

### QAIHC RESPONSE TO THE

Australian Institute of Health and Welfare, Independent Expert Panel

### **SURVEY RESPONSE**

National Health Information Strategy (NHIS)

**April 2020** 



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QAIHC receives funding support from the Australian and Queensland Governments



QAIHC response to the Australian Institute of Health and Welfare (AIHW), Independent Expert Panel- online consultation survey

#### **SUBMISSION**

### **National Health Information Strategy (NHIS)**

### About Queensland Aboriginal and Islander Health Council (QAIHC):

QAIHC was established in 1990 by dedicated and committed Aboriginal and Torres Strait Islander leaders within the community-controlled health sector.

Originally established as QAIHF (Queensland Aboriginal and Islander Health Forum), the organisation provided a voice for the community-controlled health sector in Queensland. This organisation was self-funded until 1996, when the Commonwealth Department of Health commenced funding support. QAIHC has experienced considerable growth in membership and the scope of services provided to those members since its establishment.

In 2004, the organisation was reconstituted under the Australian Investment and Securities Commission (ASIC) and assumed its current form as QAIHC.

Today, QAIHC represents 28 community-controlled health services and 14 associate members who share a passion and commitment to addressing the unique health care needs of their communities through specialised, comprehensive and culturally-appropriate primary health care.

QAIHC is the peak body representing the Aboriginal and Torres Strait Islander Community Controlled Health Organisation (ATSICCHO) sector (the Sector) in Queensland at both a state and national level. Its membership comprises of ATSICCHOs located throughout Queensland. Nationally, QAIHC represents the Community Controlled Health Sector through its affiliation and membership on the board of the National Aboriginal Community Controlled Health Organisation (NACCHO) and is regarded as an expert in its field.

QAIHC as the peak of ATSICCHOs of Queensland wish to express the collective views on behalf of our state-wide members, on the draft National Health Information Strategy framework.

The purpose of this submission is to ensure the draft National Health Information Strategy embraces and incorporates the Aboriginal and Torres Strait Islander peoples data sovereignty and governance to establish an effective and efficient national health information system.

QAIHC would like to thank the Australian Institute of Health and Welfare, Independent Expert Panel for the opportunity to provide feedback on the draft National Health Information Strategy framework.

#### **QAIHC CONTACT REGARDING THIS SUBMISSION:**

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### Introduction

1. What is your email address? policyteam@qaihc.com.au

- 2. Are you submitting on behalf of an organisation, or as an individual?

  Organisation
- 3. If submitting as an individual, what is your name?  $_{\mbox{\scriptsize N/A}}$
- 4. Do you consent to the publication of your name?  $_{\mbox{\scriptsize N/A}}$
- 5. If submitting on behalf of an organisation, which one?

  Queensland Aboriginal and Islander Health Council (QAIHC)
- 6. Do you consent to the publication of your organisation name?  $_{\mbox{\scriptsize Yes}}$
- 7. Which stakeholder group best describes your affiliation?

  State Peak Body-

Represents the Aboriginal and Torres Strait Islander Community Controlled Health Organisation (ATSICCHO) sector in Queensland at both a state and national level.

### **Principles**

- 8. When you look at the Principles in the draft Framework, is there anything missing or that should in your view not be there?
- a. Comments on the proposed principle of "Data supports improvements in Aboriginal and Torres Strait Islander Peoples' health"

QAIHC acknowledges the incorporation of a dedicated principle to ensure that Aboriginal and Torres Strait Islander peoples' data is used appropriately and commend the AIHW for this proposal.

The principle could, however, benefit from refinement. QAIHC recommend the principle focuses on ensuring data sovereignty and governance within the framework for Aboriginal and Torres Strait Islander peoples rather than providing a generic principle on what the data will achieve ("Data supports improvements in Aboriginal and Torres Strait Islander Peoples' health").

