



**Submission in response
to the Office of the
National Data
Commissioner Data
Sharing and Release
Discussion Paper**

October 2019

About NACCHO

NACCHO is the national peak body representing 144 Aboriginal Community Controlled Health Organisations (ACCHOs) Australia wide on Aboriginal and Torres Strait Islander health and wellbeing issues. NACCHO's work is focussed 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, which includes about one million episodes of care in very remote regions.

Sector Support Organisations, also known as affiliates, are State based and also 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 care services, often with a preventive, health education focus. ACCHOs 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; provision of 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 providing help with income support.

Collectively, we employ about 6,000 staff, 56 per cent whom are Indigenous, which makes us the single largest employer of Indigenous people in the country.

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1. Introduction

This submission has been prepared by the National Community Controlled Health Organisation (NACCHO) with input from:

- Aboriginal Health and Medical Research Council of NSW (AHMRC);
- Aboriginal Health Council of South Australia (AHCSA);
- Aboriginal Medical Services Alliance Northern Territory (AMSANT);
- Victorian Aboriginal Community Controlled Health Organisation (VACCHO);
- Winnunga Nimmityjah Aboriginal Health Service (Winnunga); and
- Geraldton Regional Aboriginal Medical Service.

NACCHO, AHCSA, AHMRC, AMSANT and Winnunga acknowledge the Australian Government's commitment to increase its data sharing capabilities. We note that an assertive data sharing agenda is being developed, heralded by the release of the Productivity Commission's inquiry into data availability and use (2017),ⁱ and followed by the establishment of the Office of the National Data Commissioner (ONDC) tasked with developing data sharing and release legislation.

The findings of the Productivity Commission's inquiry suggest that Australia lags behind many other countries when it comes to data sharing, and that 'protections ... are choking the use and value of Australia's data'. The inquiry report states that a 'cultural shift' is required to move from a risk averse approach to data sharing to one that is committed to increase the availability and improving the use of data.

NACCHO, AHCSA, AHMRC, AMSANT and Winnunga recognise the power of data for agencies, including governments, to evaluate performance and to inform future investments in policies, programs and projects. We are aware that access to accurate, timely, and localised data may be used to strengthen the health and wellbeing outcomes of Aboriginal and Torres Strait Islander communities by providing the evidence base for evaluating what's happening on the ground. Many of our member services routinely use qualitative and quantitative data to inform business planning and decision-making, and continuous quality improvements, under the overarching objective of improving the health outcomes of individuals, families and communities.

NACCHO, the affiliates and ACCHOs have, over decades, consistently invested resources into numerous government and other externally initiated data reform projects, including a range of new and evolving datasets and reporting platforms. NACCHO and affiliates have also developed and proposed sophisticated data collection, reporting and analytics systems - such as, for example, the Secure Aboriginal Medical Services Information System known as SAMSIS - that have not been actioned by successive governments. Further, all the affiliates have been using data systems and tools for many years, to collate, report and analyse CQI activities and inform business planning:

- AHCWA and QAIHC have developed geospatial mapping tools
- AHCSA is building its own data system for nKPIs and linking the data to comprehensive CQI initiatives
- VACCHO has recently built a comprehensive Data Lake and use of Business Intelligence tools to visualise data and increase access and timeliness of more meaningful data to ACCHOs.

Our appreciation of and respect for data is, however, also prefaced by our shared understandings of how data such as statistical collections have been used as colonial tools of surveillance and control, resulting in the destruction of Aboriginal and Torres Strait Islander culture and community. Most of the Aboriginal and Torres Strait Islander data currently collected continue to be used to perpetuate discourses of deficit and pathology, giving rise to a problematic Indigeneity and justifying government interventions including punitive measures. It is not surprising, then, that the accumulation of many generations of Aboriginal and Torres Strait Islander peoples' experiences of colonial and post-colonial interventions have coloured our relationship with data. We have an abiding concern, shaped by historical legacies of distrust, in knowing what data are collected and how this information is used, both with and without our consent.

