

# National Recommendations for Rare Disease Health Care

## 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.



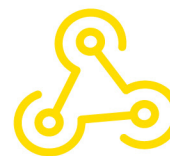
## RECOMMENDATION 5

**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.



**RArEST**

Rare Disease Awareness,  
Education, Support, and Training

[rarevoices.org.au/rarest-project/](http://rarevoices.org.au/rarest-project/)