#### Why data sovereignty is important

Data sovereignty and ownership of data governance structures by Aboriginal and Torres Strait Islander peoples supports self-determination and is a fundamental right according to Article 18 of the United Nations Declaration on the Rights of Indigenous Peoples:

"Indigenous peoples have the right to participate in decision-making in matters which would affect their rights, through representatives chosen by themselves in accordance with their own procedures, as well as to maintain and develop their own indigenous decision-making institutions".

The importance of self-determination over data governance is explained in the book "Theory on Demand, Good Data" where the authors explain:

"the power and authority over the design, ownership, access to and use of data. The governance of data has emerged as a highly contested area of debate between Indigenous peoples and the states within which they reside. For Indigenous peoples, whose traditional modes of governance were disrupted by western modes of democratic governance, reasserting themselves through self-determined governance structures is critical. Ownership of governance structures commences at the development stage, and continues through the ethics application stage and through the collection, analysis and reporting of data, and through policy translation. Indigenous peoples' ownership is integral to autonomy.<sup>2</sup>

... Good data, including good data governance, are necessary to ensure Indigenous peoples benefit from current and future data practices and to mitigate the potential for continued harm".<sup>3</sup>

<sup>&</sup>lt;sup>1</sup> The United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) adopted by the General Assembly on Thursday, 13 September 2007. <a href="https://www.un.org/development/desa/indigenouspeoples/wp-content/uploads/sites/19/2018/11/UNDRIP\_E\_web.pdf">https://www.un.org/development/desa/indigenouspeoples/wp-content/uploads/sites/19/2018/11/UNDRIP\_E\_web.pdf</a>

<sup>&</sup>lt;sup>2</sup> Angela Daly, S. Kate Devitt and Monique Mann (2019), "Theory on demand: Good Data" Chapter 2: Good Data Practices for Indigenous Data Sovereignty and Governance by Raymond Lovett, Aymond Lovett, Vanessa Lee, Tahu Kukutai, Donna Cormack, Stephanie Carroll Rainie and Jennifer Walker; page 27 <a href="https://networkcultures.org/wp-content/uploads/2019/01/Good">https://networkcultures.org/wp-content/uploads/2019/01/Good</a> Data.pdf.

<sup>&</sup>lt;sup>3</sup> Reference 1, page 35

The need to support National Aboriginal and Torres Strait Islander Data leadership and a community-led approach.

The Sector has, in the past, argued for the importance of a national level mechanism to advise on the use of Aboriginal and Torres Strait Islander health information. However, disbandment of the advisory function of the National Advisory Group on Aboriginal and Torres Strait Islander Health Information and Data (NAGATSIHID) in 2017 created a gap. The Health Services Data Advisory Group (HS DAG) provides advise on Health Data, but does not take responsibility for wider social-determent data.

In 2017 the Maiam nayri Wingara Aboriginal and Torres Strait Islander Data Sovereignty Collective was formed to exercise powers of data sovereignty. They provide a range of resources and advice, which QAIHC recommend the AHMAC, AIHW and Independent Expert Panel seriously consider in the development of the NHIS. Maiam nayri Wingara explain:

"Enacting Indigenous Data Governance <u>requires Indigenous leaders, practitioners and community members with the skills and infrastructure to advocate and participate across all sectors and jurisdictions</u>. Indigenous communities retain the right to decide which sets of data require active governance and maintain the right to not participate in data processes inconsistent with the principles asserted in this Communique."<sup>4</sup>

Maiam nayri Wingara's data development considerations include:

- "Development of new data items that represent cultural expression and practice (data of importance to Aboriginal and Torres Strait Islander peoples).
- The Australian Code for the Responsible Conduct of Research (the Code), that requires research data ownership and storage to be described.
- Research ethics<sup>5</sup> and intellectual property,<sup>6</sup> to acknowledge the sources of information and those who have contributed to the research. If Indigenous knowledge contributes to intellectual property, recognising the contribution, where appropriate, by transferring or sharing intellectual property and any benefits that result from the research'.<sup>7</sup>
- An Indigenous Data Governance group that develops data access and release protocols based on IDS principles."<sup>8</sup>

We know that when Aboriginal and Torres Strait Islander peoples take charge of developing their own strategies, the strategies better reflect their interests, values, vision and concerns, increasing ownership and accountability. However, the Government's current top-down approach still impacts on health equalities of Aboriginal and Torres Strait Islander peoples in Australia. A community-led approach to health policies and programs is the true reflection of self-determination in health, and will significantly contribute to reducing disparity in health outcomes. Incorporating a community-based approach in the NHIS will support the development of an effective and efficient health information mechanism.

