

AMSANT submission on the National Primary Health Care Data Asset discussion paper, AIHW

June 2019

Introduction

Thank you for the opportunity to provide a submission to the National Primary Health Care Data Asset.

The Aboriginal Medical Services Alliance NT (AMSANT) is the peak body for Aboriginal community controlled health services (ACCHSs) in the NT. Our members are located right across the NT from Darwin to the most remote areas. The ACCHSs sector is the largest provider of primary health care to Aboriginal people in the NT. ACCHSs deliver comprehensive primary health care in an integrated, holistic, culturally secure framework which combines a population health approach with primary health care service delivery, and are also involved in diverse health research activities.

AMSANT and the NT ACCHSs sector has a strong record of using data for needs analysis, continuous quality improvement and service planning. Each clinic in the NT Aboriginal primary health care sector has been reporting on compulsory clinical data since 2009. Our sector also has a strong record of engaging with research. Most NTAHKPIs have improved substantially over the last ten years. However, this improvement has not just been due to collection of data. There has also been substantial investment in continuous quality improvement and in supporting services to use Clinical Information Systems so that they can extract accurate clinical data and also have the skills to extract data that is of most use to their own communities. Importantly, this investment supports service and community priorities – not just those of the government. It is important that a national primary health care data asset is part of a broader strategy to improve primary health care outcomes including investment in service level capabilities in CQI, data quality and being responsive to the needs of local communities.

AMSANT's concerns regarding the National PHC Data Asset (NPHCDA) are focused on the need for strong protection of the rights and interests of Indigenous people in relation to their health data. The consultants should be aware that there are many examples of Aboriginal health data being misused or misinterpreted to the detriment of our communities. Strong safeguards are required to prevent unintended consequences of misconceived, culturally unsafe research, inaccurate interpretation and reporting, or the possible misuse of Aboriginal health data derived from PHC records.

Our strong view is that there needs to be a separate Indigenous controlled data governance structure. AMSANT has argued previously for similar Indigenous data governance for the secondary use of My Health Record data, and note that AIHW also holds governance over this data. Given these developments, we strongly urge that AIHW must consult with Aboriginal experts in this area as well as with the ACCHS sector on how to include Indigenous data governance in their governance structures.

We are also concerned about the very ambitious scope of work outlined. As the discussion paper notes, trust is essential and most crucially that patients can trust that their information is used only for the purposes it is provided and that its confidentiality is maintained. The NPHCDA has the potential to undermine the trust of patients and communities if patient level data were to accessed or used without appropriate consent, for example, through linking with other data sets or being shared with researchers. There are also opportunity costs in the substantial investment required to build a comprehensive longitudinal data set containing information about every person in Australia. Better outcomes may be achieved through a more regional approach to building service level capabilities in collecting and using clinical data and in CQI.

The potential uses of a comprehensive longitudinal patient data set include comparisons, such as comparing outcomes between practices and between ACCHSs and private general practice. Unless substantial information is collected on socioeconomic status and disadvantage as well as comorbidity, these comparisons are unlikely to be valid and could lead to very flawed conclusions. It may (particularly if there is a move to pay for performance models) mean that general practitioners become increasingly reluctant to work in poorer areas or care for people who are homeless or have severe mental illness as these patients are likely to have worse outcomes. We believe that a simpler system of aggregated data combined with local resourcing of CQI and data quality is the best way forward.

National Primary Health Care Data Asset

Overview

The Australian Institute of Health and Welfare (AIHW) received funding in the May 2018 Federal Budget to develop an enduring National Primary Health Care Data Asset. The Data Asset will fill an information gap—there is currently no national source of data to provide a comprehensive understanding of the patient’s journey and experiences within the primary health care system, including their reason for an encounter with a clinician, diagnosis, treatment and outcomes.

