

10 May 2023

Rare Voices Australia Statement: 2023-24 Federal Budget

On Tuesday 9 May, the Hon Dr Jim Chalmers MP (Treasurer of Australia) delivered the Albanese Government's 2023-24 Federal Budget. Overall Australian Government spending on health, aged care and sport in 2023-24 is \$137.6 billion.

As the national peak body for Australians living with a rare disease, Rare Voices Australia (RVA) attended the Department of Health and Aged Care's Portfolio Briefing Webinar Presentation and Q&A on Wednesday 10 May. The webinar included the Hon Mark Butler MP (Minister for Health and Aged Care); the Hon Ged Kearney MP (Assistant Minister for Health and Aged Care); the Hon Emma McBride MP (Assistant Minister for Mental Health and Suicide Prevention and Assistant Minister for Rural and Regional Health); the Hon Anika Wells MP (Minister for Aged Care and Minister for Sport); and Senator the Hon Malarndirri McCarthy (Assistant Minister for Indigenous Australians and Assistant Minister for Indigenous Health). The session was facilitated by Prof Brendan Murphy AC, Secretary of the Department of Health and Aged Care.

Below, RVA has highlighted some areas of the Federal Budget we believe are most relevant to the estimated two million Australians living with a rare disease and the rare disease sector. RVA's work is non-disease specific and is based on the commonalities of rare disease. Our advocacy focuses on rare disease policy, processes and systems. We advocate for all rare disease communities and remain committed to ongoing work with all governments to progress the systemic implementation of the Australian Government's [National Strategic Action Plan for Rare Diseases](#) (the Action Plan).

Refresh of the National Strategic Framework for Chronic Conditions

RVA is encouraged by the announcement that a refresh of the National Strategic Framework for Chronic Conditions (the Framework) will be undertaken. The purpose of the Framework is to provide overarching policy guidance for the prevention and management of chronic conditions in Australia. Post-Budget, the Department of Health and Aged Care has reached out to RVA regarding this work as the national peak body for Australians living with a rare disease. RVA looks forward to engaging in this process and will seek more information.

Interim Australian Centre for Disease Control (ACDC)

The establishment of an interim Australian Centre for Disease Control (ACDC) in the Department of Health and Aged Care (\$91.1 million) is encouraging news for Australians living with a rare disease.

Clinical Quality Registry Program

RVA is encouraged by the Australian Government's investment into Australia's first National Clinical Quality Registry Program (\$40 million over 4 years). In the Department of Health and Aged Care's Portfolio Briefing Webinar Presentation, Minister Butler noted the government's intent to "expand in the area of learning and recording" diseases. The importance of rare disease registries is acknowledged in the Action Plan.

National Disability Insurance Scheme

The 2023-24 Budget invests \$732.9 million into initiatives developed with the National Disability Insurance Agency (NDIA) in consultation with the National Disability Insurance Scheme (NDIS) Review Co-Chairs to improve capability, capacity, and systems to better support NDIS participants. Additionally, the Budget incorporates the NDIS Financial Sustainability Framework agreed by National Cabinet to ensure the longevity of the NDIS.

Rare disease appropriate NDIS supports and planning continue to be an ongoing focus for RVA. We have been working alongside several RVA Partner organisations (rare disease groups) on an ongoing basis that have experience and expertise with the NDIS to address systemic issues and gaps for people living with a rare disease who are also NDIS applicants or participants. In February 2023, RVA provided an update regarding consultations with the NDIA and [four immediate key priorities](#) identified by the NDIA, rare disease organisation/group representatives and RVA.

Mental Health

Living with a rare disease does not only impact a person's physical health; it impacts every facet of their life, including their mental health. The Australian Government is dedicating \$586.9 million to improved mental health. This includes upskilling the broader health workforce to better recognise and respond to mental health issues. In 2022, RVA commenced a mental health and wellbeing project with Mental Health First Aid (MHFA) Australia based on recommendations in the Action Plan ([read more here](#)). By December 2022, personnel from 58 rare disease organisations had completed the MHFA training. This work continues in 2023 with RVA Partners having the opportunity to engage in Aboriginal and Torres Strait Islander MHFA Training and Youth MHFA Training.

First Nations Health

Aboriginal and Torres Strait Islander people are one of the priority populations identified in the Action Plan. While Aboriginal and Torres Strait Islander people are not necessarily at greater risk of rare diseases, several factors increase the potential impact of rare diseases on Aboriginal and Torres Strait Islander people. RVA welcomes the \$818.5 million in funding that will be dedicated to First Nations health.

Telehealth and Digital Health

The Action Plan calls for the increased utilisation of digital health, including telehealth, which will increase equity of access to services for people living with a rare disease. The 2023-24 Budget states, "A \$951.2 million digital health package will improve digital systems to build a more efficient, connected and collaborative healthcare system." This news is encouraging for Australians living with a rare disease.

New Medicare Rebates

Rare diseases, like many other chronic diseases, are often serious and progressive. They typically display a high level of symptom complexity. The Australian Government is investing \$98.2 million for new Medicare rebates, which means people who require consultations of longer than 60 minutes will receive a larger Medicare rebate. This will give doctors the opportunity to provide high quality care to people with chronic or complex needs, including mental health issues.

New Listings on the Life Saving Drugs Program

The Life Saving Drugs Program (LSDP) covers the cost of specific essential medicines to treat people living with a rare disease. The 2023-24 Budget includes \$5.7 million over 5 years to new listings on the LSDP.