<sup>&</sup>lt;sup>4</sup> Maiam nayri Wingara, Indigenous Data Soverignty Communique – Indigenous Data Sovereignty Summit 20 June 2018. https://static1.squarespace.com/static/5b3043afb40b9d20411f3512/t/5b6c0f9a0e2e725e9cabf4a6/1533808545167/Communi que%2B-%2BIndigenous%2BData%2BSovereignty%2BSummit.pdf

<sup>&</sup>lt;sup>5</sup> AIATSIS, 'Gerais Guidelines for Ethical Research in Australian Indigenous Studies' Canberra: Australian Institute of Aboriginal and Torres Strait Islander Studies, 2012.

<sup>&</sup>lt;sup>6</sup> Australian National University, 'Intellectual Property Policy', https://policies.anu.edu.au/ppl/document/ ANUP\_003603.

<sup>&</sup>lt;sup>7</sup> AIATSIS, 'Gerais Guidelines for Ethical Research in Australian Indigenous Studies'.

<sup>8</sup> Maiam nayri Wingara, Indigenous Data Soverignty Communique – Indigenous Data Sovereignty Summit 20 June 2018. https://static1.squarespace.com/static/5b3043afb40b9d20411f3512/t/5b6c0f9a0e2e725e9cabf4a6/1533808545167/Communique%2B-%2BIndigenous%2BData%2BSovereignty%2BSummit.pdf

#### Examples of self-determination contributing to effective evaluations

As leaders in evaluation, QAIHC and our Members have a commitment to continuous quality improvement which ensures that all aspects of service delivery are effective, inform decision making and reflect community need. Approaches to evaluation and data collection should not merely be economic, but have a fundamentally practical, realist and participatory focus.

Examples of effective evaluations include those where the community have set priorities for the outcomes of health interventions, determined the desired outcomes, and were aware of the scope and the reasons behind evaluations. Results are also shared respectfully, transparently, and are understandable. Furthermore, they are communicated in a way which allows the learnings and outcomes to be used to continually develop and build the capacity of the program and sector.

QAIHC and our Members recognise that incorporating Aboriginal and Torres Strait Islander peoples' data sovereignty and governance as a principle will reduce the risk of inappropriate collection, access, interpretation and use of data. This will ultimately improve data applicability towards achieving overall health and wellbeing outcomes of Aboriginal and Torres Strait Islander peoples.

Recommendation 1: Change the principle "Data support improvements in Aboriginal and Torres Strait Islander peoples' health" to "Aboriginal and Torres Strait Islander peoples' data sovereignty and governance" and consider the data development recommendations of Maiam nayri Wingara in the design of the principle.

#### b. Comments on the lack of acknowledgement of holistic health

The Aboriginal and Torres Strait Islander concept of health is holistic, incorporating the physical, social, emotional, and cultural wellbeing of individuals and their whole communities (the whole-lifeview). The holistic concept also acknowledges the greater influences of social determinants of health and wellbeing including homelessness; education; unemployment; problems resulting from intergenerational trauma; grief and loss; abuse, violence; removal from family and cultural dislocation; substance misuse; racism and discrimination and social disadvantage.

Achieving optimal outcomes in Aboriginal and Torres Strait Islander data collection and application involves addressing the social, emotional, spiritual and cultural wellbeing of the whole community.

