



NACCHO

National Aboriginal Community Controlled Health Organisation

NACCHO Submission

Inquiry into Data Availability
and Use

August 2016

To: Productivity Commission



NACCHO

National Aboriginal Community
Controlled Health Organisation
Aboriginal health in Aboriginal hands

www.naccho.org.au

TITLE: NACCHO submission: Productivity Commission Inquiry into Data Availability and Use

National Community Controlled Health Organisation,
221 London Circuit, CANBERRA ACT 2600

P.O. Box 5120, Braddon, ACT 2612

Contact: Dr Robert Starling – Chief Information Officer

Email: cio@naccho.org.au

Ph: 02 6246 9300

Preamble

This initial submission has been prepared in response to the Productivity Commission's request for submissions into their Inquiry into Data Availability and Use. NACCHO is happy to discuss this submission or elements of it in person and equally happy to provide additional information on request.

Where the term "Aboriginal" is used in this submission it implies Aboriginal and Torres Strait Islander people.

Introduction

The National Aboriginal Community Controlled Health Organisation (NACCHO) appreciates the opportunity to make a submission to the Commission for its Inquiry into Data Availability and Use. Aboriginal Community Controlled Health Organisation's (ACCHO's) and its Member Services' area of expertise is Comprehensive Primary Health Care for Aboriginal people in over 140 locations across the country and 300 communities to which outreach services are provided. The Sector has direct personal interaction with individuals, or through their family members, with over 50 per cent of the total Aboriginal population nationally and close to 100 per cent in those communities where an ACCHO is located.

Data collection and availability is a significant issue for the ACCHO sector. While the collection of that data is an obligation under the terms of ACCHO's funding agreements, that data is also of significant value to government in providing a clear picture of the current health and wellbeing status of Aboriginal people and any improvements, or changes, in measures of that status over time. It is also important for reporting progress to parliament, committees, and international bodies such as the Human Rights Commission, Amnesty International, and in terms of obligations under International Conventions that Australia is a signatory.

NACCHO is of the view that this inquiry provides a significant opportunity to inform government on critical aspects of work already underway in the area of data availability and use. NACCHO also sees that work as an opportunity for government to reform and recast the presently disjointed and inconsistent Indigenous and non-Indigenous health data collections. Reform that addresses current data collection, availability and use issues in those terms offers the potential for improved return on investment of public monies through; better targeted funding; and, that funding being informed by a more veracious, reliable evidence base.

NACCHO Recommends:

1. The government undertakes significant reform of the collection, holding and analysis of health data pertaining to Aboriginal and Torres Strait Islander peoples, assuring a consistent method is applied to monitoring the whole of government policy commitment to “Close the Gap” ;
2. Standards for the definition of data items be enforced and new standards developed to ensure; consistency in data recording; and, the development of jurisdictionally-consistent activity and outcome measures;
3. The government establish a data custodian -- a central repository for all health related data for Indigenous Australians -- in collaboration with NACCHO and its Member Services. Such a pragmatic move would result in significant savings in that a central repository would realise more consistent data, allowing all stakeholders ready access to informatics that better informs practice, planning, investment, outcomes and continued quality improvement.
4. The government review the operation of section 135AA of the *National Health Act (Cth) 1953*, with the view to facilitating better considered external access to de-identified MBS and PBS data for the purpose of improved health policy evaluation and development, as well as facilitate more insightful research in the public interest.

The Potential in Public Data Management

The statement announcing the Australian Government's Public Data Policy by the Prime Minister, the Hon Malcolm Turnbull MP, of December 2015 was one of interest to NACCHO, its Members and its Affiliates. NACCHO commends the Government for its commitment in extending upon earlier work and 2009 Report¹ by the Government 2.0 Taskforce under its Chair, Nicolas Gruen, with support from the Online Services Branch of the Department of Finance and Deregulation. NACCHO notes the transference of the ongoing Government 2.0 work to the Digital Transformation Office (DTO) as part of the Prime Minister's portfolio responsibilities.

The commitment given to; optimise the use of public data; to release non-sensitive data by default; and to collaborate with the private and research sectors to extend the value of public data for the benefit of the Australian public is seen by NACCHO as a good starting point for a discourse around how actions in those terms can be harnessed to improve the circumstances of Aboriginal and Torres Strait Islander people.

Since the announcement of that commitment, NACCHO has monitored with interest the subsequent developments in public sector data management, which have been facilitated under the coordination and leadership of the Department of Prime Minister and Cabinet (PMC). NACCHO is encouraged by the progress of those developments, as outlined in PMCs June 2016 *Implementation Report*².

