diverse communities

- information on genetics and genomics and data sovereignty
- appropriate resources on transition from paediatric to adult care

Regional, rural and remote communities

- information on access to supports, including how to utilise the National Disability Insurance Scheme (NDIS)
- carer support information

Conclusions

- These centralised, customised and living rare disease resource collections enable ongoing equitable access to information for these priority populations
- Collaboration and iterative review processes were essential for appropriate curation of these resource collections
- Development of these resource collections uncovered several information gaps
- An important next step for the rare disease sector is to address the resource gaps identified through this work and collaborate with relevant experts to co-design customised resources to fill these gaps

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References

1. Australian Government. Department of Health. National Strategic Action Plan for Rare Diseases. Canberra; 2020. 63p. https://www.health.gov.au/sites/default/files/documents/2020/03/national-strategic-action-plan-for-rare-diseases.pdf

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