QAIHC's view is that restricting the scope and potential effectiveness of the policy, simply by not acknowledging the Aboriginal and Torres Strait Islander concept of holistic health, will subsequently create a barrier for NHIS to achieve desired outcomes. To address this, QAIHC recommends that the other foundations are defined and adopted in close consultation with the Aboriginal and Torres Strait Islander community.

Recommendation 2: Incorporate Aboriginal and Torres Strait Islander people's concept of holistic health in the NHIS through community consultation to ensure broader social determinants of health are addressed consistently across all the principles.

### c. Comments on the lack of clarity in the principles around how data will be collected and used

QAIHC notes that the framework has not clearly explained how data will be collected and used. It is important that NHIS must clarify the measurement process and data collection activities for Aboriginal and Torres Strait Islander peoples to build a trusted and transparent environment, ensuring safety and positive intent.

QAIHC's view is that the process for collection must involve informing the public and consulting with those affected. Incorporating an Aboriginal and Torres Strait Islander data sovereignty principle will address this need. Some examples of current gaps in the proposal include:

- In the 'data are fit for purpose' section reference is made to optimising the quality and utility of data'. In addition to utility, QAIHC would recommend words like 'quantity' 'relevance' and 'accurate' are used.
- There is a need to ensure consistency in data collection across groups. For example, currently only ATSICCHOs are required to report on national Key Performance Indicators (nKPIs) resulting in an inconsistent data set being produced. There is no equivalent method of monitoring performance of non-community controlled primary health care services. Also, data from other areas such as Alcohol and Other Drugs (AoD), Mental Health (MH) and Disability services are not always captured and shared consistently across the sector.
- Privacy and confidentiality principles are also fundamental issues that are connected with
  data sovereignty. Clear legal and regulatory methods must be in place to ensure the privacy
  and confidentiality of data are managed effectively, especially personally identifiable data.
  QAIHC's view is that an individual's information must be collected, analysed, stored, or
  shared in line with the standards, rights and obligations set by the Australian Privacy
  Principles (APPs). The APPs govern the conduct of Commonwealth agencies and private
  organisations in their collection, management, use and disclosure of records containing
  personal information.<sup>9</sup>

If recommendation 1 is not, however, adopted, there is a need to specify how data will be collected and used within each principle.

Recommendation 3: Clarify how data will be collected and used to ensure data security (privacy and confidentiality; and ethical use).

### d. Comments on "The workforce is data enabled"

QAIHC recommends the NDIA considers the balance between data literacy and over-burdening staff with requirements that add layers of bureaucracy and distract from their core function when designing this principle.

Recommendation 4: Work with QAIHC to develop a standardised system to ensure data literacy requirements of the health workforce are appropriate to the roles.

<sup>&</sup>lt;sup>9</sup> Office of the Australian Information Commissioner (2018) Australian Privacy Principles <a href="https://www.oaic.gov.au/privacy-law/privacy-act/australian-privacy-principles">https://www.oaic.gov.au/privacy-law/privacy-act/australian-privacy-principles</a>

#### The Current State

9. When you look at the achievements listed in the draft Framework, are there any other essential elements of the health information system that should be listed as achievements that are starting points for future arrangements?

QAIHC notes and agrees with the listed achievements of the Australian health information system in the proposed NHIS framework. However, QAIHC notes that none of the achievements listed resonate with the Aboriginal and Torres Strait Islander peoples' health and wellbeing.

QAIHC's view is that it is important to draw attention to how data can support the achievement of the National Close the Gap targets, incorporating various essential elements such as:

- 1. Self-determination and accountability principles across all decision-making processes
- 2. Cultural safety and identity
- 3. Respect for the shared values of Aboriginal and Torres Strait Islander peoples
- 4. Acknowledgement of Aboriginal and Torres Strait Islander peoples' holistic concept of health and its important role in addressing broader social determinants of health
- 5. Respect for Aboriginal and Torres Strait Islander peoples' cultural inheritance of past, current and future generations
- 6. Health information data sovereignty.