Of particular interest to NACCHO is one of the high-value projects being undertaken as part of that implementation in the area of Indigenous early childhood intervention. NACCHO also monitors with interest the project on better targeting of mental health services. That project is of particular interest to NACCHO, given its detailed awareness of the extent and affect of mental health issues within the Aboriginal and Torres Strait Islander population. It might be argued that it is the latter of those projects of particular salience in terms outlined in this Submission.

Target issues and Principles

Issues surrounding data availability and use have been of steadily increasing concern to NACCHO, the ACCHO sector and other policy makers. No more so than in the area of health and particularly so in the area of Aboriginal and Torres Strait Islander health. That is largely due to the holistic understanding of health afforded within an Aboriginal and Torres Strait Islander cultural context (discussed elsewhere in this Submission).

There are issues of data burden, data access, data standards, data consistency and reliability and costs. Increasing understanding of the complexity and specificity of client needs within Aboriginal health places a corresponding increase on the potential value and benefit to be had by addressing those issues. NACCHO considers the principles identified through grounding work done by the Government 2.0 Taskforce, and subsequently built upon and expressed in the Prime Minister's announcement, as providing a sound basis for the framework needed to realise much of that potential.

NACCHO has always been willing to partner with the public, private and research sectors to build collective expertise and to use whatever data gained to refine policy settings for the betterment of Aboriginal and Torres Strait Islander social, economic and health outcomes. This is especially important given NACCHO's positioning in relation to its Members, its affiliates, and the policy and

¹ Commonwealth of Australia, Department of Finance and Deregulation, Government 2.0 Taskforce Report.

² Commonwealth of Australia, Department of Prime Minister and Cabinet, Public Sector Data Management.

programme areas of critical government departments, its partner organisations and other stakeholders.

Policy development, evaluation, compliance and programmatic design in the Australian Health landscape are always evidence informed. Data capture and utilisation is central to ensuring evidence informed development, high-value data is crucial if optimal outcomes for Aboriginal and Torres Strait Islanders are to be secured. That is especially the case for those measures targeted to Close the Gap.

NACCHO experience and observation in the current data environment

The challenges impacting our sector in relation to data and the progress which our sector have made in relation to effective and efficient data systems have not occurred overnight. In some regard, many of the challenges that have needed to be overcome might be thought of as a headwind of data-related issues. Our sector has not been alone in this regard, as can be seen within the Sixth Interim Report by the Senate Select Committee on Health released in May 2016 (*Big Health Data: Australia's Big Potential: the Report*).

Indeed, NACCHO acknowledges and can relate to the evidence presented and experiences of a number of respondents and witnesses to the Committee Inquiry informing the Report and its Recommendations.

That recognition is no less so than in a range of issues relating to data access and consistency.

NACCHO highlights the Committee's specific Recommendations around PBS and MBS data as veracious. NACCHO notes the Committee's observation that it has been some 23 years since the provisions around the protection of MBS and PBS data have been debated and how, in that time, those provisions have failed to keep in step with advances, not just in technology, but also in terms of the increased levels of complexity and sophistication of analysis afforded to researchers and policy by that technological advance.

It has also not escaped NACCHO's notice that the National Health and Hospitals Reform Commission called, in 2009, for the linking of MBS and PBS data to, *"... better understand people's use of health services and health outcomes across different care settings"*, or the Productivity Commission similarly suggested, in 2013, that the Privacy Guidelines be amended, noting that, in the present environment:

*"Protecting confidentiality is warranted but the current approach is too cautious and complex with the restrictions creating unnecessary downsides and delays for evidence-based policy formulation."*³

³ Senate Select Committee on Health, 2016, Big Health Data: Australia's Big Potential. P35

Overburden: Data in the ACCHO Sector

Barrier to access is the result of regulations put in place many years ago that do not reflect the modern capabilities for data use and opportunities for value-add outside government.

