

5th October 2022

Submission for The Exposure Draft of the Data Availability and Transparency Code 2022

About Kimberley Aboriginal Medical Services (KAMS) and our Member Services

KAMS is a member-based, regional Aboriginal Community Controlled Health Organisation (ACCHO). We support and represent the interests of eight independent Kimberley ACCHOs, our Member Services, from throughout the region and Kimberley Renal Service which is a wholly owned subsidiary.

KAMS is governed by a Board made up of highly respected and experienced Aboriginal representatives from these Member Services and the communities they serve. In addition to supporting our Member Services, KAMS also delivers healthcare services through remote health centres in Balgo, Beagle Bay, Bidyadanga, Billiluna and Mulan.

Other services provided or supported by KAMS include:

- Advocacy and leadership relating to Aboriginal health and wellbeing at regional, state and national forums
- Kimberley Renal Services, which is a wholly owned subsidiary that delivers renal services in Broome, Derby, Fitzroy Crossing and Kununurra
- Auspice of headspace in Broome
- Population health programs
- Social and emotional wellbeing programs
- Research including through the Kimberley Aboriginal Health Research Alliance
- Accredited health training for Aboriginal Health Workers
- Disability support and allied health services through Kimberley Supports

ABN: 67 169 851 861







Kimberley Aboriginal Medical Services Ltd

An Organisation of Aboriginal people, for Aboriginal people; controlled by Aboriginal people.

General statement

While we understand the intended goal of the Exposure Draft of the Data Availability and Transparency Code 2022, KAMS notes there is no inclusion of Indigenous Data Sovereignty Principles or reference to the National Agreement on Closing the Gap. While the Five Safes Framework is relevant, it does not go far enough in addressing the interests of Indigenous Australians regarding data held about them by Government. Incorporating Indigenous Data Sovereignty principles like the Care Principles or Maiam nayri Wingara principles is essential in ensuring Indigenous voices are part of the Australian data conversation. The National Agreement on Closing the Gap Priority Reform Four sets out how Government and Indigenous Australians should work in partnership to share and access data.

KAMS also agrees with the issues previously raised by the National Aboriginal Community Controlled Health Organisation (NACHO) Submission on the Commonwealth Data Availability and Transparency Bill 2020 [Provisions] and Data Availability and Transparency (Consequential Amendments) Bill 2020 [Provisions] (Submission 23) and the Indigenous Data Network's (IDN) Submission on the Data Availability and Transparency Bill 2020 (Submission 24). The concerns raised in these past submissions are relevant to the Exposure Draft of the Data Availability and Transparency Code 2022 as there is a distinct lack of reference to Indigenous Australians and their data interests and is demonstrative that previous feedback has not been taken into consideration. To ensure success in the aims of the National Agreement on Closing the Gap, mechanisms allowing engagement of Indigenous Australians with Government held data needs to be embedded at all levels of data policy.

Response to select questions:

Consultation questions - Project principle: applicable processes relating to ethics

5. Under the draft data code, entities must have regard to any process of ethics applicable. Do you have any comments about this approach?

Being able to "apply one" ethics approach could lead to a situation where the access of identified Indigenous data is not subject to further oversight of Indigenous ethics boards when data is reused or shared outside of the context for which the ethics approval was originally granted.

6. Is the note provided to assist entities identify ethics processes helpful? Why, or why not? We note the inclusion of the NHMRC and AIATSIS ethics, however this does not address the wider context of Indigenous Ethics boards and the interest of Indigenous communities with regards to the reuse and sharing of Indigenous data outside of the context for which the ethics approval was originally granted.

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Consultation questions - People principle: appropriate persons

9. Are the attributes, qualifications and affiliations listed in this section appropriate and easy to understand?

This section does not include references to culturally appropriate access of Indigenous data. The identified qualifications could act as a barrier to culturally appropriate users being involved meaningfully in Government-related data projects. While appropriate for the handling of data generally, the section does not address appropriate Indigenous cultural access and control or the expectation of Indigenous Australians to be involved in the authorisation of access to government data held about them.

Attributes, qualifications and affiliations should also include contextual Indigenous knowledge for any persons accessing, using and interpreting Indigenous data.

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?

Yes, a note in Section 10 part (3 or 5) regarding culturally appropriate access with regards to qualifications or expertise.

Kind regards

Vicki O'Donnell

Chief Executive Officer

