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Submission to the Western Australia Department of Premier and Cabinet

In relation to the Privacy and Responsible Information
Sharing Discussion Paper 2019

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Summary of Recommendations

Recommendation 1: That Indigenous data governance be included as a key principle guiding the proposed approach.

Recommendation 2: That the Department of Premier and Cabinet create as a matter of urgency, an identified position for an Indigenous person to work in the team developing the new overarching data sharing framework.

Recommendation 3: The creation of a Western Australia Aboriginal Data Strategy.

Recommendation 4: Meaningful engagement with relevant Aboriginal organisations and peak bodies to determine how FPIC principles should be incorporated into the data sharing framework.

Recommendation 5: The development of a 'Western Australia Aboriginal Data Use Module' that will accredit agencies, organisations and/or researchers to access data about Aboriginal peoples.

1. Introduction

This submission is made by three academics at the Centre for Aboriginal Economic Policy Research (CAEPR) at the Australian National University. CAEPR has a well-established track record in Indigenous¹ policy research and advocacy. CAEPR has established and maintains long-term relationships with various government agencies as well as with First Nations communities throughout the world.

We welcome the work being undertaken by the Western Australia Department of Premier and Cabinet (DPC) and commend the team on their work to date. This submission is made in relation to specific issues related to Indigenous data governance.

We note that the discussion paper speaks specifically to the need for Aboriginal peoples including their communities and nations to be involved in decisions affecting them (p. 40) and welcome this acknowledgement. We agree that information *should* form a cultural, strategic and economic asset for Aboriginal nations and communities. However, this potential is not currently realised. We are gravely concerned with the Discussion Paper's lack of a detailed strategy in relation to the unique interests of Aboriginal peoples, and the distinct issues relating to the use of Aboriginal data. As a whole, the discussion paper highlights a stark absence of knowledge and skills necessary to understand and engage with Aboriginal data issues and policy. We consider the level of engagement with the unique interests and needs of Aboriginal peoples, and the risks associated with data relating to Aboriginal peoples, as wholly inadequate.

This submission addresses a number of issues that we believe are critical to safeguarding the interests of Aboriginal peoples in WA as well as putting measures in place to ensure that Aboriginal peoples benefit from the proposed legislation. This submission responds to these specific areas:

- The unique interests of Aboriginal peoples in data
- Structurally embedding Indigenous Data Governance

¹ The terms 'Indigenous', 'First Nations' and 'Aboriginal' are used interchangeably in this submission. This is due to these key terms being used differently by various jurisdictions, organisations or communities. For instance, the global movement on data sovereignty and governance of which delegates from Australia participate, uses the term Indigenous (Indigenous data sovereignty). Whereas the Western Australia Government uses the term 'Aboriginal' as evidenced in the Discussion Paper. All the while, many communities or cultural groups throughout Australia are actively moving towards the language of 'First Nations' to best describe their circumstances as well as future aspirations. This submission responds to all of these and more and hence interchanges the language at various points that responds to context.

- Creation of a Western Australia Aboriginal Data Strategy
- Consent
- Protecting Confidential Information

2. The unique interests of Aboriginal peoples in data

Indigenous peoples occupy a unique place in the global community. This is recognised through the United Nations Declarations on the Rights of Indigenous peoples (UNDRIP), which the Australian Government formally endorsed in April 2009. The needs of Indigenous peoples in Australia as elsewhere, as well as the risks and opportunities facing Indigenous peoples, are often different to the needs, risks and opportunities of the general population. That Indigenous peoples have unique rights and interests is a well-established principle in Australian public administration. For example, both land rights legislation and the Native Title Act (1993) recognise that Indigenous peoples possess unique rights to their ancestral lands and waters through their own laws and customs. The UNDRIP provides a detailed statement of the unique collective rights of the members of Indigenous polities.

For example, the Yawuru people of the north west of Western Australia hold native title rights and responsibilities over much of the township of Broome and its surrounding areas. Despite the wealth of data available on the Indigenous population of Australia, the usefulness of those dataset for Yawuru's purposes is limited. The *Knowing our Community Survey 2011* was Yawuru's first response to capture the composition of community members and other kinship groups living in Broome. Such information is vital to operations and planning for Nyamba Buru Yawuru, the Yawuru people's development and investment company. Such basic information – such as the number and demographic composition of the Yawuru population, as well as the affiliations of non-Yawuru Indigenous people living on Yawuru land – is not available in any Government dataset.