NACCHO, AHCSA, AHMRC, AMSANT and Winnunga recognise that a key reason why many Aboriginal and Torres Strait Islander people continue to experience strong distrust in government and societal institutions, which include data collecting entities, relates to their post-colonial lived realities of disadvantage, marginalisation, discrimination, racism and intergenerational trauma.ⁱⁱ The historical legacies of colonisation – including forced removal from country and acts of genocide – amidst contemporary racist and exclusionary practices continue to have devastating consequences in our communities. Aboriginal and Torres Strait Islander peoples' diverse experiences of colonialism are also key to understanding the prevalence of trauma, and why trauma exists and persists over generations.ⁱⁱⁱ

Given the historical, social and political legacies that Aboriginal and Torres Strait Islander peoples engage with in their everyday lives, data sharing and release legislation must demonstrate a respect and consideration for these lived realities. We are disappointed that the Data Sharing and Release discussion paper provides no information on how Aboriginal and Torres Strait Islander data will be handled, including whether the data governance structures, informed by Indigenous data sovereignty principles, will be applied to data sharing and release policy and legislation. Our shared concerns regarding these issues inform the basis of this submission, and relate to the following discussion paper questions:

2. What are the challenges for open release of public sector data?
5. Do the purposes for sharing data meet your expectations? What about precluded purposes?

14. What types of guidance and ongoing support from the National Data Commissioner will provide assurance and enable safe sharing of data?

2. Proposed data sharing and release legislation in the context of Aboriginal and Torres Strait Islander data sovereignty

Data are a cultural, strategic and economic resource for indigenous peoples. Yet, indigenous peoples remain largely alienated from the collection, use and application of data about them, their lands and cultures. Existing data and data infrastructure fail to recognise or privilege indigenous knowledge and worldviews and do not meet indigenous peoples' current and future data needs.

Indigenous Data Sovereignty (IDS) is a global movement concerned with the rights of indigenous peoples to own, control, access and possess data that derive from them, and which pertain to their members, knowledge systems, customs or territories. IDS is supported by indigenous peoples' rights to self-determination and governance over their land, resources and culture as described in the United Nations Declaration on the Rights of Indigenous Peoples. Implicit in IDS is the desire for data to be used in ways that support and enhance the collective wellbeing of indigenous peoples.^{iv}

We note that the Data Sharing and Release discussion paper does not address how Indigenous data will be treated.¹ This makes it challenging for us to understand how the data sharing and release agenda will impact on privacy and consent issues relating to Aboriginal and Torres Strait Islander peoples. It also limits our capacity to engage in a dialogue during this consultation phase. Greater clarification must be given regarding what the proposed new arrangements around Indigenous data would look like and involve.

Without full consideration of the issues pertaining to Indigenous datasets, the data sharing and release agenda proposed by the Office of the National Data Commissioner will be compromised, at least when it comes to understanding Aboriginal and Torres Strait Islander data, and managing it in line with privacy laws, ethics guidelines, and principles of Indigenous data sovereignty.

By Indigenous data sovereignty, we support the foundational statement of the Maiam nayri Wingara Indigenous Data Sovereignty Collective:

¹ By Indigenous data, we refer to information or knowledge, in any format or medium, which is about and may affect Aboriginal and Torres Strait Islander peoples both collectively and individually, as per the foundational statement of the Maiam Nayri Wingara Indigenous Data Sovereignty Collective, at <https://www.maiamnayriwingara.org/>

'Indigenous Data Sovereignty' refers to the right of Aboriginal and Torres Strait Islander peoples to exercise ownership over Aboriginal and Torres Strait Islander data. Ownership of data can be expressed through the creation, collection, access, analysis, interpretation, management, dissemination and reuse of Aboriginal and Torres Strait Islander data.^v

There is no discussion of the concept of Indigenous data sovereignty in the discussion paper and what this means in the new policy settings of data sharing and release. This omission implies that Indigenous data may be treated no differently than other data. In contrast, we believe additional arrangements are required to ensure the data rights of Aboriginal and Torres Strait Islander peoples are maintained and protected.

The Aboriginal community controlled health sector is underpinned by values of self-determination, which are an exercise of our rights as Indigenous peoples under the *UN Declaration on the Rights of Indigenous Peoples*. ACCHOs have a high level of community oversight and accountability. Their boards are made up of local Aboriginal and Torres Strait Islander people, and they serve and are accountable to their communities. In line with our philosophy and approach, we believe our people must be granted agency in the development and implementation of policies and programs that impact on their lives, as enshrined in the *UN Declaration on the Rights of Indigenous Peoples 2007* and the *Aboriginal and Torres Strait Islander Act 2005 (Cth)*.^{vi} Our standpoint on data sharing and release, then, is that policy and legislation must be developed in recognition of Indigenous data sovereignty, and a commitment to work with Aboriginal and Torres Strait Islander peoples and their representatives.

We urge the ONDC to consider the data sharing and release policy agenda in the historical and political contexts of Australia's First Peoples encounters with governments: data is an inherently political construct that always serves the interests of those agents who seek to collect, analyse and disseminate it. The issue of trust, or lack of trust in institutions, also relates to the extent and accuracy of information that Aboriginal and Torres Strait Islander peoples are prepared to provide. For example, depending on their relationships with different agencies, people will be comfortable about declaring Aboriginality on some forms, but not on others. This will have a flow-on effect on data linkage.