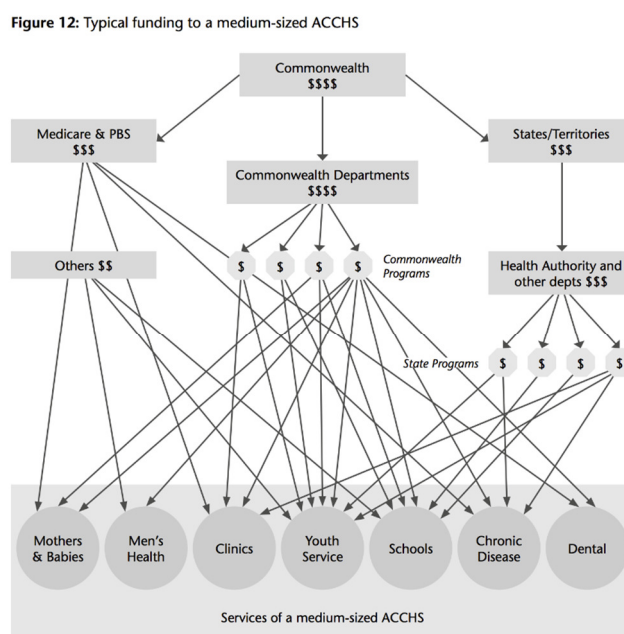
Data is mission critical to the ACCHO sector. ACCHOs deliver primary care largely from government funding. Stringent conditions for that funding are specified in the Standard Funding Agreement used by the Commonwealth for all ACCHOs. Those conditions require services to collect extensive activity and performance information, which represents a significant burden of reporting.

A study conducted through the Cooperative Research Centre for Aboriginal Health (Dwyer et al, 2009)⁴ confirmed the,

“... complexity and fragmentation of funding, and the heavy burden of acquiring, managing, reporting and acquitting funding contracts for both providers and funders” as well as suggesting there to be evidence that, “... the contractual arrangements for Aboriginal and Torres Strait Islander organisations are more complex than for mainstream organisations.”

That additional complexity was attributed, at least partly, to the reality that, “... ACCHSs (sic) provide a broad range of essential PHC⁵, rather than undertaking roles that are supplementary to mainstream public health care”. A mapping of that complexity developed within that study can be seen below.

Figure one: Funding complexity in the ACCHO Sector (Dwyer et al (2009): the Overburden Report)



⁴ Dwyer, J., O'Donnell, K., Lavoie, J., Marlina, U. & Sullivan, P. 2009, *The Overburden Report: Contracting for Indigenous Health Services*, Cooperative Research Centre for Aboriginal Health, Darwin.

⁵ That is, 'primary health care'.

Despite acknowledgement within the Study Report that progress was being made in some areas in terms of consolidation of systems for data collection and analysis⁶, it nevertheless remained that the:

*“... current practice means that activity reporting required from ACCHSs (sic) is seen as demanding, and not helpful enough for internal performance monitoring. Although funders reported on the value of data for use in support of policy decisions and ongoing funding allocations, **providers saw the data they send to health authorities as going into a black hole, with no useful feedback (such as comparisons with data from like services) or with feedback that is too delayed to be useful.**”*

NACCHO contends this continues to be the case, particularly when like data is viewed through a lens of health outcomes. Much of that data, while collected by the ACCHOs, is sent to government facilities such as the Australian Institute of Health and Welfare (AIHW) for analysis and aggregation into reports. Once the AIHW receives that data, it is no longer available to our sector for our own analysis. The role of the AIHW is determined by its regulations, which are restrictive in terms of allowing data-sharing for analysis. Analysis of data owned by the Sector is only available on a nation-wide basis to AIHW and any analyses required by the data owners are conducted by AIHW on a professional fee-for-service basis.

Data to Develop the Evidence Base: Access Issues.

Not having the ability to share that aggregated data between ACCHOs at the regional level, jurisdictional level, or by other geographies such as the Australian Statistical Geography Standard level, means that ACCHO's are unable to statistically and empirically confirm that a particular program or approach has been successful. Similarly, NACCHO, as the peak body, is not able to collate data from ACCHO's to support a policy proposal or position to government.

Treasury and the Department of Health have been on a drive to improve efficiency in health service delivery and returns to the government through cost-savings. Despite this there is absolutely no concept of data management or sharing in Primary Health in government that actually enables use of the data in isolation or, as appropriate, in combination to build a picture of what is being funded where and the outcomes.

In developing data collection approaches NACCHO would highlight the inadvertent cost implications specifically related to national data collection systems. The Department of Health (DoH) mandates specific service activity (OSR) and National Key Performance Indicator (nKPI) data collections. The data collection process has been outsourced to a private provider in recent years. Our sector has experienced major failures and worrying implications of this system and the cost benefit of the large investment made by DoH to resource its operation. Government must assure that investments in national data collection systems provide real time accurate and comparable time series data. The currently contracted service fails to meet our sectors data needs. Indeed without significant and unfunded interventions by our sector (estimated to exceed \$500,000) the existing data collection system would have corrupted valued time series data. This situation was exacerbated by poor technical capabilities within DoH, in terms of system functionality, compliance with data standards and a failure to accurately identify service implications of changes in the data collection methods used.

⁶ Op Cit, p55.

