



NACCHO

National Aboriginal Community
Controlled Health Organisation
Aboriginal health in Aboriginal hands

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Submission
on the
Commonwealth Data
Availability and Transparency
Bill 2020

November 2020

About NACCHO

NACCHO is the national peak body representing 143 Aboriginal Community Controlled Health Organisations (ACCHOs) Australia wide on Aboriginal and Torres Strait Islander health and wellbeing issues. NACCHO's work is focused on liaising with governments, its membership, and other organisations on health and wellbeing policy and planning issues and advocacy relating to health service delivery, health information, research, public health, health financing and health programs. Our members provide about three million episodes of care per year for about 350,000 people across Australia, including about one million episodes of care in very remote regions.

Sector Support Organisations, also known as affiliates, are State based and represent ACCHOs offering a wide range of support services and Aboriginal and Torres Strait Islander health programs to their members including advocacy, governance and the delivery of state, territory and national primary health care policies.

ACCHOs range from large multi-functional services employing several medical practitioners and providing a wide range of services, to small services which rely on Aboriginal Health Workers/Practitioners and/or nurses to provide the bulk of primary health care services, often with a preventive, health education focus. Our 143 ACCHOs operate approximately 700 facilities, including about 450 clinics. ACCHOs and their facilities and clinics contribute to improving Aboriginal and Torres Strait Islander health and wellbeing through the provision of comprehensive holistic primary health care, and by integrating and coordinating care and services. Many provide home and site visits; medical, public health and health promotion services; allied health; nursing services; assistance with making appointments and transport; help accessing childcare or dealing with the justice system; drug and alcohol services; and help with income support.

Collectively, we employ about 6,000 staff, 56 per cent of whom are Indigenous, making us the second largest employer of Aboriginal and Torres Strait Islander people in the country.

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Recommendations

NACCHO recommends that:

- The *Data Availability and Transparency Bill 2020* be re-written to align with the National Agreement on Closing the Gap, and particularly the fourth Priority Reform (shared access to data and information at a regional level).
- The membership of the National Data Advisory Council includes an Aboriginal or Torres Strait Islander representative.

Key Points

- The National Agreement on Closing the Gap creates a partnership between Aboriginal and Torres Strait Islander representatives and government organisations to guide the improved collection, access, management and use of data to inform shared decision-making for the benefit of Aboriginal and Torres Strait Islander people
- In order to implement the National Agreement, governments must provide Aboriginal and Torres Strait Islander communities and organisations access to data and information on which decisions are made, subject to meeting privacy requirements, and ensure data security and integrity.
- Aboriginal and Torres Strait Islander communities and organisations should be empowered to access, use and interpret data for local decision-making
- Aboriginal and Torres Strait Islander communities and organisations should be supported by governments to build capability and expertise in collecting, using and interpreting data in a meaningful way.

Introduction

NACCHO welcomes the opportunity to provide comments on the exposure draft of the *Data Availability and Transparency Bill 2020* (the Bill), explanatory materials, and the Accreditation Framework discussion paper. This submission is written by NACCHO with valued input provided by the following Affiliates, Queensland Aboriginal and Islander Health Council (QAIHC), Aboriginal Health Council of South Australia (ACHSA) and Victorian Aboriginal Community Controlled Health Organisation (VACCHO).

NACCHO acknowledges the Australian Government's commitment to increase its data sharing capabilities. However, the Bill contains no information on how Aboriginal and Torres Strait Islander data will be collected and handled, including if and how data governance structures will be applied to data sharing and release.

Data is a cultural, strategic and economic asset for Aboriginal and Torres Strait Islander people¹. Archaeological evidence shows Aboriginal and Torres Strait Islander peoples have occupied Australia for at least 65,000 years. During this time, Aboriginal and Torres Strait Islander communities developed sophisticated knowledge systems for managing the environment and understanding, interpreting and communicating information². Aboriginal and Torres Strait Islander people must be the cultural custodians of their data, and data should be collected and measured with the agreement of Aboriginal and Torres Strait Islander communities.

Since colonisation, Aboriginal and Torres Strait Islander people have been largely excluded from the language, control and production of data at community, state and national levels³. Access to data is important in empowering Aboriginal and Torres Strait Islander people to obtain a comprehensive picture of the status of important issues in community, including health, education, employment and social determinants of health.

The health and other disadvantages of Aboriginal and Torres Strait Islander peoples in Australia are well known and documented. To track progress and improvements, accurate data is necessary to measure health and other outcomes, determinants of health, access to health services, and the burden of diseases and their complications. Shared access to data and information at a regional level is imperative for Aboriginal and Torres Strait Islander organisations seeking to support their communities.