The discussion paper states that 'consent will not be required in all instances of data sharing' (p.33). This is of concern to us, given the limits of de-identification. The identifiability of data is particularly pertinent in situations where proposed longitudinal analysis is undertaken in relation to individual consumer data, or where personal health information is linked with other datasets. The case study below highlights issues of de-identification and re-identification of people's personal health information.

Case Study: Winnunga Nimmityjah Primary Mental Healthcare Minimum Dataset Reporting

Winnunga Nimmityjah Aboriginal Health and Community Services is an ACCHO that services the ACT region and beyond. In 2017, Winnunga expressed its concerns over the Primary Mental Healthcare Minimum Dataset (PMHC-MDS) which is a reporting requirement of the Department of Health Primary Health Networks, Primary Mental Health Care Funding Pool. The PMHC-MDS requires reporting of highly detailed individual client personal mental health information to Primary Health Networks. Client information is 'de-identified' but date of birth, Indigenous identification and detailed health care provider information is required. In small communities, this level of detail could be used to re-identify individuals. Requesting client fully informed consent to report mental health information is necessary but could jeopardise the relationship of trust between clients and the ACCHO. The use of screening tools that are not specified in clinical guidelines was also mandated, infringing on the ACCHO's clinical autonomy.

Winnunga decided the reporting requirements were unacceptable and eventually declined funding. This resulted in money intended for Indigenous mental health going to a mainstream organisation which does not have the same reach or capacity to address the issue in the ACT. Stories like this highlight the need for funding for Aboriginal and Torres Strait Islander mental health to have respectful and reasonable governance and reporting which is guided by Aboriginal and Torres Strait Islander peoples and organisations.

We are encouraged to note that, in accordance with Commonwealth *Privacy Act 1988* definitions, the ONDC will 'set higher protections for sensitive data in a binding Sensitive Data Code', including culturally sensitive data; and that it plans to consult on the Sensitive Data Code alongside the draft legislation in early 2020 (page 32). Sensitive information is defined in the *Privacy Act 1988* as:

- (a) information or an opinion about an individual's:
 - (i) racial or ethnic origin; or
 - (ii) political opinions; or
 - (iii) membership of a political association; or
 - (iv) religious beliefs or affiliations; or
 - (v) philosophical beliefs; or
 - (vi) membership of a professional or trade association; or
 - (vii) membership of a trade union; or
 - (viii) sexual orientation or practices; or
 - (ix) criminal record; that is also personal information; or
- (b) health information about an individual; or
- (c) genetic information about an individual that is not otherwise health information; or

- (d) biometric information that is to be used for the purpose of automated biometric verification or biometric identification; or
- (e) biometric templates.^{vii}

We look forward to engaging more closely with the ONDC in consultations on the Sensitive Data Code.

3. Indigenous data governance

Indigenous data governance refers to:

the right of Aboriginal and Torres Strait Islander peoples to autonomously decide what, how and why Aboriginal and Torres Strait Islander data are collected, accessed and used. It ensures that data on or about Aboriginal and Torres Strait Islander peoples reflects our priorities, values, cultures, worldviews and diversity.^{viii}

The data sharing and release discussion paper states that the National Indigenous Australians Agency (NIAA) is working on a whole-of-government approach to Indigenous data, including the development of an Indigenous data strategy. We note, however, that the timelines for presenting data sharing and release legislation to the Australian Parliament will come before the Indigenous Data Strategy is finalised. It is unclear how this whole-of-government strategy will intersect with, if at all, the data sharing and release legislation. It is concerning that;

- Development of the Indigenous Data Strategy by the NIAA will have no external input from the Community Controlled Sector or other relevant Aboriginal and Torres Strait Islander organisations
- As it is only in its early stages, it is likely that it will not be ready in time for the tabling of the draft legislation in mid-2020
- The NIAA appear not to have considered any of the issues outlined by NACCHO and Affiliates including Indigenous Data Sovereignty and protections around people unknowingly having potentially sensitive data shared across social Government Agencies

Our position is that the sharing and release of Aboriginal and Torres Strait Islander client data must be designed in negotiation with Aboriginal and Torres Strait Islander peoples. We believe it is essential for data governance principles and structures to recognise and accommodate the need for Aboriginal and Torres Strait Islander peoples' self-determination and community-control in all steps of collecting and using data. In practice, this means ensuring the collection, reporting, sharing and release of Aboriginal and Torres Strait Islander peoples' data is culturally appropriate, safe, competent and in the best interests of Aboriginal and Torres Strait Islander peoples, and the benefits of sharing outweigh the harms.