### 10. When you look at the limitations listed in the draft Framework, are there any key limitations from a national perspective that are missing?

a. Existence of 'institutional racism' in the current Australian health care system:

Central to ensuring data is collected and used appropriately, is making sure that data management systems and processes are not unconsciously biased towards any group. QAIHC has substantial experience in working with Queensland Health to address institutional racism. QAIHC notes the NHIS framework has not incorporated institutional racism as a key limitation.

Not identifying institutional racism as a limitation raises two immediate concerns:

- a) Does the NHIS have true representation of Aboriginal and Torres Strait Islander peoples in the development of NHIS (National, State or community level), including in leadership roles?
- b) Are the existing strategies to work in partnership with Aboriginal and Torres Strait Islander peoples and ATSICCHOs sufficient to address risks of institutional racism?

Institutional racism is evident in the Australian health care system and has a profound impact on improving health and wellbeing outcomes of Aboriginal and Torres Strait Islander peoples. Institutional racism is distinctive and separate to personal racism where racist features are directly or indirectly linked with the policies, program, structures, attitudes, hierarchies, practices and perspectives of the organisation. Also, institutional racism may appear in different forms within the system. It is characterised as the absence or insufficiencies of appropriate considerations intentionally or unintentionally which leads to racial disadvantages<sup>10,11</sup>. Systemic racism greatly influences

<sup>10</sup> Australian Indigenous Doctors' Association (AIDA). Policy Statement <a href="https://www.aida.org.au/wp-content/uploads/2017/08/Racism-in-Australias-health-system-AIDA-policy-statement\_v1.pdf">https://www.aida.org.au/wp-content/uploads/2017/08/Racism-in-Australias-health-system-AIDA-policy-statement\_v1.pdf</a>

<sup>11</sup> Institutional racism in Australian healthcare: a plea for decency. Barbara R Henry, Shane Houston and Gavin H Mooney. MJA Vol 180 17 May 2004

Aboriginal and Torres Strait Islander people's access to health care as well as limits individuals from receiving the same quality of healthcare services available for non-Indigenous Australians.<sup>12</sup>.

Discussions about how institutional racism may be present within the Australian Government and health service policies and practices are essential to addressing disparities between Aboriginal and Torres Strait Islander peoples and other Australians. Such conversations must be de-stigmatised in order to objectively understand how inequalities may be unconsciously perpetuated by institutions intended to support minority groups.

#### Recommendation 5: Include institutional racism as a limitation.

#### a. Lack of consistency in data collection:

QAIHC believes that high quality and nationally consistent health data is essential to inform the development and implementation of policies for improving health and wellbeing outcomes for Aboriginal and Torres Strait Islander peoples. The lack of a coordinated national approach has created a gap in Aboriginal and Torres Strait Islander peoples' health information. This significantly impacts our ability to achieve health outcomes for Aboriginal and Torres Strait Islander peoples.

In the current Australian health care system, the lack of consistency in data collection and reporting on nKPI data between ATSICCHOs and mainstream health service providers is the example of inconsistent national approach in data collection. This is limiting data quality and comparability for some purposes. To address the issue, NHIS must ensure data consistency, mandating nKPI reporting for all health service providers across Australia and focusing on improving data literacy amongst the health workforce.

Furthermore, acknowledgment of the widespread fragmentation of data is critical for improving data quality and interoperability that can improve health service delivery. This is particularly relevant with respect to supporting an integrated continuum of care across primary and tertiary settings.

The gaps in Aboriginal and Torres Strait Islander peoples' health information data requires attention and should recognise that accurate identification of ethnicity is lower in tertiary care when compared with the ATSICCHO sector. Greater explanation about why the data may be 'insufficient' is required. For example, the issue of small data counts inhibiting analysis that may demonstrate evidence of change, or risk patient re-identification.

Recommendation 6: Recognise existing data collection inconsistencies as a limitation.

### 11. From your perspective, what are the top three key limitations that are creating barriers to successful use of health information in Australia?