The lack of consistent data management and sharing is set to become an even greater issue for Aboriginal and Torres Islander health, particularly in areas such as mental health and social and emotional wellbeing (SEWB), as Indigenous-specific health funding in those areas is increasingly being commissioned by Primary Health Networks, with funds allocated by the Department of Health, as well as other agencies such as Prime Minister and Cabinet.

The accepted obligation upon ACCHOs of comprehensive reporting has a history dating back to the mid-1990s. It has resulted in ACCHOs acquiring advanced expertise in electronic health record systems to address the complex and often challenging tasks of data gathering and measuring population and individual health outcomes. Current reporting centres for ACCHOs in those terms include the Online Service Reports (previously Service Activity Reports), along with 21, of an ultimate 24, Australian national Key Performance Indicators (nKPIs). The Health Ministers' Advisory Council (AHMAC) required and approved those nKPIs, covering maternal and child health, preventative health risk factors and certain chronic diseases, as measures indicating progress towards "Closing the Gap".

Purchasing and Commissioning Services: A Risk of Data Expertise Gap?

Barrier to access is created by poor government contracting to out-source organisations with even poorer contract monitoring when non-compliance is highly evident.

The type of data being collected by ACCHOs is extensive. It ranges from primary health care, maternal and child health care, social and emotional wellbeing services and substance-misuse services and more. That data includes personal details about the client including age, gender, occupation and details about medical conditions and the lodging of MBS numbers. The data collected also includes information about the ACCHOs, including numbers of client contacts, services used, staffing numbers and employment roles. All of which represents data invaluable to government, as there is no other comprehensive data collection on the health of Aboriginal Australians. For the Australian government to remain informed of the health of Aboriginal people, that data needs to be preserved and maintained and funded accordingly.

In recent years, however, there has been an appetite by government to fund multiple providers in the ACCHO sector. New market entrants, without the high levels of expertise demonstrated within the ACCHO sector, pose a serious risk to the continuity of data collection and its statistical consistency. It is unlikely that new market entrants into the Aboriginal primary health care domain will have the acquired expertise, at levels held by ACCHOs, to readily proceed with that data capture, or interpret, assess and appropriately disseminate it as a routine part of everyday service delivery.

For instance the ACCHO patient records contain a wide-range of data items which far exceeds the present norms of private general practice, including the requirements for extensive data recording that are not part of regular Medicare Claims record keeping. Similarly, not-for-profit providers are likely to require a considerable developmental lead time to build satisfactory operational expertise in that field. Without those competencies, vital data and data collection on Aboriginal health care will be compromised or lost.

Data Standards and Efficacy

For data to be valuable it needs to be consistent; you need to be able to compare apples with apples. In the ACCHO sector there are numerous filters that need to be considered. One of those filters is geography, be it urban, regional, outer regional, remote and / or very remote. Other important filtering elements are the social disadvantage indices.

Those lenses need to be applied to collections of both Indigenous and non-Indigenous data to enable direct comparisons. Having a reliable and accurate evidence base is vital for policy making, budgeting, commissioning and delivering programs. There are significant inconsistencies in the measures required to be used for the calculation of values for reports within and between departments. This is increasingly apparent to NACCHO in the context of 'health' -- as understood within an Aboriginal and Torres Strait Islander cultural construct -- between the Departments of Health, Prime Minister and Cabinet and Social Services.

ACCHOs are the primary health care providers of choice for Aboriginal people. Studies have shown that Potentially Preventable Hospitalisations are highest where there is limited access to GP services (Grattan Institute 2016). Personally de-identified hospitalisation data is collected and made available differently, however, in each jurisdiction.

I.e. Different disease, pathology and medications terminologies are used in the different provider sectors.

Broader and deeper access to geographically and demographically consistent, intersecting, data sets would assist greatly in ensuring that research efforts more accurately inform the development and implementation of Commonwealth and COAG policies and public investments in service provision for Aboriginal people.

Access in those terms would also better facilitate more insightful and higher level research with the potential to better:

- integrate cultural and scientific knowledge;
- address multidisciplinary service delivery challenges;
- build research capabilities and sustainable capacity within the Sector and its communities;
- inform the provision of seamless patient experiences; and,
- support preventive and early intervention field practices to minimise and overcome the main risk factors contributing to the Burden of Disease for Aboriginal and Torres Strait Islander Australians (as identified by the ACCHO Sector and AIHW).

The downstream effect of those efforts, combined with others discussed above, would also realise greater confidence in achieving:

- inter-governmentally agreed performance indicators (nKPIs) towards closing the gap in Indigenous health status, and
- the goals of the Implementation Plan for the National Aboriginal and Torres Strait Islander Health Plan 2013–2023.