The *Yawuru Wellbeing Survey* in 2015 was the next step towards articulating and capturing Yawuru ways of being and doing and the Yawuru philosophy of mabu liyan. Mabu liyan reflects the Yawuru sense of belonging and being, living well in connection with country, culture, others and oneself. Yawuru women and men have co-produced data on their own wellbeing throughout the whole process from content, design to collection and use of the resulting data. Data by Indigenous peoples, which represents their unique interest means data on connection to country and culture, self-determination, family and community strength are equally as important as data profiling their social and economic outcomes. The conceptualising of wellbeing through the lens of mabu liyan

reflects Yawuru priorities and worldviews. Selecting and measuring indicators of wellbeing this way will result in the production of a Yawuru wellbeing index which was first envisioned by the CEO of Nyamba Buru Yawuru, Mr Peter Yu. Enabling and resourcing Indigenous groups to collect and monitor how their wellbeing is changing over time, according to benchmarks they set, can serve to better inform the indigenous policy landscape in Western Australia. It also allows Aboriginal peoples to monitor and assess the impact of native title settlements. Collecting data in this way empowers First Nations groups to collect data relevant for them, rather than inheriting data that focusses on a narrow set of outcomes and informed by non-Indigenous values.

Many Aboriginal communities and nations in Western Australia face comparable circumstances with the Yawuru people. We provide this example to illustrate that despite the publication of reams of data about the Indigenous population in reports such as the Productivity Commission's *Overcoming Indigenous Disadvantage* or the *Report on Government Services*, there remains a distinct lack of data available to Indigenous peoples that is directly relevant to their needs and aspirations. Examples of these data include populations and demography of distinct Indigenous groups; rates of Indigenous language use at different fluency levels; information regarding lands, waters and resources; level of educational attainment among younger generations; levels of income among group members; indicators of community identified health and wellbeing to name but a few. Yet few official departments, agencies, research institutions or data collectors of other persuasions, create and collect data that reflects these needs. Certainly none do so while differentiating between members of different Indigenous polities or nations.

It is unrealistic to expect Indigenous communities and nations to foster meaningful and generational change, or to negotiate treaties or other agreements with governments, if the data required for leaders and governing bodies to make informed decisions does not exist. Yet this is precisely the situation Aboriginal people, their communities and nations, face today.

Data design, collection, storage and dissemination practices that exist today operate with limited or no input from Indigenous peoples. The result of this erasure from data structures is that Indigenous peoples rely on data that has been collected *on* or *about* rather than *for* or *with* Indigenous peoples. This results in data collections which are often not of relevance to Indigenous peoples, in which Indigenous peoples may be invisible, which may be inaccessible to Indigenous governing bodies and organisations and that position Aboriginal people as a problem. The Discussion Paper itself through the case-study of 'Improving Aboriginal children's ear health' (p. 41), evidences these issues.

In the absence of suitably qualified professionals in the areas of Indigenous data governance, departments such as the Western Australian Auditor General will continue to focus on data that is deficit focused. As stated in the Discussion Paper, 'no one knows how bad the situation is for Aboriginal children at a whole of state level at any specific point in time' (p. 41). Whilst it may be the case that no one knows how 'bad' the situation is for Aboriginal children, interpreting data through such a lens blinds agencies, organisations or researchers (among others) from seeing the strengths of Aboriginal children in Western Australia. The continued use of deficit language is a symptom of the absence of Indigenous control of Indigenous data. To be clear, we do not question the need to understand issues such as Aboriginal child ear health. However, a focus on deficits can obscure a focus on areas where ear health in Aboriginal children is less of a health issue and identifying the preconditions that negate such a widespread chronic health issue, preconditions which may not be measured and recorded in current data collections. Indigenous data governance arms data users with the knowledge, language and skills to shift these practices.

Indigenous data governance matters because the interests of Indigenous peoples are not always identical to the interest of the general population. Indigenous data governance refers to the right of Indigenous peoples to autonomously decide what, how and why Indigenous data are collected, accessed and used. It aims to ensure that data on or about Indigenous peoples is collected and used in ways that reflect their priorities, values, cultures, worldviews and diversity (Maiam nayri Wingara, 'Indigenous Data Sovereignty Communique', 20 June 2018).

We note that from the outset of the discussion paper through the *Message from the Minister*, the Hon. John Quigley MLA, that 'the organisation people should be able to trust the most is the Government that serves them' (p. 2). We agree that the issue of **trust** to be of paramount importance as DPC pursues a data sharing agenda. However, we note that trust in government collection and use of data is especially low among Aboriginal peoples. This lack of trust is reasonable. For centuries, data has been used by Governments as a weapon against Aboriginal people in Western Australia (e.g. in the removal of Aboriginal children) rather than to empower Aboriginal communities and nations. If this trust deficit is to be rectified, then checks-and-balances need to be implemented to ensure that data is used for the benefit of Aboriginal peoples. We believe that this can be achieved by embedding principles of Indigenous data governance throughout the data reform agenda.

Recommendation 1: That Indigenous data governance be included as a key principle guiding the proposed approach.

