

Many Voices ONE GOAL.

YOUR NATIONAL STRATEGIC ACTION PLAN FOR RARE DISEASES

VISION:

The best possible health and wellbeing outcomes for Australians living with a rare disease.

CRITICAL ENABLERS:

Multi-stakeholder involvement and engagement

Collaborative governance and leadership

State, national and international partnerships

High quality, comprehensive collection, and effective use, of rare disease data



Pillar 1 AWARENESS AND EDUCATION



Pillar 2 CARE AND SUPPORT



Pillar 3 RESEARCH AND DATA

Priority 1.1: Increase every Australian's awareness of rare diseases including, where applicable, relevant prevention measures.

Priority 1.2: Ensure Australians living with a rare disease have access to information and education that enables them to be active participants in their rare disease journey.

Priority 1.3: Develop a national rare disease workforce strategy that responds to current and future demands, including the impact of genomics.

Priority 2.1: Provide rare disease care and support that is integrated and appropriate for all Australians living with a rare disease, while being both person and family-centred.

Priority 2.2: Ensure diagnosis of a rare disease is timely and accurate.

Priority 2.3: Facilitate increased reproductive confidence.

Priority 2.4: Enable all Australians to have equitable access to the best available health technology.

Priority 2.5: Integrate mental health, and social and emotional wellbeing, into rare disease care and support.

Priority 3.1: Enable coordinated and collaborative data collection to facilitate the monitoring and cumulative knowledge of rare diseases, informing care management, research and health system planning.

Priority 3.2: Develop a national research strategy for rare diseases to foster, support and drive all types of research for rare diseases, contributing to agreed priorities and systematically addressing gaps.

Priority 3.3: Ensure research into rare diseases is collaborative and person-centred.

Priority 3.4: Translate research and innovation into clinical care; clinical care informs research and innovation.

THESE PRINCIPLES ARE THE FOUNDATION FOR THIS ACTION PLAN:

Person-centred | Equity of Access | Sustainable Systems and Workforce



Taking Action Together | Visit rarevoices.org.au/actionplan