The top three limitations that must be addressed in the NHIS are:

- 1. Institutional racism and the lack of transparency and ownership of data held by a few
- 2. The absence of a national strategy or framework and supporting legislation
- 3. Health workforce overburdened with unrealistic expectations

<sup>&</sup>lt;sup>12</sup> Purdie, Nola; Dudgeon, Pat; and Walker, Roz, "Working Together: Aboriginal and Torres Strait Islander Mental Health and Wellbeing Principles and Practice (First Edition)" (2010). <a href="https://research.acer.edu.au/indigenous\_education/24">https://research.acer.edu.au/indigenous\_education/24</a>

### Where do we want to be; what opportunities should we grasp?

## 12. From your perspective, what are the three key opportunities to address the limitations and barriers to successful collection, collation and use of health data and information in Australia?

The three opportunities that must be addressed in the NHIS are:

- 1. Governance of national health information: Accountability, governance, data security and quality assurance processes
- 2. Health workforce is data-enabled and there are the IT systems to support it
- 3. Aboriginal and Torres Strait Islander peoples' inclusion in all leadership and governance in collection, use and management of data.

# 13. Are there key health questions about health outcomes for Australians and/or Australia's health system more generally that cannot currently be answered because of current health information limitations? What is needed to answer them?

#### Key health question 1

How can we measure, record and respond to the interplay that the social determinants of health have on health and wellbeing outcomes for Aboriginal and Torres Strait Islander peoples?

**What is needed:** Consensus and standardisation of clinical indicators that can be accessed by all stakeholders across jurisdictions.

### Key health question 2

What is the burden of disease for intentional self-harm, and how can this data be used to guide suicide prevention activities?

**What is needed:** Standardisation of self-harm clinical data collection practices, with a focus on interoperability across services and ethical surveillance for suicide prevention purposes.

### 14. When you look at the opportunities listed in the draft Framework, are there any missing?

QAIHC notes that the 'Health information infrastructure is agile and innovative' section requires inclusion of the ATSICCHO sector in the development of data dictionaries to enable greater interoperability.

The absence of the ATSICCHO sector's involvement in 'The data support improvements in Aboriginal and Torres Strait Islander peoples' health' section is remiss and must be addressed.

### How to make this happen - Priority areas for investment and implementation steps:

### 15. When you look at the priority areas for investment/implementation listed in the draft Framework, are there any missing?

Yes, the following priority areas are missing:

- 1. "Governance of national health information: bullet 4" needs to include recognition of the need for a level of accountability of the ethics process so that the intent behind ethical decision making is monitored and followed.
- 2. "A trusted and transparent environment: bullet 3" (My Health Record) currently the primary use of My Health Record has not been achieved and the sector is not ready for secondary use rollout. Prioritised focus is needed to develop an efficient system and structure for effective primary use of My Health Record data which will subsequently support the secondary use of My Health Record data.
- 3. "Data are used to drive better services and better health outcomes" There is a need to embed a culture of change within the system for the development of a sustainable data governance and management practice to inform best practice and knowledge translation.
- 4. "Data supports improvements in Aboriginal and Torres Strait Islander peoples' health" we recommend this title is changed (see Q1). With that change, there is a need to recognise the input of cultural wisdom in epidemiology. An active engagement strategy is required to ensure that communities can access and understand how their data is being used, which is valued and implemented through the strategy. The importance of cultural determinants, connection to culture and country and cultural safety shouldn't just be underpinning the data, it should be underpinning the ways that data is captured and used. This prioritisation of culture within data collection and methods needs to be wider than just health services.