Contact Details

1. What is your email address? (Required)

[Your email address is required as it will assist in recovering your responses in the unlikely event you lose access to your saved work]

2. Who are you providing a submission on behalf of? (Required)

Please select only one item

Individual

Organisation

3. If submitting on behalf of an organisation, which one? (Required)

Aboriginal Medical Services Alliance Northern Territory (AMSANT)

4. Do you consent to the publication of your organisational name? (Required)

Please select only one item

Yes, I do consent to the identification of my organisation.

No, I do not consent to the identification of my organisation

Not applicable

5. Which stakeholder group best describes your affiliation?

Please select only one item

Consumer

Provider of primary health care services

Commissioner of primary health care services

Policy maker

Researcher

Provider of clinical information system/infrastructure

Introduction

The following five questions apply to the development of the National Primary Health Care Data Asset, its uses, priorities, barriers and enablers.

- **What do you see as the key areas of opportunity in developing the National Primary Health Care Data Asset?**

For mainstream general practices to contribute to PHC data as ACCHS have been doing this for the past 10 years for the NT Aboriginal Health Key Performance Indicators (NTAHKPIs), and the past 8 years for the national Key Performance Indicators (nKPIs). Compulsory aggregated clinical indicators across general practice will build a solid foundation of data on which to base

CQI, identification of disease /service gaps which require attention, and accountability. The general practice sector must be supported with CQI and data training and infrastructure to ensure this is useful to both general practitioners and patients as well as the government. The RACGP has also developed a set of voluntary indicators which could be further developed.

Another issue is that only clinical data is collected from the ACCHS sector. AMSANT has been funded to develop and pilot some non-clinical indicators across five domains including corporate services/ workforce, health promotion, research, advocacy and policy and cultural safety, community engagement and community control. The crucial work in these areas is largely invisible in the ACCHS sector despite its importance to the performance of the sector. Note that some of these domains are best suited to being voluntary whilst others such as workforce turnover, or proportion of Aboriginal workforce, could become compulsory.

- **What are your top primary health care data needs?**

Our top primary health care data needs are for strong Indigenous data governance.

The ACCHS sector is data rich, and currently there is no way to compare with mainstream services – including data quality. AMSANT supports general practice activity data. Currently the NTAHKPIs and the nKPIs are collected and reported by ACCHSs – there is no comparable data for mainstream GP activity. Because ACCHSs already report on the nKPIs and the NTAHKPIs (in addition to other reports to funders), we suggest that mainstream GPs begin with the nKPIs that are relevant to their practice (e.g. number of MBS item 715 may not be relevant for practices that see few Aboriginal patients). The RACGP has also developed a set of voluntary indicators for general practice and these may also be useful (clinical indicators for general practice).

ACCHSs also have to report other patient data such as the mental health MDS and social services MDS. There is considerable frustration that there are several different ways, methods, portals and websites for reporting. Having only one place to report to would be very helpful. Other concerns about the mental health and social service MDS is that they violate Indigenous data governance principles as they collect detailed individual level patient data on very personal issues, potentially enabling data linkage etc. Consent is supposedly obtained but as patients/ consumers are meant to provide this data prior to receiving the service, the consent is coerced. There is also no Indigenous oversight of these detailed and potentially stigmatising data sets.

Please rank in order of importance the following topics from the Data Development Plan (1 being the most important and 6 the least).

1. Data governance
2. Reporting requirements
3. Data element selection
4. Data flow models
5. Data indicators
6. Data sources

- **From your perspective what are the top three key barriers and their enablers in developing the National Primary Health Care Data Asset?**

Barrier #1

Lack of an Indigenous data governance structure

Enabler #1

Establish an Indigenous data governance structure, perhaps within the AIHW, which also holds responsibility for governance of other data including in relation to the secondary use of My Health Record data. Importantly, such a structure requires the power to make decisions, not be merely advisory and should be led by the Maïam nayri Wingara Indigenous Data Sovereignty Network, NACCHO and other Aboriginal and Torres Strait Islander peak bodies. Governance structures should include majority Aboriginal membership including representatives from ACCHSs as well as academics with a strong understanding of Indigenous data governance (e.g Professor Maggie Walters).