Unnecessary Costs

The barrier to access is that there is no authoritative source for data responsible for knowing and publishing what data is even being collected let alone determining its accessibility and use.

Governments, state and federal, currently spend significant amounts of public funds collecting, storing and analysing data. The range of that data is rich and broad reaching. Unfortunately, those data sets cannot be married up and have no way to speak to each other. There needs to be a change in the way publicly funded health data is collected and held to make it more accessible and usable and be allowed to develop its potential for adding evidence and value to budget decisions.

Better funded, managed, coordinated and targeted data collections would:

- support the translation of research into improved health care practice and policy;
- support and be more conducive to multidisciplinary research;
- supports research in diverse environments including universities, medical research institutes, hospitals, primary health care and in the community;
- enable and encourage collaborative enterprises (for example, partnerships with individuals and communities providing the data, research users, relevant government departments, national coordination and international linkages);
- offer greater potential for schemes for strategic research, such as targeted Calls for Research and Government initiatives (such as dementia research), national networks and international collaborations

The benefits to government of doing this will be more effective and targeted government policy, budgets and programs.

Barrier to access is inconsistent recording of data, with no enforced standards for data item definitions and irregular reporting periods and geographies that ensure data discovery and linkages are near impossible. Limiting access to and use of consistent data makes quantifiable improvements in cost-effectiveness and efficiencies impossible to assess. The ACCHO Sector is aware of this and is actively promoting more effective collaboration with Government to realise and relay those benefits

About NACCHO and its Member Services

Based in Canberra, the National Aboriginal Community Controlled Health Organisation (NACCHO) is the national peak Aboriginal health body. NACCHO represents the interests of its Membership, which is comprised of over 140 Aboriginal Community Controlled Health Services (ACCHOs), to the federal level of government and its bureaucracy.

It is important to highlight and acknowledge the different understandings of health between a western context and an Aboriginal cultural context. The western understanding of health is an absence of disease; someone is healthy if they do not have a disease, or illness. The Aboriginal understanding of health is holistic and includes land, the physical body, the mind, clan, relationships, and lore. Health, in an Aboriginal cultural context, is the social, emotional and cultural wellbeing of the whole community, not just the individual.

As the voice of its Members, NACCHO is the national authority on Aboriginal comprehensive primary health care. NACCHO's authority comes from over 40 year's engagement with health care services that have been established and operated by local Aboriginal communities, through locally elected Boards of Management, to deliver holistic, comprehensive and culturally appropriate health care.

Also directed by a Board of Management, with representation upon that Board sought from among its Members so as to embody community control, NACCHO has been pivotal in improving the circumstances for Aboriginal and Torres Strait Islander people. It has achieved this by working with its Members and its affiliate State and Territory peak Aboriginal Community Controlled Health bodies to agree upon, then work to address, a national agenda for Aboriginal and Torres Strait Islander health and relevant social justice matters.

NACCHO advocates to government in terms of evidence-supported, community-developed responses and solutions to the deep-seated social, economic and political conditions that prevail in many Aboriginal communities; which conditions affect the holistic health of people within those communities. NACCHO strives to maintain the highest levels of professionalism and to remain apolitical in its advocacy.

NACCHO has, and continues to be, a living embodiment of the aspirations of Aboriginal communities and their struggle for self-determination. NACCHO's long-term objectives as an organisation are defined within its Constitution as:

- The alleviation of poverty within the Aboriginal community;
- The advancement of Aboriginal spirituality;
- To provide constructive educational programmes for members of the Aboriginal community; and,
- To deliver holistic and culturally appropriate health and health-related services to the Aboriginal community.

About the ACCHO sector

The first ACCHOs were established in the early 1970s in response to recognition by Aboriginal and Torres Strait Islander people that mainstream services were not dealing adequately with their health needs. ACCHOs of today are evolutions of that genesis, providing innovative, high-quality, multidisciplinary and culturally-safe models of holistic care in response to community needs.

Those models of care are distinctive mixes of local community and cultural authority, blended with a broad span of service responses. Those responses range from the promotion of healthy life choices and chronic diseases prevention and management, through to enabling personally-empowered and smooth client journeys supported by comprehensive electronic health records. The unique syntheses of those community-controlled care models cannot be replicated in public or private-for-profit mainstream systems of primary health care.

ACCHOs operate in urban, regional, remote and very remote Australia. They range from large multi-functional services employing several medical professionals and health workers providing a wide range of services in urban and regional centres, to small or hub and spoke services providing the bulk of comprehensive primary care services, often with a preventative, health-education focus. ACCHOs form a network, but each is autonomous and independent both of one another and of government.

Figure two: Map of NACCHO Member Services