#### 16. What are your top three priorities for investment and implementation?

The top three priorities for investment and implementation are as follow:

- 1. Aboriginal and Torres Strait Islander people's data sovereignty and governance
- 2. A trusted and transparent/secure environment which is culturally safe
- 3. The health workforce is data-enabled

### **Summary:**

### 17. When you look at the suggested approach to governance of health information in the draft Framework is there anything missing or wrong

QAIHC acknowledge that AHMAC has tasked, via its Health Services Principal Committee and the AIHW, an Independent Expert Panel to oversee development of a NHIS. However, QAIHC's experience is that more proactive direction is required; and the strategy must focus on developing a mechanism that ensures:

- 1. Aboriginal and Torres Strait Islander people's data sovereignty, governance and selfdetermination. This should be enacted through Aboriginal and Torres Strait Islander involvement at all levels of the strategy's development.
- 2. Data security, privacy and confidentiality
- 3. Ethical collection and use of data
- 4. Consistency in data collection and reporting
- 5. Aboriginal and Torres Strait Islander peoples' specific data are collected in line with Closing The Gap (CTG) targets.
- 6. Aboriginal and Torres Strait Islander peoples' concept of holistic health is applied
- 7. Broader social determinants of Aboriginal and Torres Strait Islander peoples' health are incorporated
- 8. Cultural safety: QAIHC's view is that cultural safety is about respecting the cultural rights, values, beliefs and expectations of Aboriginal and Torres Strait Islander peoples while handling (collecting and using) information related to their health and wellbeing. Cultural safety must be a key principle of the NHIS.
- 9. Risk mitigation: QAIHC's view is that to ensure risk of mishandling of health information, the AIHW Independent Expert Panel must develop a 'Risk Management Plan'.

### 18. Are you aware of other strategies for health information in Australia or elsewhere that could inform this strategy?

QAIHC's recommend that the NHIS should align with the Closing the Gap targets set for Aboriginal and Torres Strait Islander peoples health and wellbeing. We believe that the following key documents could inform the NHIS to ensure delivery of an efficient national health information system:

- 1. National Aboriginal and Torres Strait Islander Health Plan 2013-23
- 2. The Closing the Gap targets (refreshed)
- 3. Aboriginal and Torres Strait Islander health and cultural safety strategy 2020-2025
- 4. Canadian Government: Canadian Institutes of Health Research, <u>Health Research Data:</u> Strategies and policies
- 5. Health Information Strategy for New Zealand 2005
- 6. WA Health Information Management Strategy 2017-21
- 7. The Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities (NHMRC, 2018) and the AIATSIS Guidelines for Ethical Research in Indigenous Research (2012).

### 19.Do you have 1-2 high profile examples where data has made a clear contribution to a successful health outcome that you are willing to share?

#### **Example 1. Rheumatic Heart Disease (RHD)**

Enhancements to Queensland Health's 'The Viewer' (Version release 7.1.1) have increased visibility for clinicians regarding medication management for patients. The Viewer now shows the RHD prophylaxis record from the Queensland RHD Register on *Medications tab* (RHD Prophylaxis) and on *Patient tab* (Problem list). When a new RHD record is added to the Viewer, it will create a *Problem record* that can be viewed to help clinicians manage the monthly medication regime for their patients. ATSICCHO clinicians are not able to edit this information, however, the enhancements represent one system improvement that has the potential to aid the clinical care of Aboriginal and Torres Strait Islander patients of HHSs and ATSICCHOs. To effect more positive change that is needed to make significant and systemic change, further enhancements are required to create interoperability across systems that are built on reciprocity. For example, automated reporting and notification of RHD medication needs across all health services.

### 20. Do you have any further suggestions or comments?

QAIHC would like to reiterate the fact that Aboriginal and Torres Strait Islander peoples must have the ability to develop and deliver strategies and programs affecting them to ensure Aboriginal and Torres Strait Islander peoples' right to self-determination. This can be achieved through creating opportunities of a real and active involvement of Aboriginal and Torres Strait Islander peoples at every level of decision-making. For this reason, QAIHC recommends that the Independent Expert Panel appoint a representative from the ATSICCHO sector to lead the development of the NHIS. To achieve this NHIS Independent Expert Panel and AIHW should work collaboratively with the national peak body the National Aboriginal Community Controlled Health Organisation (NACCHO) and collaborate on actions.



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