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Declared Interests/affiliations:

- *Indigenous Data Network Community Data Project* 2021-24| Funding: National Indigenous Australian's Agency | Project Lead: Professor Marcia Langton | Melbourne School of Population & Global Health, University of Melbourne.
- *Improving Indigenous Research Capabilities: Building and Aboriginal and Torres Strait Islander Data Commons* 2021-23| Funding: Australian Research Data Commons | Project Lead: Professor Marcia Langton | Melbourne School of Population & Global Health, University of Melbourne.

Members of the Indigenous Data Network sit on various related Expert Committees and Working Groups including the *Commonwealth Deputy Secretaries Data Group Sub-Committee on Governance of Indigenous Data* and the *Data Champions Network Working Group: Governance of Indigenous Data.*

To the National Data Commissioner Gayle Milnes,

This submission is made on behalf of the Indigenous Data Network (IDN) to comment on issues of concern related to the *Data Availability and Transparency Act 2022* (The Act), the *Data Availability and Transparency Code 2022 [Exposure Draft]* (DATA Code) and the Data Availability and Transparency Scheme (DATA Scheme). The IDN is an initiative of the Indigenous Studies Unit, Melbourne School of Population and Global Health, University of Melbourne[1].

Executive Summary

Our concerns principally relate to how The Act and proposed DATA Scheme will impact on the Aboriginal Community Controlled sector's[2] access to government held data. The Act sets out its aim to establish a process for government agencies to share public data between government entities and

[1] https://mspgh.unimelb.edu.au/centres-institutes/centre-for-health-equity/research-group/indigenous-data-network
[2] Aboriginal Community Controlled Organisations and Aboriginal Peak Bodies

Australian universities for the express purpose of provision of government services, informing public policies and programs, and research and development (R&D).

The Aboriginal Community Controlled sector are not expressly referred to in The Act, The Exposure Draft or DATA Scheme as entities (users/data service providers), however this sector are leading entities delivering government services, informing public policies and programs, and R&D for the Aboriginal and Torres Strait Islander population of Australia.

Further, we note that Australian Governments have made prior commitments to enable greater access to government data for the Aboriginal Community Controlled sector via the *National Closing the Gap Partnership Agreement 2020*. Thus, this omission in the legal framework as set out by The Act and subsequent DATA Scheme leads to questions about the considerations made, and planning going forward, for the equitable inclusion of the Aboriginal Community Controlled sector.

First, we ask how the Aboriginal Community Controlled sector might be supported through the DATA Scheme processes to achieve Accredited user or data service supplier status, or if any other provisions or mechanisms might be considered to ensure their inclusion in the scheme? The accreditation framework provides that the Minister and the Commissioner may accredit Australian entities (with or without reasonable conditions) if entities have appropriate data management and governance policies and can keep the data private and secure. If unsupported, these requirements will create significant and cumbersome practical and financial challenges for ACCOs and Aboriginal Peak Bodies if they seek to enter data sharing agreements with the government as per commitments made within the *National Agreement on Closing the Gap 2020.*

Second, we request further information articulating any planned resourcing that will be provided to support Aboriginal and Torres Strait Islander communities and organisations to engage with the DATA Scheme to ensure public data about them is shared with them.

Third, we request the development and broader circulation of further explanatory documents written in plain English outlining key elements of The Act and DATA Scheme so that they can be easily understood by all, particularly given the potential extensive implications of the data framework both now and into the future for our highly diverse national population.

Fourth, we advocate for the inclusion the CARE[3] principles of Indigenous Data Governance in the DATA Scheme. The CARE (Collective benefit, Authority to control, Responsibility, and Ethics) Principles address some of the power disparities and historical contexts for Indigenous peoples internationally to facilitate the "application and use of Indigenous data and Indigenous Knowledge for collective benefit" (Global Indigenous Data Alliance 2020), of which we assert should be a key concern for the aims of Australia's legal data framework.