Barrier #2

Lack of data from mainstream services. It is inconsistent that ACCHSs report extensively through KPIs and are closely scrutinised while mainstream services lack similar requirements for evaluation and accountability. As mainstream services are also publicly funded through Medicare it is appropriate that they should have the same level of accountability as ACCHSs, focused on standards of care and CQI.

Enabler #2

The National Primary Health Care Data Asset could be a vehicle for establishing requirements for data collection and accountability from mainstream services.

Barrier #3

Trust in safety and security of data, and appropriate use of data

Enabler #3

A strong Indigenous data governance, and one repository for data to be held (see response re data flows)

- **In order of priority rank the following uses of the National Primary Health Care Data Asset (1 being the top priority and 7 the lowest priority).**

1. Help identify gaps in the provision of primary health care services

2. Support quality improvement
3. Enable better population health planning
4. Shape primary health care programs and policies
5. Provide the best evidence to be able to reduce hospitalisations and emergency department attendance
6. Facilitate increased efficiencies in care delivery through comparison of patient outcomes and services across geographic and socioeconomic gradients
7. Improve patient outcomes and experiences

Data sources

Section 3 of the Data Development Plan outlines existing and new primary health care data sources and how they will inform the Data Asset. We are particularly interested in your views of our proposed new data sources and the phased approach to their implementation, what you see as the pros and cons of the potential models of data flow (Figure 3.2) and if there is anything additional we should consider in the decision-making process when assessing data sources for inclusion (Figure

3.3).

1. Which is your preferred model of data flow from general practice to the Data Asset (Figure 3.2)? Please select only one item

General practice direct to Data Asset

General practice to Primary Health Network to Data Asset

General practice to Clinical Information System to Data Asset

General practice to Data Collator to Data Asset

General practice to Primary Health Network to State and Territory Health Department to Data Asset

Other

Comments: To clarify, ACCHSs use the CIS to report the nKPIs and NTAHKPIs. Data is recorded in the CIS (in the NT, this is predominantly Communicare) in the form of a patient clinical record, and the reports are then created within the CIS, and the CIS exports these reports to the Health Data Portal (HDP) (for the nKPIs) or the NTAHKPI system portal. Therefore the 2 options of GP direct to

DA, or GP to CIS to DA are confusing – the CIS is a required step. It would be a similar process for the PHC Data Asset.

Direct data transfer to the data asset is the much preferred option. It is not in line with Indigenous data governance principles and data security in general for data to be transmitted to multiple organisations.

As outlined in the introduction, we do not believe collection of patient level data is appropriate for either Aboriginal primary health care or general practice. It is intrusive and it would be very time consuming for GPs to ask consent of patients. The discussion paper has not clearly set out the benefits of this level of data collection or provided any international examples.

2. What are the implications, opportunities and challenges for the proposed general practice data flow models (Figure 3.2)?

Data flow should be as simple as possible while maintaining security of the data. It has taken 8 years of ACCHSs reporting the nKPIs to develop a system (direct reporting to the HDP) that finally seems to be easy, safe and useful. The NTAHKPIs have always used direct reporting. The nKPIs initially involved several third parties to report through and we recommend that AIHW reviews the experiences and lessons learned from this process. Our experience and that of our member services was that third party reporting proved burdensome, with significant data quality issues experienced. The significant problems encountered led to a decision that ACCHSs report the nKPIs direct to the HDP. This has reduced the burden enormously and improved data quality.

Once data is in the HDP, services can then release data to other organisations eg state/territory govts, or the PHN if they so desire – but it is not compulsory. The National Primary Health Care Data Asset should follow a similar process. The proposed data flow to the PHN is problematic, because it includes additional steps in the data flow. In addition, the PHNs are developing their own data governance policies and there is no national standard for PHNs to adhere to. Indigenous data governance standards cannot be guaranteed in the PHNs. Direct reporting, in our experience with the NTAHKPIs and the nKPIs, also reduces the burden of reporting, and reduces the risk of data quality issues. It also reduces the risk of breaches to data security.