3. Structurally embedding Indigenous Data Governance

Indigenous data governance as a concept is entirely absent from the *Privacy and Responsible Information Sharing* Discussion Paper. This reflects a public-sector wide lack of expertise on the topic. The notably limited section addressing 'Involving Aboriginal people and organisations in decisions affecting their communities' (p. 40) is vague and without substance.

We acknowledge that DPC has established partnerships with peak bodies such as the Western Australian Aboriginal Health Ethics Committee (WAAHEC) and draw on these peak bodies to advise on issues relating to Aboriginal data. However, this is not enough. We are of the firm belief Indigenous data governance principles need to be embedded within the any new framework including resulting legislation. Indigenous data governance should also be embedded within the DPC *structurally* as part of its own staffing and governance, in order to meaningfully address and embed Indigenous data governance into its daily business. Indigenous data governance must be embedded into the institutional architecture of the WA Government, with the DPC being of particular importance as it progresses the data sharing reform agenda. Doing this will allow for Indigenous data governance to be woven throughout the new framework and any resulting policies.

Given the timelines to which the DPC is working, we believe it is imperative that the Department create, as a matter of urgency, an identified position for a suitable-qualified Indigenous person to work with the team developing new data sharing framework. There is now a considerable body of expertise relating to Indigenous Data Governance within Indigenous organisations such as *Maiam nayri Wingara* and the Indigenous Data Network. These networks of expertise should be urgently drawn-on as the new Data Sharing and Release Legislation is developed.

Recommendation 2: That the Department of Premier and Cabinet create as a matter of urgency, an identified position for an Indigenous person to work in the team developing the new overarching data sharing framework.

4. Creation of a Western Australia Aboriginal Data Strategy

To promote the needs of Aboriginal peoples, their communities and nations through embedding Indigenous data governance across the WA public sector and in legislation, we believe that the new data framework must investigate and create a 'Western Australia Aboriginal Data Strategy'.

The objectives of such a strategy should include:

- Advocating for the needs of Aboriginal peoples in relation to data
- Have the knowledge to identify and codify culturally sensitive data
- Ensure that sufficient protections exist that safeguard culturally sensitive data
- Provide advice to the WA Government and the public sector
- Monitor the use of Aboriginal data and the linking of Aboriginal data sets
- Oversee the accreditation of people or agencies wanting to access Aboriginal data
- Facilitate Aboriginal communities and organisations' access to government data about themselves
- Provide a line of accountability to key Aboriginal leaders and peak bodies on Aboriginal data matters

The creation of a Western Australia Aboriginal Data Strategy, if done correctly, responds to the issues outlined in the Discussion Paper, 'Involving Aboriginal people and organisations in decisions affecting their communities' (p. 40). Specifically, it responds to *how* 'the proposed framework provides an opportunity to recognise and reflect the importance of involving individuals or communities in the way information is collected, managed, used and shared' (p. 40).

It is timely to invest in a Western Australia Aboriginal Data Strategy as the Federal Office of National Data Commissioner and the National Indigenous Australian Agency are also developing a whole-of-government Indigenous data strategy. Simultaneous creation of these strategies will enhance the opportunity to align the principles and values and strengthen Indigenous data governance at both levels of government. This approach aligns with a key principle outlined in the Discussion Paper: 'Alignment with other jurisdictions' (p. 25).

Creating and embedding a Western Australia Aboriginal Data Strategy will provide the basis from which the Government can meaningfully engage in a dialogue with the Aboriginal communities throughout Western Australia in relation to their data. It also serves as an important mechanism to communicate how Aboriginal data is being safeguarded, accessed and interpreted. This is particularly pertinent in Western Australia where a long history of linking data exists despite the fact that the WA public sector is one of only two jurisdictions in Australia without an overarching legislation on privacy and responsible sharing (p.7). While the linking of data has potential for improving outcomes for Aboriginal peoples through better identification of Aboriginal people, to date Aboriginal people have been minimally involved in these processes. This is important to ensure

additional ethical considerations around consent can be established². In so doing, a Western Australia Aboriginal Data Strategy can become a key instrument that builds trust between the WA Government and Aboriginal peoples throughout Western Australia.

Recommendation 3: The creation of a Western Australia Aboriginal Data Strategy.

5. Consent

'States shall consult and cooperate in good faith with Indigenous peoples concerned through their own representative institutions in order to obtain their free and informed consent prior to the approval of any project affecting their lands or territories and other resources...'

