

Submission Response

Productivity Commission – Inquiry into data availability and use

8 August 2016

The Aboriginal Health Council of Western Australia welcomes the opportunity to provide a brief submission to the Productivity's Commission inquiry into data availability and use.

1. PRIORITISING ABORIGINAL HEALTH

The underlying priority for AHCWA in responding to this inquiry is to improve, through enhancing the use of data, the health of Aboriginal people and their communities.

Health, along with Aboriginal health, are in a situation of continual crisis in our country, with worsening incidences of chronic disease and arguably the ineffective allocation of resources to reverse current trends. However over the past decade overall health expenditure has grown at 5 per cent above inflation with a majority of this expenditure invested in hospitals and mainstream health services. This in our opinion indicates misguided allocations of resources, partly as a result of incorrect analysis of data, in relation to effectively address the health needs our population.

The Aboriginal Community Controlled Health Services (ACCHSs) sector has consistently proven itself to be the strongest contributor in improving Aboriginal health in line with our Closing the Gap aims. This is against a backdrop of consistent difficulties in accessing funding for services and programs across primary health care, and the burden of sometimes excessive and even occasionally ill-considered reporting requirements.

As such we believe that there is scope and potential to significantly benefit from improved access to, and use of, data. The goal of such would be to enhance evidence-based policy making, appropriately target funding, and improve the ability of health services to deliver effective programs. This must be led by governments, who as part of that need to be more transparent and accountable about the way data has been held and used. Data collection and sharing must also be respectful of the principles of Aboriginal ownership, and seek to empower community involvement in all processes of data analysis and collection.

2. INCREASING THE AVAILABILITY OF DATA

AHCWA supports increasing the availability of data, but contends that any increase must be intended to and ultimately shown to be improving health outcomes.

In increasing the availability of data, it is vital to ensure that best use is made of existing and new data for Aboriginal health, and that any increase is respectful of Aboriginal needs relating to data collection and sharing. The NHMRC has recently recommended the specific improvement of existing data analysis on the health of Aboriginal people, which it said was “scattered and often difficult to access”, with significant gaps.

In Western Australia, our Department of Health has developed an effective data linkage system. We suggest that the Commission as part of their inquiry review the relevance of this system, and consider whether it could be expanded nationally. We also refer the Commission to the Queensland Aboriginal and Islander Health Council’s ‘Data Governance Protocols’ as a guideline to increasing the availability of data relating to Aboriginal health.

3. IMPROVING INDIVIDUALS’ ACCESS TO DATA

AHCWA has thus far been supportive of developments relating to improving individuals’ access to health data.

With the development of My Health Record (previously Personally Controlled Electronic Health Record, or PCEHR) individuals now have access to a summary of their medical information including medications and medical history. However, there is concern with regards to privacy, governance and liability and there has been a slow uptake by consumers.

One of our member services, the Kimberley Aboriginal Medical Services (KAMS) is using a web-based electronic health record called MMEx for 22,000 mostly Aboriginal people in the Kimberley region of Western Australia. With a patient’s consent, the record can be shared with the hospitals, visiting specialists and allied and mental health professionals. All care plans, medications and communications concerning the patient are electronic.

The benefits of these approaches is that everyone is contributing to the same electronic record. Health providers have to work collaboratively, because their changes are immediately seen by everyone involved in the care of the patient.

AHCWA recommends that governments look at ways at improving individual access to and understanding of data, in a way that ensures improvement in the delivery health care. This should also be developed with ensuring that data literacy is improved amongst the Aboriginal population, so consumers are able to attain a clear understanding of their health status and required medication.

4. STANDARDISING THE COLLECTION, SHARING AND RELEASE OF DATA

AHCWA supports standardising the collection, sharing and release of data across the health system.

Currently, difficulties exist in ensuring that data flows in a cohesive and/or standardised manner. In the recent release of the *2016 National Research Infrastructure Capability Issues Paper*, Chief Scientist Alan Finkel commented that “currently, the population and health service use of data relating to Indigenous Australians is scattered and often difficult to access. There are significant barriers to using this data as Indigenous identifiers are often missing or incomplete.”

We have been proactive in working towards establishing data sharing and collection processes that maintain and protect not only ownership of ACCHS sector data, but also how this data is then used.

However, our sector continues to experience risks in data collection such as the:

- Use of data without the establishment of data protocols that are based on the principles of Aboriginal ownership or in accordance with data governance principles of the ACCHS sector.
- Use of aggregated data by funders to inform broader needs analysis that may not reflect health needs accurately.
- Loss control around how ACCHSs’ owned data is used.

5. ENHANCING AND MAINTAINING INDIVIDUALS’ AND BUSINESSES’ CONFIDENCE AND TRUST

AHCWA asserts that individual and business confidence and trust in the way data is used is low and urgent attention is required in order to enhance the collection and use of health data.

It is similar to the sentiment expressed by communities to ‘research’. Dr Pat Anderson, former Chair of the Lowitja Institute, stated that: *“Decades of research carried out by non-Aboriginal researchers, based in non-Aboriginal institutions, had left many of us deeply suspicious of the ‘r’ word ... The research agenda was set in forums to which few of us had access. There were few Aboriginal researchers. And research methodology was still focused on Aboriginal people as subjects of research; research was something carried out ‘on’ us as Aboriginal people, not ‘with’ us and certainly not ‘by’ us. Worse still, despite the large volumes of research to which we were subjected, very little seemed to be translated into practice; the research projects came and went, but health service delivery and policy remained the same.”*

In enhancing individuals' and businesses' trust and confidence in the way health data is used, any approach should be underpinned by the following key principles as identified in the SEARCH model:

- Strong governance to ensure engagement with and develop leadership within ACCHSs.
- Explicit focus on using the data to improve health.
- Ensuring ACCHSs' leadership in data collection.
- Developing strategies to support ACCHSs' use of the data
- Building Aboriginal research capacity.

For more information on the SEARCH project, please see the following –

<https://nacchocommunique.com/2016/07/20/naccho-aboriginal-health-study-of-environment-on-aboriginal-resilience-and-child-health-search/>

6. MOVING FORWARD WITH DATA

Summarising the above, AHCWA recommends the following:

1. Governments need to be more transparent and accountable about the way data is held and used.
2. There needs to be an explicit focus on using data to improve health and we must further develop strategies to support ACCHSs' use of data.
3. There needs to be a national focus on enhancing education around data analysis and ensuring consistent communication and messaging about how Aboriginal health data will be used.
4. There is not a one size fits all approach to data availability and use. Aboriginal communities and services must be involved in every step of data collection and analysis, to ensure it meets their specific needs. This should involve building the capacity of individuals to analysis data and Aboriginal organisations to commence research.
5. Governments must recognise the importance of standardized data, and the opportunities it presents to increase efficiency in health service delivery. ACCHSs need to be supported in enhancing the ability to collect standardised data.

The Aboriginal Health Council of Western Australia advocates on behalf of 21 Aboriginal Medical Services in Western Australia, to ensure that the health needs of the State's communities are represented at all levels.