3. What potential data flow models could capture other primary health care data sources: allied health, community, dental?

Use the same model as for GPs – as above

4. Are there additional sources of primary health care data you would like to see included?

5. How satisfied are you with the decision-making matrix for assessment of new data sources?

Highly satisfied

Satisfied

Somewhat satisfied

Dissatisfied

Strongly dissatisfied

Comments:

As outlined previously, in general we do not support individual unit record data collection and we are concerned that mainstream data governance frameworks do not comply with Indigenous data sovereignty requirements. It is essential that as a principle, data collected is fit for purpose and does not exceed the level of detail required for the purpose it is being collected. Individual unit record data collection should not be required where aggregated, non-identified data is sufficient. In each and every case where individual data collection is proposed, consideration should be required of evidence of the need and possible alternative data sources and ensuring appropriate consent is obtained. We have previously commented that current Commonwealth data collection for the mental health MDS and social services MDS includes individual data that is not required, and for which there has been no process of consultation with our sector or demonstration of need and consideration of alternatives, and where patient consent can be construed as coercive. The lack of appropriate decision-making processes remains a major risk in establishing the NPHCDA.

6. Do you have any additional comments or suggestions regarding data sources?

Data governance

The AIHW's strong and proven data governance structure is key to ensuring the trust of patient and providers regarding the management of any data within the National Primary Health Care Data Asset. Your views on the capacity for existing and proposed data governance arrangements to manage the Data Asset are sought.

1. How satisfied are you with the proposed data governance arrangements?

Highly satisfied

Satisfied

Somewhat satisfied

Dissatisfied

Highly dissatisfied

Comments:

2. Do you have any additional comments or suggestions regarding data governance?

In the absence of other options, AMSANT agrees that the AIHW is the most appropriate option for providing data governance over the National PHC Data Asset. However, AMSANT considers that additional strengthening of the AIHW's data governance structure is required to ensure the rights and interests of Indigenous people are protected. We have argued for a similar structure for the secondary use of My Health Record data. We note that AIHW is also the governing body for this data.

It is essential that the National PHC Data Asset includes a strong Indigenous data governance structure to safeguard against the risks of inappropriate use of data as mentioned above, and also as an expression of the inherent rights we hold as Indigenous peoples. Development of the principles of Indigenous data governance has been contributed to from a range of sources including international instruments such as the UN Declaration of the Rights of Indigenous Peoples (UNDRIP) and the work of national Indigenous data bodies including the National Advisory Group on Aboriginal and Torres Strait Islander Health Information and Data (NAGATSIHID), and the Maiam nayri Wingara Indigenous Data Sovereignty Network (<https://www.maiamnayriwingara.org/>). A number of the Articles of UNDRIP, including Article 31, define rights to Indigenous autonomy in relation to internal and local affairs and in relation to our cultural, human and genetic resources. NAGATSIHID developed the National Aboriginal and Torres Strait Islander Health Data Principles endorsed by AHMAC in 2006.

The Maiam nayri Wingara Indigenous Data Sovereignty Network represents a global Indigenous movement which asserts rights and control over data and how it is used. The National Indigenous Data Sovereignty Summit on 20th June 2018 endorsed the following the following foundation statements:

- In Australia, '*Indigenous Data*' refers to information or knowledge, in any format or medium, which is about and may affect Indigenous peoples both collectively and individually.
- '*Indigenous Data Sovereignty*' refers to the right of Indigenous people to exercise ownership over Indigenous Data. Ownership of data can be expressed through the creation, collection, access, analysis, interpretation, management, dissemination and reuse of Indigenous Data.
- '*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 ensures that data on or about Indigenous peoples reflects our priorities, values, cultures, worldviews and diversity.

Exercising Indigenous Data Governance enables Indigenous peoples, our representative and governing bodies to accurately reflect our stories. It provides the necessary tools to identify what works, what does not and why. Effective Indigenous Data Governance empowers our peoples to make the best decisions to support our communities and First Nations in the ways that meet our development needs and aspirations.