[3] https://www.gida-global.org/care

Last, we raise concerns about what emerges as a shift from transparency and accessibility in this DATA Scheme, to the restriction of access to existing public data. This must be reconsidered. Following consultations with Dr Bernadette Hyland-Wood (please see Public Submission by Hyland-Wood 14 Sept 22), the IDN agree that the DATA Code does not incorporate knowledge and practice that has been promoted by discussions relating to Indigenous data sovereignty, digital information best practices, nor does it follow recent legislation created in multiple leading international jurisdictions, that could act as guides.

National Closing the Gap Partnership Agreement: Strategic Priority Reforms

Key Question: **How has The Act and the DATA Scheme taken into consideration the commitments of The National Agreement on Closing the Gap 2020, such as the commitment to providing 'access to the same data and information they use to make decisions' (Commonwealth of Australia, Department of Prime Minister and Cabinet 2020) to Aboriginal communities and organisations?**

In 2020, the *National Agreement on Closing the Gap 2020* (*National Agreement*) came into effect. The *National Agreement* is framed by four Priority Reforms for action, new accountability measures for governments, and shared monitoring and implementation arrangements.

The four priority reforms framing the refreshed Closing the Gap strategy articulate and respond to the voices and aspirations of Aboriginal and Torres Strait Islander people. They are as follows:

- **Priority 1.** Formal partnerships and decision making ensuring Aboriginal and Torres Strait Islander own governance and decision-making structures are supported.
- **Priority 2.** Building the community-controlled sector: investment and capacity building for the workforce, capital infrastructure, service provision and governance.
- **Priority 3.** Confronting institutionalised racism in government institutions and agencies to ensure Aboriginal and Torres Strait Islander people can access the services they need in a culturally safe way.
- **Priority 4.** Sharing data and information with Aboriginal and Torres Strait Islander people to ensure Aboriginal and Torres Strait Islander people have more power to determine their own development.

Priority Reform Four recognises that access to regional disaggregated data is necessary for Aboriginal and Torres Strait Islander people to make informed decisions about their lives and futures. It also supports the implementation of Priority Reforms 1-3. New targets developed in the *National Agreement* included specific targets for each Priority Reform Area. The target associated with Priority Reform Four is to: "Increase the number of regional data projects to support Aboriginal and Torres Strait Islander communities to make decisions about Closing the Gap and their Development" (Commonwealth of Australia, Department of Prime Minister and Cabinet 2020). The outcome, as

articulated by the National Agreement, is for "Aboriginal and Torres Strait Islander people have access to, and the capability to use, locally-relevant data and information to set and monitor the implementation of efforts to close the gap, their priorities and drive their own development" (Commonwealth of Australia, Department of Prime Minister and Cabinet 2020).

There are four specific data and information sharing elements that set out the expectations of Priority Reform Four:

1. *Partnerships are in place to guide the improved collection, access, management and use of data to inform shared decision-making.*
2. *Governments provide communities and organisations with access to the same data and information they use to make decisions.*
3. *Governments collect, handle and report data at sufficient levels of disaggregation, and in an accessible and timely way.*
4. *Aboriginal and Torres Strait Islander communities and organisations are supported by governments to build capability and expertise in collecting, using, and interpreting data in a meaningful way.*

(Commonwealth of Australia, Department of Prime Minister and Cabinet 2020)

Governments also made further commitments to share available, disaggregated regional data, establish partnerships between government custodians of data and Aboriginal and Torres Strait Islander people, make data more transparent, and build data capacity within Aboriginal and Torres Strait Islander organisations. These commitments should be cross-referenced and embedded within the DATA Scheme.