United Nations Declaration on the Rights of Indigenous Peoples, article 32(2)

Indigenous peoples have the right to have their Free, Prior and Informed Consent (FPIC) obtained on activities affecting them as peoples. **Free** means that consent is given without coercion, intimidation or manipulation; **Prior** means that consent must be sought before every significant stage of a project and that Indigenous peoples have sufficient time to understand the information received, seek advice and if required, negotiate; **Informed** means that all parties must share information regarding the potential environmental, social, cultural and economic impacts, that information is provided in a clear and easily understandable manner that facilitates informed decision making and; **Consent** means that Indigenous peoples must have the option to support or reject proposals they receive.

FPIC is detailed in a number of international legal conventions including the UNDRIP, International Labour Organisations (ILO) Convention 169, United Nations International Covenant of Civil and Political Rights (ICCPR) and the Committee on the Elimination of All Forms of Racial Discrimination (CERD). In Australia, FPIC is embedded in the Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) 'Guidelines for Ethical Research in Australian Indigenous Studies' (GERAIS) as well as the National Health and Medical Research Council's (NHMRC) 'Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders'. Taken together, there is now a clearly defined and well established

² See Background document by Ray Lovett <https://www.lowitja.org.au/content/Document/PDF/1-Data-linkage-Roundtable-background-paper.pdf>

need to obtain consent in a culturally appropriate and sensitive manner on projects and activities relating to Indigenous peoples.

Currently, FPIC for Aboriginal people as a concept is notably absent from the Discussion Paper. More worryingly is the lack of acknowledgement and engagement at any level of the unique considerations of obtaining consent from Aboriginal peoples and communities. There are clearly Indigenous-specific considerations regarding consent to access and use data about Aboriginal peoples, communities and nations including in relation to Country. The relationships with Country is of special significance as one of the issues being considered is the 'Shared Land Information Platform (SLIP)' (p. 19). The extent of native title in Western Australia is vast, with a great many Aboriginal groups negotiating various agreements in relation to land use. The fact that Aboriginal peoples unique rights and interests in lands and waters, unique interests that are recognised by the Western Australia Government, has been overlooked is but one example of why Indigenous data governance requires urgent attention. There are obvious needs to treat culturally sensitive data, especially as it relates to Aboriginal peoples' rights and interest in the lands and waters, differently from non-Indigenous data. This is but one example where the principles outlined in FPIC must be observed.

We acknowledge that there are no simple answers to the consent question. Embedding FPIC as it is currently understood and applied by researchers or companies working with Indigenous groups may be impractical. Despite these difficulties, DPC have demonstrated that they are willing to confront complex challenges and uncover solutions to foster 'better outcomes for the community' (p. 16). We believe there is an imperative to acknowledge that consent for data collection and dissemination is different when speaking about Aboriginal peoples' data. We urge DPC to engage with relevant Indigenous organisations and peak bodies in a meaningful way to determine what an appropriate approach to FPIC might look like in the context of the data sharing framework.

Recommendation 4: Meaningful engagement with relevant Aboriginal organisations and peak bodies to determine how FPIC principles should be incorporated into the data sharing framework.

6. Protecting Confidential Information

We welcome the considerations of sharing confidential information under these reforms (p. 42). Yet in the absence of a thorough discussion highlighting the special considerations of data as it relates to Aboriginal peoples, we remain unconvinced that appropriate mechanisms will be put in place to protect culturally sensitive data.

The skills, capabilities and knowledge required to protect, manage and use data relating to Aboriginal peoples are different to those for the general population. Consequently, we suggest this is an issue of paramount importance to be addressed through a Western Australia Aboriginal Data Strategy. Furthermore, we believe that there is significant value in DPC working closely with the Federal Office of National Data Commissioner as they develop an accreditation model for agencies, organisations or researchers (among others) wanting to access and use public sector data. We believe there are opportunities for an Indigenous specific accreditation module requiring data users accessing data about Indigenous peoples to be appropriately trained.

An Indigenous Data Use accreditation module may include training about the unique risks of working with Indigenous peoples and principles of Indigenous data sovereignty. Additionally, such a training module may assess data users on their knowledge of the Five Safes as well as Indigenous specific data principles such as the CARE Principles developed by the Global Indigenous Data Alliance.³ Developing training for users of Indigenous data that aligns with CARE as well as the Five Safes will create a strong group of data users applying their skills in ways that protect Indigenous communities and their data and that enhance the ability of Indigenous communities to promote sustainable self-determination. It would be completely appropriate for such a module to be adapted to fit the unique circumstances of Aboriginal communities in Western Australia. The accreditation, perhaps called the 'Western Australia Aboriginal Data Use Module', should be developed by Aboriginal communities in Western Australia and Indigenous peoples from throughout Australia with expertise in Indigenous Data Governance.

Recommendation 5: The development of a 'Western Australia Aboriginal Data Use Module' that will accredit agencies, organisations and/or researchers to access data about Aboriginal peoples.

³ For more information on the Global Indigenous Data Alliance including CARE principles see <https://www.gida-global.org/>