The Summit delegates asserted that in Australia, Indigenous peoples have the right to:

- Exercise control of the data ecosystem including creation, development, stewardship, analysis, dissemination and infrastructure.
- Data that is contextual and disaggregated (available and accessible at individual, community and First Nations levels).
- Data that is relevant and empowers sustainable self-determination and effective self-governance.
- Data structures that are accountable to Indigenous peoples and First Nations.
- Data that is protective and respects our individual and collective interests.

This in turn builds on existing longstanding Aboriginal action to take control of health services and health research that affect us, exemplified by the Aboriginal community controlled health sector. Our sector in the NT have used clinical information systems (CIS) and electronic shared records for over a decade to take control of our health and to improve the quality of our health services. Our existing ownership of our own health data through Aboriginal community controlled health services (ACCHSs) has driven our sector's longstanding involvement in health research and AMSANT and a number of our member ACCHSs have our own widely recognised processes for assessing and approving health research projects, including projects that seek access to data held by ACCHSs. We have developed standards for the collection and use of data that are used in the assessment of health research projects and we also collect and use our own data for health research within the sector to improve the quality of service delivery.

AMSANT's understanding is that all data relating to Aboriginal people irrespective of where it is stored (in ACCHSs' or government databases) should be managed under Indigenous data governance principles.

This is also exemplified by the fact that in other comparable nations with Indigenous populations, Indigenous data governance standards are far in advance of those in Australia.

- In Aotearoa NZ, the Te Mana Raraunga Charter (an audit tool to assess frameworks) states principles of data sovereignty as they apply to Maori data. The charter was born in 2015 when the NZ Government launched two initiatives: the IDI (Integrated Data Infrastructure) which is a longitudinal dataset (and infrastructure) which links data across administrative systems (tax, health, education, justice, migration, benefits) with little Maori governance and likely to replace the census. Another is the New Zealand Data Futures. Strong links exist internationally with Indigenous data sovereignty networks in Australia, and many similarities apply.
- In Canada, OCAP® (Ownership, Control, Access, Possession) is a set of standards that establish how First Nations data should be collected, protected, used or shared. Since 2010, the First Nations Information Governance Centre (FNIGC) has operated on behalf of First Nations to ensure that OCAP is applied through a certification process for research projects, surveys and information management systems. More information on OCAP® can be located on the FNIGC website (<http://fnigc.ca/ocap.html>).
- Also in Canada, the Institute for Clinical Evaluative Sciences (ICES) in Ontario uses governance processes for use of routinely collected health data with Indigenous identifiers:
 - Access to and use of data with Indigenous identifiers is approved by data governance committees organised and populated by the relevant Indigenous organisations.

- Linked datasets with Indigenous identifiers are not routinely available to researchers and analysts, who must make specific application and seek approval from the relevant data governance committee before they can access them.
- Researchers are required to discuss their projects with Indigenous community representatives, who may collaborate in the planning conduct and reporting of the studies.
- Researchers and staff at ICES participate in ongoing initiatives to orient them to Indigenous worldviews, research principles, and historical and social contexts.
- Staff at ICES are working with representative organisations to build capacity among Indigenous organisations and communities to train Indigenous analysts and epidemiologists.
- Study results are co-interpreted with the communities and their representatives, who have a lead role in deciding how the results will be communicated more widely.

In the British Columbia First Nations' Data Governance Initiative (BCFNDGI <http://www.bcfndgi.com/>), First Nations across Canada are focusing on data governance and collaborating with the Canadian Government. Alberta has established a Regional First Nations Information Governance Centre which is primarily funded by Health Canada. Quebec First Nations are working collaboratively to build data governance and information management capacity, working with their government partners to address their unique needs.

The international examples and Indigenous data governance initiatives in Australia referred to above, point to what is current and emerging best practice in data governance and should provide impetus for the Commonwealth to work collaboratively with relevant Indigenous organisations and community representatives on developing an appropriate governance structure for the National PHC Data Asset.

