



FAIR FOR RARE

Why Australia needs a National Plan for Rare Diseases?

ISSUE

Australia needs a coordinated, national approach to rare diseases: a National Rare Diseases Plan.

Why is this important?

- Patients with rare diseases account for a disproportionately high cost to the healthcare system in comparison to other patients.
- Rare diseases are hidden within the system due to their low prevalence and lack of specific coding.
- Data are needed to quantify the collective impact of rare diseases on healthcare, and to inform policies, service planning, clinical guidelines and research.
- The available evidence highlights significant medical, social, economic and emotional impacts felt as a result of rare diseases.
- Reports from consumers indicate that care for rare diseases is fragmented and uncoordinated, and thus potentially inefficient and ineffective.
- There are currently significant opportunities that Australia can leverage in order to develop a rare diseases plan, including international networks and guidance.
- Rare diseases share commonalities, being complex, multi-systemic, and are often life-threatening, incurable and non-preventable.

What would a National Rare Diseases Plan deliver?

- Clear national guidance on rare diseases management and research for policy makers, clinicians, researchers and consumers.
- A coordinated response to rare diseases that builds on existing structures and maximises opportunities, and can be delivered within existing resources.
- Recognition of rare diseases as a collective group, demonstrated through a coordinated policy response the development of a national definition for rare diseases.

With Compliments

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Why Australia needs a National Plan for Rare Diseases?

- An increased evidence-base, achieved through supporting consistent coding and surveillance, mapping services accessed to support rare diseases, and facilitating clinical, research and consumer collaboration, within Australia and internationally.
- Optimal and efficient diagnosis, treatment and care, and better health and wellbeing for Australians living with rare diseases, their carers and families.

Current Situation

- Governments indirectly support rare diseases through the delivery of care and services which are accessed by individuals living with rare diseases, their families and carers.
- Access to services has been described as fragmented and lacking coordination.
- There are frequent reports, and substantial case studies and anecdotal evidence, of inadequate or inappropriate treatments for rare diseases.
- Within many jurisdictions there are examples of excellent clinics and recognised expertise, but these are largely siloed and there are no pathways by which they might be promulgated and accessed consistently across Australia.
- There are significant opportunities to learn from and engage with international efforts in the rare diseases sector.

Key Facts and Figures

- Statistically, a rare disease is one that affects up to 1 in 2,000 Australians.
- There are approximately 5,000 to 8,000 rare diseases.
- It is estimated that rare diseases affect 6 to 8% of the population. This is more than 1.2 to 2 million Australians, and is almost one and half times the number of Australians with diabetes.
- It is estimated that more than 400,000 children are living with a rare disease in Australia.