

# National Recommendations for Rare Disease Health Care

**The National Recommendations for Rare Disease Health Care** (the Recommendations) were written by health professionals, academics, and people living with rare disease to guide health professionals in providing quality care for people living with rare disease.

The Recommendations were developed as part of the **Rare Disease Awareness, Education, Support and Training (RAREST) Project**, a collaboration between Rare Voices Australia, the University of New South Wales, Macquarie University, and the University of Western Australia, and funded by the Australian Government.

- A rare disease is a health condition that affects fewer than 1 in 2,000 people<sup>1,2</sup>
- There are over 7,000 different rare diseases,<sup>1,2</sup> affecting around 8% of Australians<sup>3</sup>
- This means that although each condition is rare, an estimated 2 million people live with rare disease in Australia

## RECOMMENDATION 1

**Deliver person-centred care that values diversity and lived experience** as people living with rare disease are often experts in their own conditions and have changing, complex needs



## RECOMMENDATION 2

**Facilitate timely and accurate diagnosis** as a rare disease diagnosis can lead to better clinical care, peer support, reproductive confidence, and access to services and clinical trials



## RECOMMENDATION 3

**Engage in two-way knowledge sharing with colleagues and Centres of Expertise in and across jurisdictions** as no one can be an expert in over 7,000 rare diseases



## RECOMMENDATION 4

**Respond to the inherent uncertainty of rare disease, by facilitating connections with rare disease and patient advocacy groups, research including clinical trials, and new therapies and technologies** as fewer than 5% of rare diseases have a curative treatment but knowledge is rapidly expanding



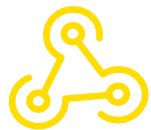
## RECOMMENDATION 5

**Recognise and support mental health, social and emotional wellbeing needs** as living with rare disease affects all facets of people's lives



## RECOMMENDATION 6

**Promote integrated and coordinated care across the lifespan** as people living with rare disease require a wide range of health and support services



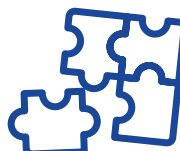
## RECOMMENDATION 7

**Facilitate health promotion, reproductive choices, and preventive measures for both genetic and non-genetic rare diseases** as some rare diseases may be preventable, or their impact reduced through these measures



## RECOMMENDATION 8

**Engage in relevant continuing education, reflective practice, and quality improvement** as knowledgeable and skilled health professionals can greatly improve outcomes for people living with rare disease



Read the full Recommendations at:  
[rarevoices.org.au/national-recommendations](https://rarevoices.org.au/national-recommendations)  
Read more about the RAREST Project at  
[rarevoices.org.au/rarest-project](https://rarevoices.org.au/rarest-project)



**RAREST**

Rare Disease Awareness,  
Education, Support, and Training