Indigenous Data Governance

Key Question: **How has The Act and the DATA Scheme taken into consideration the considerable national and international scholarship and advocacy in the area of Indigenous Data Governance?**

Indigenous data is any, and all data generated by, about or for Aboriginal and Torres Strait Islander people in Australia. By Indigenous data governance, we mean the roles, functions and relations that clearly define the owners, custodians, and stewards of Indigenous data. Indigenous data is a class of asset that supports the self-determination of Indigenous Australians. Indigenous data governance sets the foundations for data democracy at the community level, supporting Indigenous access, generation, and use of data.

It is important to distinguish between the principles of Indigenous Data Sovereignty and the operational procedures of Indigenous Data Governance, where sovereignty is an assertion of rights to government data and, governance recognises ACCOs as data generators rather than data consumers only.

The Act, The DATA Code and the DATA Scheme fail to acknowledge or refer to Indigenous data governance, of which we view as a significant oversight with the potential for enduring negative implications for the Aboriginal and Torres Strait Islander population of Australia. Australian governments are custodians of significant holdings of Indigenous data, both historical and contemporary.

As such, there are national ethical obligations and responsibilities that must be upheld by governments to ensure just and equitable relationships with Aboriginal and Torres Strait Islander peoples going forward. To this end, we recommend that The DATA Scheme embeds the internationally developed and widely endorsed CARE Principles for Indigenous data governance (see p.6).

The CARE Principles for Indigenous Data Governance

- Collective benefit: Data ecosystems should be designed and function in a way that supports Indigenous peoples to derive benefit from the data. Collective benefit incorporates inclusive development and innovation, improved governance and citizen engagement, equitable outcome.
- Authority to control: Indigenous peoples' rights and interests in Indigenous data must be recognised and their authority to control such data be empowered. Authority to control includes recognising rights and interests, data for governance, and governance of data.
- Responsibility: to share how Indigenous data are used to support Indigenous peoples' self-determination and collective benefit. Indigenous data holders are responsible for positive relationships with Indigenous peoples, expanding capability and capacity, also resources must be provided to generate data grounded in the languages, worldviews, and lived experiences of Indigenous peoples.
- Ethics: Indigenous Peoples' rights and wellbeing should be the primary concern at all stages of the data life cycle and across the data ecosystem. Ethics include: minimising harm and maximising benefits, address justice, and take into account future use.

We recommend amending the five Data Sharing Principles (DATA Code, Part 2, section 5-13) of project, people, setting, data, and output, to incorporate the CARE Principles.

Responses to Consultation Questions 5, 6, 9-11, 15 & 18

There are several other points that we wish to bring to your attention so that they may be considered at greater length, to abide by the principles of transparency and accessibility.

In response to the following questions:

- **5. Under the draft data code, entities must have regard to any process of ethics applicable. Do you have any comments about this approach? And;**
- **6. Is the note provided to assist entities identify ethics processes helpful? Why, or why not?**

Institutions using data, including government entities, all have ethics requirements and systems that can include long and intensive due diligence process in terms of obtaining Aboriginal and Torres Strait Islander ethics. Caution should be applied in terms of all data access and any ethics requirements if ethics has already been obtained elsewhere to ensure there is no doubling up or unnecessary additional requirements that might further impede research timeframes.

There is a broader issue here - perhaps beyond the scope of this framework - of data and research ethics surrounding Aboriginal and Torres Strait Islander data, especially as it relates to the disaggregation of data from existing data sets where the initial collection of the data was done across the population, potentially without any regard for the community and cultural protocols, nor the risks and challenges associated with such disaggregation. Such policies generally applying to the collection of new data as part of new research, but this is a framework for the sharing of existing data held by the Government. Most existing ethics processes don't capture this, and there seems to be no requirement, either through this framework or the DATA itself, that this be considered.

It is useful to see the AIATSIS ethics frameworks (https://aiatsis.gov.au/research/ethical-research/research-ethics-framework) mentioned as an example in the note to section 7 of the draft code, but it could be necessary to broaden this to Indigenous Ethics Boards more generally as a category.

