



Rare Care Centre
Clinical Centre of Expertise for
Rare and Undiagnosed Diseases



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Delayed diagnosis, limited treatment options, and disease complexity are commonly experienced. Building capacity among rare disease organisations is a priority of the Australian National Strategic Action Plan for Rare Diseases.(1) We aimed to understand the capacity needs of rare disease organisations when advocating for improved services and outcomes for their respective communities.

What does it mean to live with a rare disease?



RARE
Rare Disease Awareness,
Education, Support, and Training




Scan the QR code to learn more about The RARE Project

Opportunities for change

Accessing reliable information

Although no health professional can be an expert in all rare diseases, partnerships can be formed between health professionals and patients and patient support groups to learn more about the condition. You can do so via the QR code below to the RARE Portal.

Support for all people living with rare diseases

Rare diseases often impact people's mental health and wellbeing, and can result in out-of-pocket expenses.

Checking in on people's wellbeing and helping facilitate access to appropriate mental and socio-economic supports is important. You can do so via the QR code to the RARE Portal.



Scan to visit:
The RARE Portal

What is a rare disease?

A rare disease is a chronic and complex condition that affects **less than five in 10,000** people!

How many rare diseases are there?

Over **7,000 known rare diseases** exist with more yet to be named. Unknown or unclassified diseases are referred to as **undiagnosed diseases**.

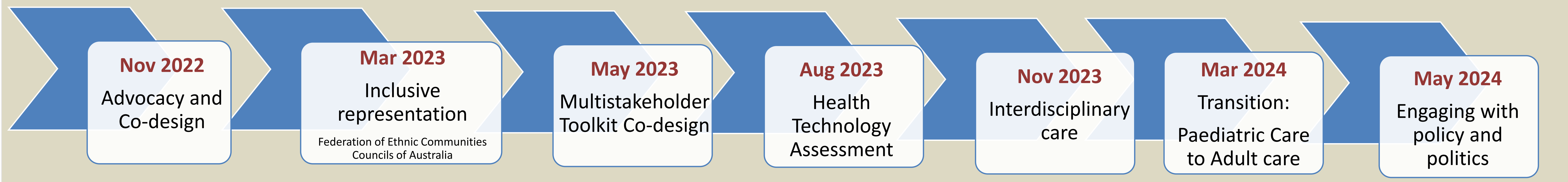
What are the types of rare diseases?

80% are of genetic origin, however, other non-genetic rare diseases include rare cancers, infections, and autoimmune disorders!

How many Australians live with a rare disease?

An estimated two million Australians currently live with a rare disease which is **approximately 8% of Australians**.

ARDO-CoP Sessions held



Implicitly held knowledge and capacity building

Common purpose for improvement

Communication

Relationships

ARDO CoP

Transparency

Trust among members

Shared practice, tools, initiatives, resources

Shared tacit knowledge and expertise

Shared stories

Orienting Value Aspirations
"The surprising outcome occurred with the expanded understanding of the sector. I did not realise how each patient support group was experiencing similar issues, difficulties, and rewards from their work. There is great strength in sharing this knowledge"

Enabling Value
"Meeting others and working with them has given me a lift to continue."

Realised Value
"It helps me figure out what I needed to know and disseminate within my organisation to build our capacity."

Strategic Value
"It helps me figure out what I need to know and disseminate within my organisation to build our capacity"

Immediate Value
"I leave each session feeling more connected and having learnt something"

- ARDO-CoP members found the sessions valuable and consistently expressed the desire to continue the ARDO-CoP beyond the span of the RAREST Project. They valued having direct input into governance and decisions about topics for discussion.
- Growing the member base will be important to ensure the consistent presence needed for productive discussions and learning.
- As the ARDO-CoP continues to adapt and expand, they will be challenged to maintain a balance between inclusivity and manageability.
- Ongoing adaptations and refinements are inevitable and encouraged to maintain a robust and valued community of practice.

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1. Australian Government Department of Health. National Strategic Action Plan for Rare Diseases [internet]. Available from: <https://www.health.gov.au/resources/publications/national-strategic-action-plan-for-rare-diseases> [accessed 2024 July], 2020.

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