Development of an Indigenous data governance structure will maximise the benefits of the NPHCDA for Aboriginal and Torres Strait Islander peoples as well as for all Australians. Such a structure could build on the work of the Maïam nayri Wingara Indigenous Data Sovereignty Network. Strong links exist internationally between Indigenous data sovereignty networks in Australia, the US and Canada where data integration has created an opportunity to demonstrate the benefit of collaborating with first nations to improve national research standards. It would also include Aboriginal peak body organisations, including the National Aboriginal Community Controlled Health Organisation (NACCHO), AMSANT, Aboriginal Peak Organisations of the NT (APO NT) and peak bodies from other jurisdictions. For example, AMSANT and our members have developed NT-specific/ service-specific Indigenous research governance processes, for assessing and contributing to cutting edge health research projects.

An Indigenous data governance structure will be even more important if the Data Asset considers individual level data collections. As outlined previously, in general we do not support individual unit record data collection and we are concerned that mainstream data governance frameworks do not comply with Indigenous data sovereignty requirements. It is essential that as a principle, data collected is fit for purpose and does not exceed the level of detail required for the purpose it is being collected. Individual unit record data collection should not be required where aggregated, non-identified data is sufficient. In each and every case where individual data collection is proposed,

consideration should be required of evidence of need, possible alternative data sources and ensuring appropriate consent is obtained. We have previously commented that current Commonwealth data collection for the mental health MDS and social services MDS includes individual data that is not required for the purposes it is collected, and for which there has been no process of consultation with our sector or demonstration of need and consideration of alternatives, and where patient consent can be construed as coercive. The lack of appropriate decision-making processes remains a major risk in establishing the NPHCDA, underpinning the need for the development of an Indigenous data governance structure.

Data requirements

Section 5 outlines information pertaining to the data requirements.

1. How much do you agree with the proposed list of core data elements suggested in Table 5.1?

Strongly agree

Agree

Somewhat agree

Disagree

Strongly disagree

Comments:

As noted, we strongly disagree with unit record data and suggest that the AIHW should begin the process for negotiating collecting aggregated clinical indicator data from general practice. The degree of data to be collected as outlined in this table is very detailed and substantial and is not an appropriate starting point. We suggest a small number of compulsory indicators be initially considered and a process be established to consult on further data needs based on a comprehensive assessment of purpose, need and evidence. The benefits of collecting information on every patient encounter from every general practice have not been outlined. The BEACH survey which collected such data on a representative sample of general practice was much more feasible and contained.

Some issues identified by AMSANT:

- Tobacco smoking:
 - Is there really a suitable data standard for this?
 - A certain amount of people use tobacco in non-smoking ways eg chewing, particularly in Central Australia
- MBS items:

- Some PHC activity is hidden if relying on MBS eg when allied health services are funded
- Does not include all activity by nurses & AHPs/AHWs
- PBS: Remote PHC access s100 medications so PBS will not provide accurate data on medicines
- Reason/s for encounter:
 - Unreasonable to collect longitudinal data on each patient encounter.
 - Currently not counted by many ACCHS
 - There can be more than one reason for encounter – patient reasons may differ from clinician reasons
- Alcohol consumption: can be difficult to assess in dry communities where some people may binge during town trips but otherwise don't drink for extended periods of time
- Episodes of care (EoC) or encounters can be problematic. EoC are often used as a proxy for service provision but EoC can vary from a 5 minute consultation to several hours, particularly when providing comprehensive primary health care, and patient centred care. An example is when a patient may be seen in one day over several hours by multiple providers eg GP, nurse, Aboriginal health practitioner and diabetes educator – and perhaps a specialist. This is recorded as one EoC. In remote areas, an EoC may include emergency care which can also last several hours – more than 8 hours if patient retrieval cannot occur immediately, and also involve several staff.

