MCKELL INSTITUTE

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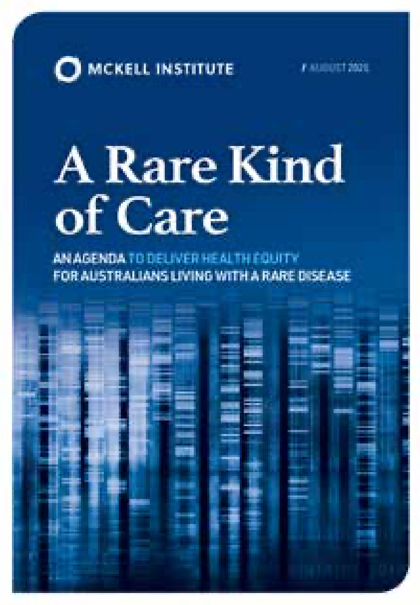
BRIEFING

A Rare Kind of Care

AN AGENDA TO DELIVER HEALTH EQUITY FOR AUSTRALIANS LIVING WITH A RARE DISEASE



Overview

The McKell Institutes latest report, *A Rare Kind of Care: An agenda to deliver health equity for Australians living with a rare disease*, examines the current state of Australia's rare disease policy landscape, identifying policy gaps, and provides eight recommendations aimed at ensuring all Australians living with a rare disease experience health equity.

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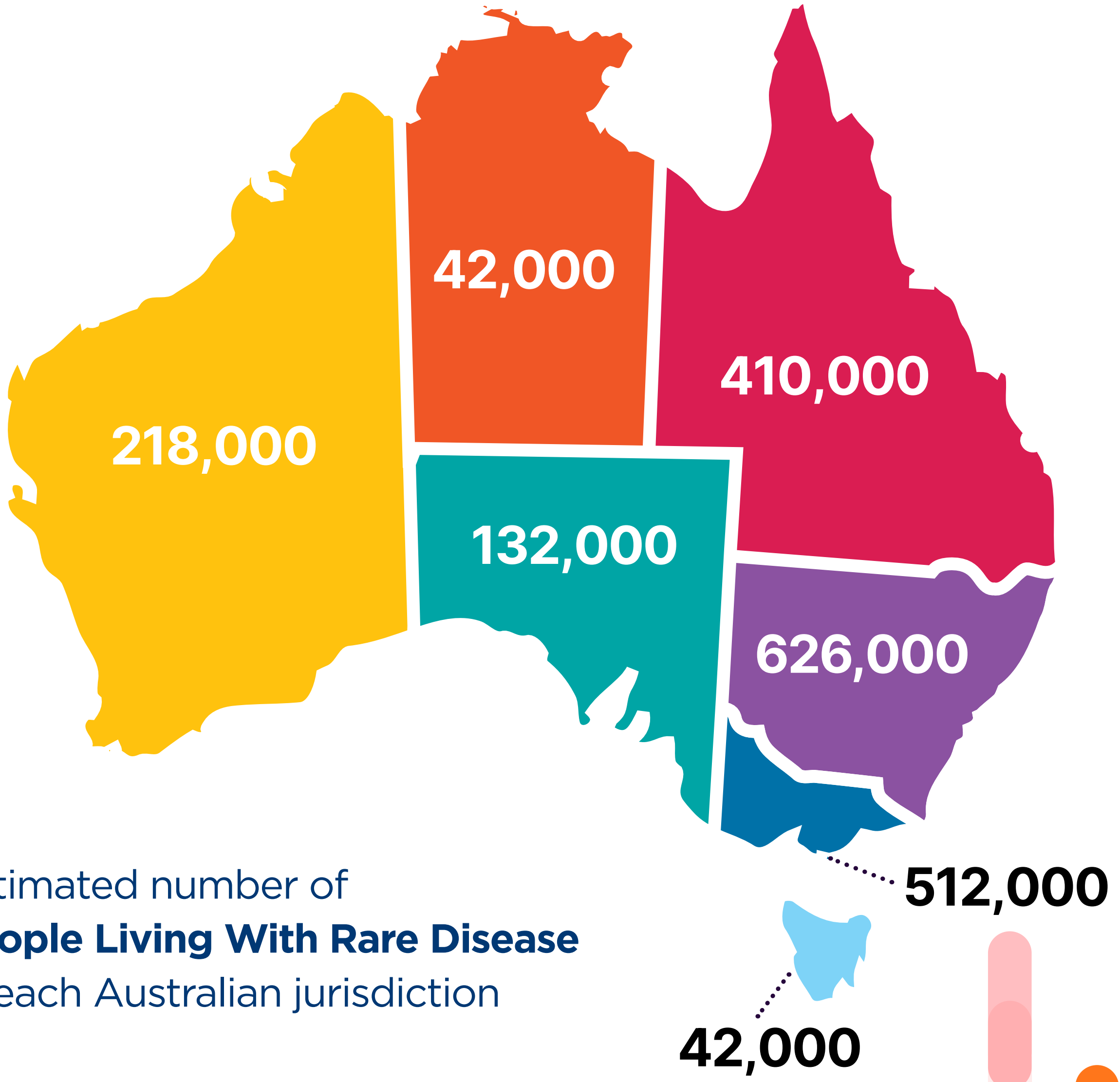
Two million Australians live with rare disease. While individual incidence of rare diseases are indeed rare, in aggregate, the total number of people living with a rare disease is significant.