It is our hope that the ONDC consider strengthening the data sharing and release policy and legislative agenda by supporting Indigenous Data Governance CARE Principles that emphasise:

- Collective benefit. Data ecosystems designed and function in ways that enable Indigenous peoples to derive benefit from the data.
- Authority to control. Indigenous peoples' rights in Indigenous data must be recognised and their authority to control such data be empowered.
- Responsibility. Those working with Indigenous data have a responsibility to share how those data are used to support Indigenous Peoples' self-determination and collective benefit.
- Ethics. Indigenous peoples' rights and wellbeing should be the primary concern at all stages of the data life cycle and across the data ecosystem.^{ix}

Further, we believe that a national Aboriginal and Torres Strait Islander data governance structure is required to protect the data rights of Aboriginal and Torres Strait Islander peoples. The establishment of such a structure, that includes Indigenous representation with decision making powers, will ensure that the focus of data sharing and release will benefit our communities. At a broader policy level, it would also more effectively contribute to Close the Gap priorities.

The establishment of a national level Indigenous governance structure will also serve to highlight the cultural value of data collected from Aboriginal and Torres Strait Islander peoples for Aboriginal and Torres Strait Islander peoples. We note that a significant focus of current administrative data is on Aboriginal and Torres Strait Islander peoples' deficits. As a result of this deficit data, a particular view of Aboriginal people emerges, one that 'homogenises and dehumanises' and blames communities by 'transforming disadvantage into moral failure, and suggesting that these communities do not so much confront constrained opportunity as lack a willingness to take up opportunities.'^x It is time for a new data narrative, one that is more reflective of the hopes and aspirations of Aboriginal and Torres Strait Islander peoples, that recognises the existing strengths within and across our communities by providing meaningful narratives on community healing.

4. Concluding comments and recommendations

NACCHO, AHCSA, AHMRC, AMSANT and Winnunga recognise the value of proposed data sharing and release for improving government investment into policies and programs that benefit all Australians. We look forward to further discussions with the Office of the National Data Commissioner as data sharing and release legislation is developed to ensure data sovereignty rights for Aboriginal and Torres Strait Islander peoples.

We recommend:

1. Further development of the data sharing and release legislation must take into consideration Aboriginal and Torres Strait Islander data sovereignty principles in line with the Maiam nayri Wingara Indigenous Data Sovereignty Collective; and
2. The Office of the National Data Commissioner establish a national level Indigenous data governance committee in line with Indigenous Data Governance CARE Principles, with Aboriginal and Torres Strait Islander representation and decision making powers, to oversee Indigenous data sharing and release pertaining to all levels of the proposed framework as set out in the discussion paper.

ⁱ Productivity Commission. 2017. *Data Availability and Use: Overview and Recommendations*. Commonwealth of Australia: Canberra.

ⁱⁱ Australian Bureau of Statistics. 2016. *Aboriginal and Torres Strait Islander Population*. <https://www.abs.gov.au>; Australian Institute of Health and Welfare. 2017. *Australia's Welfare*. Canberra.

ⁱⁱⁱ Human Rights and Equal Opportunity Commission. 1997. *Bringing them Home. Report of the National Inquiry into the Separation of Aboriginal and Torres Strait Islander Children from their Families*. Sydney; Australian Institute of Health and Welfare. 2018. *Aboriginal and Torres Strait Islander Stolen Generations and descendants. Numbers, demographic characteristics and selected outcomes*. Canberra.

^{iv} Joseph A Cannataci. 2018. *Special Rapporteur on the right to privacy*, a report to the United Nations Human Rights Council. A/73/45712, pp.11-12.

^v <https://www.maiamnayriwingara.org/>

^{vi} *Aboriginal and Torres Strait Islander Act 2005* (Commonwealth), <https://www.legislation.gov.au/Details/C2016C00689>; UN Declaration on the Rights of Indigenous Peoples, https://www.un.org/development/desa/indigenouspeoples/wp-content/uploads/sites/19/2018/11/UNDRIP_E_web.pdf

^{vii} <https://www.legislation.gov.au/Details/C2014C00076/Download>, pages 27-28.

^{viii} <https://www.maiamnayriwingara.org/>

^{ix} <https://www.gjda-global.org/care>

^x Fogarty, W., Bulloch, H., McDonnell, S. & Davis, M. 2018, Deficit Discourse and Indigenous Health: How narrative framings of Aboriginal and Torres Strait Islander people are reproduced in policy, The Lowitja Institute, Melbourne, p. 17.