With regard to the following:

- 9. Are the attributes, qualifications and affiliations listed in this section appropriate and easy to understand? And
- 10. Would this section of the draft data code benefit from other illustrative examples provided as a note? If yes, what examples and under which subsections?

'Appropriate persons' should be described with greater accuracy/specificity for section 10. There is a focus on technical, professional and education qualifications – which is generally appropriate. We note that there is no reference to those who are culturally appropriate, or sufficiently connected to Aboriginal and Torres Strait Islander communities such that they ought to be deemed appropriate to access, analyse, use and share Indigenous Data.

Regarding the following:

- 11. Is this section (section 11 – reasonable security standards) adequate in clarifying what are reasonable security standards?

The structure of this section of The Code is arguably as it should be from a data security perspective but may pose challenges (practically and financially) to community organisations. This is linked to section 11 (3) which states that non-Commonwealth bodies may be required to comply with

departmental security standards: this would all be determined on a case-by-case basis through the making of the agreements. This could create challenges for ACCOs becoming authorised entities.

Regarding the following:

- **15. In practice, the output principle requires entities to agree how the accredited user will use shared data. Overall, how could the draft data code be improved to best assist entities apply the output principle?**

With Section 13 (2) on Output Principles, it is worth considering that despite outputs being 'not limited' by the sub-section, 'Publications' should be broadened beyond academic journals or government reports to capture the work of community organisations, this is because the term 'publication' being described in the context of academic journals and government reports potentially limits the scope of what kinds of publications are acceptable. However, this may be sufficiently captured in that the output becomes whatever is agreed upon within the data sharing agreement.

With Section 16 (Unreasonable or impracticable to seek consent), the definitions are linked to the possibility of reaching out to 'individuals' which is appropriate given the approach to consent in section 15. There is scope to consider including that if the data relates to Aboriginal and Torres Strait Islander people and communities, those communities should be contacted as part of the process of seeking consent or have representatives participating in ongoing dialogue with the Data Commission. Efforts to inform communities about their data and its use must also be recognised here.

Regarding the following:

- **18. asks Does this part of the draft Data Code (section 18 – Whether public interest justifies sharing personal information without consent) provide an adequate list of factors for data custodians to consider when determining whether the public interest justifies the sharing of personal information without consent? Would this section benefit from an example provided in a note, and if so, can you suggest one?**

Section 18 (d) refers to benefits of groups of people, and section 18 (e) includes reference to cultural benefits and costs. These could be strengthened through referring to Aboriginal and Torres Strait Islander data specifically – including the use and sharing of data should be undertaken with community inclusion. It also needs to recognise the costs associated both with the process of accreditation and the systems required by communities including Aboriginal Community Controlled Organisations.

Recommendations

This submission has outlined numerous concerns and questions related to The Act, The DATA Code and the DATA Scheme. Specific recommendations include:

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1. **Clearly outline and include the role of the Aboriginal Community Controlled sector** in the DATA Scheme, with specific regard to the responsibilities set out in the National Partnership Agreement.
2. **Clarify the support available** to the Aboriginal Community Controlled sector to be accredited within the DATA Scheme, or other provisions/mechanisms for their equitable inclusion.
3. **Develop and broadly circulate plain English explanatory documents** to be circulated to the wider public outlining the data framework and its implications for the Australian public.
4. The DATA Scheme should **include explicit references to Indigenous Data Governance Principles**. The IDN recommends the incorporation of the CARE Principles.
5. **Align the Australian data legislative framework with internationally leading legislative data frameworks** (e.g., GDPR): seriously consider, reassess, and remove the potential barriers the Act, The DATA Code and the DATA Scheme will create for Aboriginal and Torres Strait Islander communities and organisations when accessing public data.

We hope that you will make time to consider and respond to the recommendations and queries set out in this submission to strengthen The Act and DATA Scheme and ensure appropriate and equitable inclusion in the commendable processes of making public data more available and transparent.

Kind Regards,

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