FINDINGS SUMMARY

rare voices
AUSTRALIA®

RARE METABOLIC DISEASE WORKFORCE WHITE PAPER

Towards a Strengthened Rare Disease Workforce for Australia

BACKGROUND

The National Strategic Action Plan for Rare Diseases (the Action Plan)[1] called for the development of a national rare disease workforce strategy that responds to current and future demands, including the impact of genomics. The Action Plan is Australia's first nationally coordinated effort to address rare diseases. Its collaborative development was led by Rare Voices Australia (RVA), the national peak body for Australians living with a rare disease.

The *Rare Metabolic Disease Workforce White Paper: Towards a Strengthened Rare Disease Workforce for Australia*[2] (White Paper), a pilot project focusing on the workforce challenges of the rare metabolic condition workforce, is an initial step to progress a national rare disease workforce strategy. The White Paper highlighted the breadth and scope of rare metabolic services being provided around Australia. Many of the pilot's findings will be transferable to other groups of rare diseases and will inform the development of a rare disease workforce strategy more broadly.

RARE METABOLIC CONDITIONS:

- Include over 1,600 different disorders.[3]
- Affect 50 per 100,000 people globally, including an estimated 12,700 Australians.[4]
- Require multidisciplinary specialist metabolic care.

ABOUT THE RESEARCH

RVA engaged Equity Economics and Development Partners to undertake a comprehensive review and analysis of the Australian rare metabolic workforce.

KEY CONTRIBUTORS

The development of the White Paper was possible due to the significant contributions of an experienced workforce Steering Committee with representation from the Australasian Society for Inborn Errors of Metabolism (ASIEM), together with a range of healthcare professionals, patient groups and individuals living with rare metabolic disease and their families.

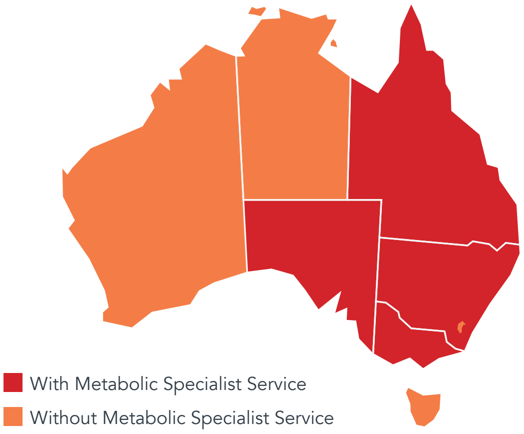
METHODS

- Literature review
- National Metabolic Workforce Questionnaire
- National Patient and Carer Experience Survey
- Industry Survey
- Workforce Focus Groups
- Patient Group Leader Focus Groups
- Input from International Experts

KEY FINDINGS

- Australian specialist metabolic services are operating beyond capacity.
- Despite the efforts of committed and expert clinicians, hospital staff, patient groups, families, allied health providers and many others, critical shortages in professional expertise and resources are hampering best practice care for patients living with a rare metabolic condition. Resounding frustration and a palatable desire for change were evident across all the voices that contributed to this research.
- The role of and need for a specialised rare metabolic workforce are not well understood by medical peak bodies and administrators, making it difficult to address the serious issues facing the workforce, patients and their families.
- To facilitate the reforms and investments needed across the workforce, greater recognition of the specialty of metabolic medicine and more formal training pathways are paramount.
- Patients and healthcare professionals flagged the need for more formalised care pathways, better models of care and individualised care plans in line with those already in use for complex chronic health conditions.
- Inadequate funding and care models are significant barriers to optimal multidisciplinary care required by rare metabolic patients.
- Across some services, there are critical workforce shortages that cannot easily be rectified.
- At times, the standard of care received by patients is dependent on their diagnosis and postcode, highlighting serious inequities that must be urgently addressed.
- Transitions from paediatric to adult services were consistently reported as an area of concern for workforce, patients and carers.
- Mental health support is not typically part of formalised multidisciplinary metabolic care and the impact of this is being felt by patients.
- Australian specialist metabolic services are almost universally not sufficiently resourced—lacking workforce and infrastructure—to contribute to innovation or facilitate clinical trials.

STATES AND TERRITORIES WITH AND WITHOUT A METABOLIC SPECIALIST SERVICE



OF RARE METABOLIC PATIENTS AND CARERS SURVEYED:

40%

said that specialised metabolic services were not fully meeting their needs.

31%

felt that the increased reliance on telehealth during the COVID-19 pandemic, decreased the quality of their health care.

HOW THESE FINDINGS COMPARE TO INTERNATIONAL BEST PRACTICE

Overall, Australia's rare metabolic health care does not compare well with international best practice. International models, like the European Reference Network (ERN) and MetabERN[5], provide a potential way forward for vital systemic change. A move towards this network type approach with established criteria for rare disease Centres of Excellence also aligns with the Action Plan's foundation principles: person-centred; and sustainable systems and workforce; as well the critical enabler: state, national and international partnerships.[1]

NEXT STEPS FOR A STRENGTHENED METABOLIC WORKFORCE IN AUSTRALIA

Australia has an urgent need to invest in the rare metabolic workforce and improve outcomes and access to health care for Australians living with a rare metabolic condition. The key findings support the need for further strategic work towards a more sustainable metabolic workforce to provide the best quality care and outcomes for patients living with rare metabolic conditions in Australia, today and into the future.

Following this White Paper, RVA will:

- Communicate these findings to all key stakeholders;
- Develop draft strategic actions in response to the key findings;
- Engage and collaborate with Commonwealth, state and territory governments, hospital administrators and ASIEM to review draft strategic actions and develop effective and sustainable solutions; and
- Finalise strategic actions to progress much needed change in each jurisdiction that is aligned with international best practice.

The White Paper findings should be further leveraged to respond to broader rare disease workforce issues in Australia. Continued work in this area should be prioritised by all jurisdictions to respond to the Australian Government's Action Plan, in which workforce is a foundation principle and priority.

DOWNLOAD THE FULL WHITE PAPER

www.rarevoices.org.au/whitepaper

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