2. How much do you agree with the potential indicators for general practice outlined in Table 5.3?

Strongly agree

Agree

Somewhat agree

Disagree

Strongly disagree

Comments:

Some issues identified by AMSANT:

- Recording weight and height. Although obesity levels are very concerning, general practice is not well resourced or supported to tackle this issue and particularly in poorer areas, there is a dearth of referral options. Just measuring rates of obesity will do little to change the issues. It would be much better to tackle this issue at the prevention end – e.g. address food security and cost of healthy food particularly in remote communities.
- 3. & 18. What is the definition of chronic conditions?
- 4. What is the definition of preventable hospitalisations

- 11. What is the definition of a mental health diagnosis
 - 14. Patient experience of GP care: how is this ascertained in non-English speaking communities? What about other PHC providers such as nurses (who make up the largest PHC workforce in the NT) and AHPs/AHWs? One example of how surveys can result in error is the NT Health Performance Framework quoted an estimate of 15% of Aboriginal people using ACCHSs for PHC, sourced from the 2012 Australian and Torres Strait Islander Health Survey. The nKPIs and NTAHKPIs show this to be a vast underestimate. The nKPIs provide an estimate that approximately 80% of the NT Aboriginal population access either ACCHSs or DOH remote PHC; and the NTAHKPIs provide an estimate that of these, approximately 65% of people use ACCHSs for their PHC.
 - Proportion of regular clients with a chronic disease for whom a Team Care Arrangement (MBS item 723) was claimed. In many poorer areas, people cannot afford to access private allied health providers who usually charge a gap fee.
 - Note that the ACCHSs already report on the nKPIs and GP indicators may be best to align with these. Not to have 2 different but similar reporting requirements. The nKPIs may be a good place to start for other practices to report on where relevant
 - The number of indicators. The NTAHKPIs currently have 20 indicators, and the nKPIs have 24 indicators. A meeting of PHC staff a few years ago strongly wanted a limitation on the number of indicators, preferring no more than 20.
3. **Please list any primary health care data gaps not identified in the Data Development Plan.**
- Non-clinical indicators
- Cultural training/safety
- Workforce/staff turnover

4. Do you have any additional comments or suggestions regarding data requirements?

Should probably work with the CQI PIP to ensure reporting once only. In addition, context of PHC services and the communities they serve need to be considered in any reporting.

Summary

1. From your perspective, what else should the AIHW be considering in the development of the Data Asset?

Utilising data sets we already have and not continually adding data sets without a rigorous process of evaluation of need and alternatives that includes consultation with the relevant data providers as well as consideration through an appropriate Indigenous data governance structure.

In general, the AIHW should avoid collecting patient level data.

2. What do you see as the biggest risks in developing a National Data Asset and how would you mitigate them?

1. There is a risk that indicators drive clinical practice, in the tools used to collect data, and focus on the things that are easily counted, to the detriment of other elements, such as Indigenous self-determination (as demonstrated by Aboriginal community control of health services), and the social determinants of health that contribute to a significant proportion of health outcomes. This is one reason to limit the number of indicators.
2. The lack of appropriate decision-making processes remains a major risk in establishing the NPHCDA, underpinning the need for the development of an Indigenous data governance structure. A strong Indigenous data governance structure is required to ensure accountability to Indigenous peoples, protection and respect for our individual and collective interests, and to safeguard against the risks of inappropriate use of data.
3. A further major risk is that the National Data Asset adopts an inappropriate data flow structure to the PHNs. This is particularly problematic because there is no national data governance standard for PHNs meaning that Indigenous data governance standards cannot be guaranteed, and would also preclude the establishment of a national Indigenous data governance structure such as could be achieved through a national organisation such as the AIHW. In addition, it would introduce additional steps in the data flow with attendant risks of data security, an increase the complexity and burden of reporting, and risk of data quality issues.

3. Do you have any final advice or comments for the AIHW?

The Data Development Plan references the Canadian Institute for Health Information (CIHI) – could the Commonwealth also consider the same model - an independent, not for profit organisation. This may increase the public's trust in the Data Asset and other data functions of the AIHW.

We believe this is an over ambitious plan whose long-term benefits have not been clearly articulated and where the legitimate privacy considerations for patients and potential erosion of trust between clinicians and patients have not been taken seriously.