

Submission

Australian Institute of Health and Welfare (AIHW) - National Primary Health Care Data Asset - Data Development Plan

8 August 2019

The Aboriginal Health Council of Western Australia (AHCWA) is the peak body for 23 Aboriginal Community Controlled Health Services (ACCHSs) providing primary health services across diverse regional, rural and remote locations in Western Australia. AHCWA exists to support and act on behalf of our 23 Member ACCHSs, and our principal vision is for Aboriginal people in WA to enjoy the same level of health and wellbeing as all Western Australians.

The security of Aboriginal health and wellbeing data is a very high priority for ACCHSs across Western Australia. Best-practice collection and ethical sharing of data, the responsible use of data by other agencies, integrity in data reporting and the acknowledgement of data sovereignty are key principles, strongly protected by ACCHSs, Aboriginal people and their communities.

AHCWA acknowledges the development of a National Primary Health Data Asset (the Asset) which was presented to WA ACCHSs CEOs in Broome on 2 July 2019 by Mr Michael Frost, Group Head, Primary Health Care and Veterans Group at the Australian Institute of Health and Welfare (AIHW).

Given the significant importance of data for the development of health service priorities, planning and evaluation, it is essential that ACCHSs are closely consulted on any activity being funded or undertaken by the Commonwealth Government in relation to Aboriginal health and wellbeing data.

Through this submission, AHCWA and its member ACCHSs declare themselves as key interested stakeholders in the development of the National Primary Health Data Asset.

Key Feedback

- AHCWA and its member services acknowledge that there is a major gap in data across the primary health care system and that coordinated, inclusive and transparent collaboration across the health sector is required to address this issue.
- AHCWA and its member services acknowledge consultations on the Asset were conducted in each capital city, however, there was insufficient targeted engagement with ACCHSs or Aboriginal communities as part of this process. AHCWA notes the initial consultations are the first step on a longer process.
- While the ACCHS sector acknowledges the benefits that could come from the ability to link different data collections, there are important cultural, privacy and security issues that must be addressed and agreed. As stated by Mr Frost in his presentation to WA ACCHSs CEOs, community trust in the data asset will play a big part in its success.

- Data sovereignty is a key priority for Aboriginal people and their communities. The increasing use of data in health presents an important opportunity for the ACCHS sector to establish a joint position on data ownership and governance at a state level, and across jurisdictions.

Recommendations

AHCWA and its member ACCHSs strongly recommend that:

- More extensive consultation and engagement with the ACCHS sector is undertaken at all stages of the Asset project as it progresses. This includes the provision of a copy of the revised Data Development Plan seeking feedback from the ACCHS sector.
- Any research or data collection involving Aboriginal people be subjected to rigorous ethics approvals processes. The ACCHS sector emphasises the importance of cultural safety and adhering to cultural protocols in the way data is collected, used and represented. In WA, any health and wellbeing data being collected about Aboriginal people for the purposes of research must go through the WA Aboriginal Health Ethics Committee (WAAHEC) approvals process.
- Terminology around data collection, usage and reporting is culturally safe and appropriate for the ACCHS sector.
- Any new data collection system fits into existing workflow structures and processes, and does not create additional work for ACCHSs already working under very difficult situations and heavy workloads. Further, when developing new software for the Asset it is essential that it is compatible with existing systems within the ACCHS sector.
- Shifting the dialogue on Aboriginal health from a deficit to a strengths-based model is essential in any data projects being undertaken. Too often, statistics demonstrating Aboriginal health and wellbeing focus on deficits and limitations when, instead, data should be reframed to reflect achievements in health outcomes. This could be achieved through consulting with ACCHSs on how data is interpreted, presented and shared.
- Any data collected is able to be analysed by region. Amalgamating data across regions and jurisdictions has the potential to dilute achievements being attained in some regions which has implications for future service planning and development.
- Data from the ACCHS sector should not be released without ACCHSs endorsement.
- Clarity is required about how ACCHSs will access data about their services once it has been submitted to a national database, and whether fees will be imposed for this access.
- AIHW engages further with Aboriginal academics and researchers around the collection, use and representation of data relating to Aboriginal people.
- Further information is provided on the representatives currently on the Aboriginal and Torres Strait Islander (ATSI) Health Services Data Advisory Group.