Many Australians living with rare disease receive inadequate treatment, support and care, which varies considerably between jurisdictions. Access to specialist health care tailored for rare disease patients is often a 'postcode lottery' or based on other factors such as age or disease awareness. This report undertakes a comprehensive mapping exercise of existing programs, and argues for a more coordinated, best-practice informed national approach to this policy area.



Estimated number of
People Living With Rare Disease
in each Australian jurisdiction

Key Findings

FINDING 1

While each disease may be ‘rare’, collectively, rare diseases affect up to 8 per cent of the Australian population, with this proportion multiplied when the impacts on family, friends and carers are taken into consideration.

FINDING 2

There is growing evidence of the disproportionate fiscal impact of rare disease, providing the opportunity for policymakers to consider innovative, cross-sector policy responses to effectively and efficiently meet the needs of Australians living with rare disease.

FINDING 3

Australians living with rare disease are subject to a “postcode lottery” due to patchy and inconsistent policy settings across each jurisdiction. These policy settings often result in a long journey to diagnosis, delayed or poor access to treatment, including specialist care and missed opportunities to receive early and innovative medicines, including through clinical trials.

FINDING 4

The publication of the National Strategic Action Plan for Rare Diseases, and the initiatives it champions, provide a foundation for more effective policy responses by all levels of government. Despite the efforts of patient groups and clinicians, implementation of the Action Plan has been patchy at the national level and has not been supported through the development of comprehensive state and territory rare disease policies and action plans.

FINDING 5

All aspects of rare disease policy, across health and social systems, need greater focus and resourcing from the national and state and territory governments to ensure health equity for Australians living with a rare disease.

FINDING 6

Successful programs exist, despite funding uncertainty and inconsistent government support and planning. Such programs should become the ‘norm’ rather than the exception so Australians living with a rare disease have access to world class support no matter where they live in Australia. There is an opportunity to learn from successful programs and models and replicating them across jurisdictions.

FINDING 7

The Australian government has a leadership role in coordinating and funding a national, best-practice response to rare diseases to address the significant inequities currently faced by Australians living with rare disease. The Australian government has a crucial role in improving affordable and timely access to innovative medicines and treatments for rare diseases through the Pharmaceutical Benefits Scheme (PBS) and other programs.

FINDING 8

While there are long-term reforms required to realise the objectives of the National Strategic Action Plan on Rare Disease, there are also shorter-term actions that state, territory and Australian governments can pursue.

Recommendations

A Rare Kind of Care advances eight recommendations for the consideration of both the Commonwealth and State Governments:

RECOMMENDATION 1

The Commonwealth should develop and legislate a Rare Disease Act, which legislates the establishment of an Office of Rare Disease (ORD). The ORD would be responsible for overseeing the implementation of the Action Plan, and coordinate reforms to rare disease policy and the delivery of health services for people living with a rare disease in Australia.

RECOMMENDATION 2

Implement the National Strategic Action Plan for Rare Disease, with priority given to the formation of an implementation group.

RECOMMENDATION 3

Ensure access to innovative medicines by reforming the PBS.

RECOMMENDATION 4

State and territory governments should develop rare disease strategies for their jurisdictions, aligned to the National Strategic Action Plan.

RECOMMENDATION 5

'Centres of Expertise' for rare disease should be expanded around the country, with support from the Commonwealth government.

RECOMMENDATION 6

Strengthen Australia's diagnostic and screening framework.

RECOMMENDATION 7

Expedite the establishment of the National One Stop Shop for clinical trials.

RECOMMENDATION 8

The Commonwealth should partner with the states and territories to design and implement a workforce strategy specific to rare disease.

For more information, visit www.mckellinstitute.com/research/ararekindofcare