

15 September 2023

Rare Voices Australia Statement Aboriginal and Torres Strait Islander Voice to Parliament

As the national peak body for Australians living with a rare disease, Rare Voices Australia (RVA) is dedicated to driving the best outcomes for Australians living with a rare disease, including Aboriginal and Torres Strait Islander peoples. Aboriginal and Torres Strait Islander peoples were identified as a priority population in the Australian Government's [National Strategic Action Plan for Rare Diseases](#) (the Action Plan). The Action Plan is the first nationally coordinated effort to address rare disease in Australia. While Aboriginal and Torres Strait Islander peoples are not necessarily at greater risk of rare diseases, several factors increase the potential impact of rare diseases on Aboriginal and Torres Strait Islander peoples.

Aboriginal and Torres Strait Islander Voice to Parliament

On Saturday, 14 October 2023, Australians will vote in a referendum about whether to change the Constitution to recognise the First Peoples of Australia by establishing a body called the Aboriginal and Torres Strait Islander Voice (the Voice). Voters will be asked to vote 'yes' or 'no' to a single question. The question on the ballot paper will be:

"A Proposed Law: to alter the Constitution to recognise the First Peoples of Australia by establishing an Aboriginal and Torres Strait Islander Voice.

Do you approve this proposed alteration?"

More information about the Aboriginal and Torres Strait Islander Voice to Parliament (the Voice to Parliament), including what the Voice will do and how it will be set up, is available via the [Australian Government's website](#).

Rare Disease and the Aboriginal and Torres Strait Islander Voice to Parliament

RVA welcomes the referendum as it provides Australians with the opportunity to change the Constitution to recognise the First Peoples of Australia by establishing the Voice. RVA recognises the importance of people having access to credible information so that they can make informed choices, including regarding policy change.

'Equity of access' is a foundation principle of the Action Plan. The Voice will make representations to the Australian Parliament and the Executive Government on legislation and policy that is significant to Aboriginal and Torres Strait Islander peoples. This will give Aboriginal and Torres Strait Islander peoples a greater say on matters that impact them. The Voice would consult with grassroots communities and regional entities to ensure its representations are informed by their experience, including the experience of those who have been historically excluded from participation.

'Person-centred' is a foundation principle of the Action Plan. As the national peak body for Australians living with a rare disease, RVA will continue to support systemic change that is person-centred and that equips and empowers people. As RVA continues to lead the collaborative implementation of the Action Plan, our person-centred approach sees us working with all key stakeholders in the rare disease sector, including people living with a rare disease, governments, key peak bodies, researchers, clinicians and industry. As Action Plan implementation progresses and RVA continues to develop content for priority populations, including for Aboriginal and Torres Strait Islander peoples, we will continue to consult with representative organisations such as the National Aboriginal Community Controlled Health Organisation (NACCHO) and the Australian Alliance for Indigenous Genomics (ALIGN). As part of the [Rare Disease Awareness, Education, Support and](#)



[Training \(RArEST\) Project](#), resources are also being developed with [Lyfe Languages](#), which strives to improve communication between health professionals and Indigenous language-speaking people.

RVA has always acknowledged the diversity in the rare disease sector and similarly, we understand there will be a diversity of views across peoples and communities concerning the Voice to Parliament. We encourage all stakeholders in the rare disease sector to engage in respectful and informed dialogue regarding all matters, including the Voice to Parliament.