31 October 2023

Mr Richard Beasley SC
Commissioner
The Special Commission of Inquiry into Healthcare Funding

Dear Mr Beasly,

Rare Voices Australia (RVA) commends the New South Wales government's intentions to review the funding of NSW health services and welcomes this opportunity to provide input into the Special Commission Inquiry into Healthcare Funding (Inquiry). The Terms of Reference are highly relevant in the context of rare disease healthcare.

Rare diseases, like many other chronic diseases, are often serious and progressive. People living with rare disease face common challenges, including the struggle for a timely and accurate diagnosis, limited access to the right rare disease expertise, limited treatment options and high degrees of symptom complexity necessitating access to a wide variety of specialties through coordinated multidisciplinary teams. Any efforts to improve healthcare funding in NSW should consider these challenges. These complexities require a carefully planned and nuanced approach to healthcare funding that is efficient, sustainable and responsive to change.

This funding review is timely regarding the Australian Government's recent commitment to equitable expansion of the Newborn Bloodspot Screening (NBS) program through national consistency and delivery of wrap around specialist care.[1] There is opportunity to leverage the Commonwealth investments to this program. The NSW Government has made a commitment to timely implementation of conditions recommended for NBS. Workforce readiness is crucial to this. Through this Inquiry, NSW can lead the way in Australia building and strengthening health workforce capacity through systematic and sustainable funding reforms.

About Rare Voices Australia

RVA is the national peak body for the estimated two million Australians living with a rare disease. RVA has a strong track record in systemic advocacy for broad rare disease policy reform across government departments, including health, disability and research. RVA's work is non-disease specific.

RVA led the collaborative development of the National Strategic Action Plan for Rare Diseases[2] (the Action Plan), the first nationally coordinated effort to address rare diseases in Australia. The Action Plan includes 3 interrelated pillars—Pillar 1: Awareness and education, Pillar 2: Care and Support, and Pillar 3: Research and Data.

Rare Disease and the Health Workforce in Australia – through the lens of rare metabolic disease care

The rare disease workforce in Australia is often under resourced and funding models are not-fit-for-purpose to optimally manage the complexity of rare conditions. There are limited treatments for rare disease. For many people living with a rare disease, clinical trials are the only way to access treatment. However, the health workforce in Australian is not resourced to embed research into clinical care. Until this happens patients cannot access best practice in rare disease care.

A key priority in the Action Plan, Priority 1.3, is the development of a national rare disease workforce strategy that responds to current and future demands, including the impact of genomics. As a first step to achieving this, RVA engaged policy researchers and an expert project steering committee to conduct research and build evidence around the strengths and gaps in the healthcare system managing the care of people living with rare metabolic diseases. Rare metabolic diseases are a large group of over 1,600 complex multisystem rare diseases affecting approximately 12,700 Australians. These conditions are often diagnosed in asymptomatic newborns via newborn bloodspot screening.

This work led to publication of the Rare Metabolic Disease Workforce White Paper – Towards a strengthened Rare Disease Workforce in Australia (the White Paper),[3] which includes 5 key findings, highlighting critical workforce shortages and insufficient resources leading to suboptimal care for these patients even in Australia's most renowned specialist metabolic services. With only 4 specialist rare metabolic disease services in Australia resources are spread thin to accommodate for patients in other jurisdictions and funding for outreach services is limited and, in some cases, not available. There is also a lot of reliance on the goodwill of already burned-out clinicians.

Stakeholders consulted in development of the White Paper highlighted insufficient resources were likely attributed to a lack of appropriate fundings models for the rare metabolic disease workforce. According to many clinicians and members of the White Paper expert steering committee, activity-based funding models were not able to respond to the complex multidisciplinary care required for rare metabolic patients. One potential solution to this is block funding in line with the model used to fund metabolic services in the United Kingdom.

From our discussions with various stakeholders as the peak body, RVA suspects activity-based funding may not be being used to its full potential within these Australian services. Many clinicians and management staff are too time poor to learn ways to optimise the use of activity-based funding. Finding ways to modify or extend activity-based funding models and finding time to educate clinicians and staff on the optimal use of these existing models is highlighted in the Priority Actions under Goal 1: 'Sustainable Systems and Workforce', of the National Strategy for Australian Rare Metabolic Workforce (attached).

The White Paper includes details of the current services (at the time of writing) available for people living with a rare metabolic disease in NSW (see separate attachment). A Summary document outlining the current status (at the time of writing) of rare metabolic care in NSW is also attached separately. The Summary details a list of urgent key actions and next steps, including detailed recommendations for investment to improve rare metabolic care in NSW.

National Strategy for Australia's Rare Metabolic Disease Workforce

After the White Paper was launched in February 2022 RVA led a consultative process to develop a National Strategy for Australia's Rare Metabolic Disease Workforce (the Strategy). The goals, recommendations and priority actions in the Strategy were developed for broader applicability to the whole rare disease workforce. The goals for a recognised, connected, consistent, sustainable and innovative rare metabolic disease workforce directly align with the Terms of Reference in this consultation.

RVA looks forward to hearing results from the Special Commission and any systemic change that leads on from this work. RVA is open to further discussions and involvement in this important initiative by the NSW government towards a person-centred healthcare workforce resourced to meet current and future need and respond swiftly to innovation.

Kind regards,

Nicole Millis
Chief Executive Officer
Rare Voices Australia

References

1. Rare Voices Australia. RVA Education Webinar – Expanding Newborn Bloodspot Screening: progress Made and Next Steps. Accessed 30 October 2023. https://rarevoices.org.au/rva-education-webinar-expanding-newborn-bloodspot-screening-progress-made-and-next-steps/
2. Australian Government. Department of Health. National Strategic Action Plan for Rare Diseases. Canberra; 2020. 63 p.
3. Equity Economics and Rare Voices Australia. Rare Metabolic Disease Workforce White Paper: Towards a Strengthened Rare Disease Workforce for Australia. February 2022. 32 p. rarevoices.org.au/launched-rare-metabolic-disease-workforce-white-paper/https://www.health.gov.au/sites/default/files/documents/2020/03/national-strategic-action-plan-for-rare-diseases.pdf