National Strategy for Australia's Rare Metabolic Disease Workforce

Background

In 2022, Rare Voices Australia (RVA) published the *Rare Metabolic Workforce White Paper* (White Paper).[1] The White Paper, together with sector consultation, informed development of the *National Strategy for Australia's Rare Metabolic Disease Workforce* (the Strategy).[2]

The Strategy is an evidence-based, expert-backed framework of goals, recommendations and priority actions that address current high levels of unmet need through a nationally consistent and sustainable workforce.

Scan the QR codes to read more about the White Paper and the Strategy.

Metabolic Workforce White Paper

Metabolic Workforce Strategy

Why is the Strategy important for the broader rare disease sector?

The Strategy's goals for a recognised, connected, consistent, sustainable and innovative rare metabolic disease workforce, should be further leveraged to respond to broader rare disease workforce challenges in Australia.

This aligns with Priority 1.3 of the Australian Government's National Strategic Action Plan for Rare Diseases, 'Develop a national rare disease workforce strategy that responds to current and future demands, including the impact of genomics'.[3]

Rare metabolic diseases

- Affect an estimated 12,700 Australians[4]
- Are a highly heterogenous group of complex, multisystemic conditions
- Place overwhelming medical and social burden on families[5]
- Require multidisciplinary team care overseen by specialist metabolic expertise[1]

White Paper findings

- Australians living with a rare metabolic disease have high levels of unmet need, and the care they receive depends on their postcode
- Critical workforce shortages are preventing best practice care for these patients
- Insufficient resources in specialist metabolic services are preventing access to innovative new treatments and clinical trials

Implementing the Strategy

A person-centred approach to implementing this Strategy is essential and is the responsibility of all stakeholders, including governments, hospital administrators, healthcare providers, specialist physician groups and policymakers across states and territories, and at a national level.

References

1.Equity Economics and Rare Voices Australia (2022). Rare Metabolic Disease Workforce White Paper Towards a Strengthened Rare Disease Workforce for Australia, February 2022. Available From: https://rarevoices.org.au/wp-content/uploads/2022/02/RareMetabolicDiseaseWorkforce_WhitePaper.pdf

2.Rare Voices Australia Equity Economics (2023). National Strategy for Australia's Rare Metabolic Disease Workforce, February 2023. Available From:

3.Australian Government Department of Health. National Strategic Action Plan for Rare Diseases. Canberra; 2020. 63 p. Available From: https://www.health.gov.au/resources/publications/national-strategic-action-plan-for-rare-diseases

4.Australian Bureau of Statistics (2021). Births Australia; 2020 Available From: https://www.abs.gov.au/statistics/people/population/births-australia/latest-release

5.Anderson M, Elliott, EJ, Zurynski YA. Australian families living with rare disease: Experiences of diagnosis, health services use and needs for psychosocial support. Orphanet J. Rare Dis. [Internet]. 2013;8:22. Available from: https://doi.org/10.1186/1750-1172-8-2

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National Goals and Recommendations for a Strengthened Rare Metabolic Disease Workforce

Goal 1: Sustainable Systems and Workforce

Recommendation 1.1
Urgently respond to critical funding shortages to increase the capacity and sustainability of existing services for paediatric and adult patients.

Recommendation 1.2
Urgently address critical workforce shortages.

Recommendation 1.3
Adopt a revised funding framework for both clinical and diagnostic specialist metabolic services that adequately responds to and captures:

- *All service activities, including but limited to care management/ coordination and data collection;*
- *Unserviced patients; and*
- *Underserviced patients.*

Recommendation 1.4
Through a multifaceted approach, modify or extend the current activity-based funding models to better respond to the complexity and resource intensity of tasks associated with rare metabolic care.

Recommendation 1.5
Ensure adequate, responsive and sustainable staff to patient ratios across all roles in a metabolic service.

Recommendation 1.6
Enable funding models to expand services to respond to future needs. Existing service funding growth should be indexed to projected growth in demand and changing requirements of the patient population.

Goal 2: Connected and Coordinate Care

Recommendation 2.1
Develop, strengthen and formalise Models of Care for rare metabolic diseases that incorporate multidisciplinary teams and care coordination.

Recommendation 2.2
Develop and adopt nationally or jurisdictionally consistent and formalised diagnostic, clinical care and transition pathways for each rare metabolic disease group, based on available services (e.g. using 'HealthPathways' or similar).

Recommendation 2.3
Strengthen care coordination using individualised care plans as standard practice for rare metabolic patients, similar to existing individualised chronic care plans.

Goal 3: Consistent Care Informed by Specialist Metabolic Expertise

Recommendation 3.1
Reduce urgent gaps by resourcing fit-for-purpose reciprocal arrangements in all states and territories for the diagnosis and management of rare metabolic diseases.

Recommendation 3.2
Patient care should always be informed by specialist metabolic expertise to reduce inconsistencies.

Recommendation 3.3
Demonstrate progress towards implementing the full range of metabolic workforce expertise in each state and territory.

Recommendation 3.4
Progress the establishment of a network of specialised 'whole-of-life' metabolic service hubs incorporating research and innovation, in line with international direction for rare metabolic care (e.g. MetabERN).

Goal 4: Recognition of the Metabolic Specialty and Best Practice Criteria

Recommendation 4.1
Recognise the importance of specialist metabolic care for the estimated 12, 700 Australians living with a rare metabolic disease.

Recommendation 4.2
Develop and/or recognise a best-practice framework for rare metabolic services for all Australians, that includes guidance on the roles of the specialised metabolic workforce and connections with other specialties.

Recommendation 4.3
Develop and embed formal training pathways for the rare metabolic workforce that include adult and paediatric metabolic clinicians, dietitians, nurses, allied health and mental health professionals, and biochemical genetic pathologists.

Goal 5: Care Responsive to Innovation

Recommendation 5.1
Establish dedicated staff and infrastructure within specialist metabolic services for ongoing participation in research, clinical trials and clinical management of newly approved health technologies.

Recommendation 5.2
Build capacity for Australia-wide coordination of specialist metabolic services to deliver innovative therapies so all Australians living with a rare metabolic disease have timely access to clinical trials and newly approved health technologies.

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