Alignment with the National Agreement on Closing the Gap

The Coalition of Peaks and governments agreed to and signed the National Agreement on Closing the Gap (National Agreement) in 2020. The National Agreement demonstrates commitment from all levels of government to making a change in the development and implementation of policies and programs that impact on the lives of Aboriginal and Torres Strait Islander people⁴. The National Agreement sets a strategy to close the gap that is strongly based on, and underpinned by, Aboriginal and Torres Strait Islander peoples' priorities. The fourth Priority Reform is data-related, ensuring Aboriginal and Torres Strait Islander people have access to, and the capability to use, locally relevant data and information to monitor progress against strategic priorities and drive local development⁵.

¹ Maiam nayri Wingara, *About us*, <https://www.maiamnayriwingara.org/about-us>.

² National Health and Medical Research Council, *Engaging Aboriginal and Torres Strait Islander people in guidelines development*, <https://www.nhmrc.gov.au/guidelinesforguidelines/plan/engaging-aboriginal-and-torres-strait-islander-people-guideline-development>.

³ Maiam nayri Wingara, *About us*, <https://www.maiamnayriwingara.org/about-us>.

⁴ Coalition of Peaks (2020). National Agreement on Closing the Gap.

⁵ National Agreement on Closing the Gap, (2020). Coalition of Peaks.

NACCHO recommends the Data Commissioner re-write the Bill to align it with the National Agreement and to include appropriate consideration and measures for the sharing and protection of data for and with Aboriginal and Torres Strait Islander peoples.

Aboriginal and Torres Strait Islander data

The Bill makes no mention of Aboriginal and Torres Strait Islander data, a significant oversight considering the amount of data which is collected about the lives and experiences of Aboriginal and Torres Strait Islander people. Cultural safety in the collection, storage and use of data will empower Aboriginal and Torres Strait Islander people and organisations need a day in the collection and access to data, in order to make informed decisions to improve the lives of their people. Data is important for the advancement of Aboriginal and Torres Strait Islander self-determination and development⁶.

There must be laws and policies that recognise the rights of Aboriginal and Torres Strait Islander people to access data and regulate the behaviour of institutions and individuals involved in gathering, disseminating and sharing data and knowledge. Aboriginal and Torres Strait Islander people and organisations have been given little historic and current opportunity to contribute to decision making on what data should be collected about them and their communities and why⁷. This Bill presents an opportunity to begin the reforms agreed to in the National Agreement.

Ensuring Aboriginal and Torres Strait Islander peoples have shared access to data and information will empower communities and guide them in advocating for better health and health care⁸ and other improved wellbeing outcomes. Historically non-Indigenous people have decided how to manage data relating to Indigenous people and communities⁹. This approach has meant Aboriginal and Torres Strait Islander people have had little control over what data is collected, how it is collected and what is done with it.

National Data Advisory Council

As the primary function of the National Data Advisory Council is to provide advice to the National Data Commissioner, it is important that the membership of the Council is diverse and representative. NACCHO recommends that at least one of the members appointed by the National Data Commissioner to the National Data Advisory Council is an Aboriginal or Torres Strait Islander person. This will ensure considerations relating to Aboriginal and Torres Strait Islander data will be included in the advice provided to the National Data Commissioner.

⁶ Tahu Kukutai, John Taylor ed. *Indigenous Data Sovereignty: Toward an Agenda*, Centre for Aboriginal Economic Policy Research, Australian National University Press, Research monograph no. 38, 2016.

⁷ Social Ventures Australia, *Data sovereignty, community control and better outcomes*, 29 November 2018, <https://www.socialventures.com.au/sva-quarterly/data-sovereignty-community-control-and-better-outcomes/>.

⁸ Jennifer Walker, Ray Lovett, Tahu Kukutai, Carmen Jones, David Henry, *Indigenous health data and the path to healing*, *The Lancet*, Vol. 390, 4 November 2017, www.thelancet.com.

⁹ Winyama Digital Solutions, *Why you need to know about Indigenous Data Sovereignty*, <https://www.winyama.com.au/news-room/why-you-need-to-know-about-indigenous-data-sovereignty>.

Conclusion

The National Agreement is a blueprint for how Commonwealth, State, Territory and local governments must share decision making with Aboriginal and Torres Strait Islander peoples. The National Agreement has the objective of overcoming the entrenched inequality that exists in all Australian society¹⁰. The Bill as drafted demonstrates no consideration of it will affect Aboriginal and Torres Strait Islander peoples, and their access to data. NACCHO strongly encourages the Data Commissioner to redraft the Bill to include specific references to the sharing of data with Aboriginal and Torres Strait Islander peoples to institutionalise shared decision making and the sharing of data, as outlined in the National Agreement.

¹⁰ *National Agreement on Closing the Gap*, July 2020, p. 3.