

**QAIHC SUBMISSION TO THE
Australian Bureau of Statistics**

SUBMISSION

**National Aboriginal and Torres Strait
Islander Health Survey**

March 2021



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QAIHC SUBMISSION TO THE AUSTRALIAN BUREAU OF STATISTICS

SUBMISSION

National Aboriginal and Torres Strait Islander Health Survey

About the Queensland Aboriginal and Islander Health Council (QAIHC)

The Queensland Aboriginal and Islander Health Council (QAIHC) was established in 1990 by dedicated and committed Aboriginal and Torres Strait Islander leaders within the community-controlled health Sector (the Sector). From our first meeting 30 years ago, we have grown to become a national leader in Aboriginal and Torres Strait Islander health, and as a voice for our 26 members, the Aboriginal and Torres Strait Islander Community Controlled Health Organisations (ATSICCHOs) in Queensland, two regional bodies and 14 Affiliate Members.

Like our ATSICCHOs, we embody self-determination; we are governed by an Aboriginal and Torres Strait Islander board that is elected by our Members.

QAIHC Members work tirelessly to provide culturally appropriate, comprehensive, primary health care services to local Aboriginal and Torres Strait Islander communities in Queensland. Collectively they have established more than 60 clinics across the state to service the population. Our two regional bodies – The Institute for Urban Indigenous Health (IUIH) and Northern Aboriginal and Torres Strait Islander Health Alliance (NATSIHA) also provide support to our Members.

Our Members provide more than just holistic Primary Health Care models, they help the whole community and regional economies by encouraging whole of community wellbeing, thus creating local jobs and ensuring local design of services.

Nationally, we represent ATSICCHOs through our affiliation and membership on the board of the National Aboriginal Community Controlled Health Organisation (NACCHO) and are regarded as an expert in our field.

QAIHC, as the peak of ATSICCHO's in Queensland, wishes to express the collective views on behalf of our Members on the National Aboriginal and Torres Strait Islander Health Survey.

The purpose of this submission is to ensure the National Aboriginal and Torres Strait Islander Health Survey is designed to meet the cultural and health and wellbeing needs of Aboriginal and Torres Strait Islander peoples. QAIHC would like to thank the Australian Bureau of Statistics for the opportunity to provide feedback on the upcoming National Aboriginal and Torres Strait Islander Health Survey.

QAIHC CONTACT REGARDING THIS SUBMISSION:

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SECTION A: About you

1. Can you please provide your name?

The Queensland Aboriginal and Islander Health Council (QAIHC)

2. Are you Aboriginal and/or Torres Strait Islander?

- Yes
- No
- The peak body representing the Aboriginal and Torres Strait Islander Community Controlled Health Organisation (ATSICCHO) sector

3. Which State or Territory do you live in, or if you work for an organisation, where is it based?

- NSW VIC QLD WA SA TM
- ACT NT Outside Australia- provide location:

4. What do you think are the key emerging health issues facing Aboriginal and Torres Strait Islander people today?

- Mental health and social emotional wellbeing
- Suicide
- Chronic disease (obesity, cancer, diabetes, Cardio Vascular Disease)
- Smoking
- Renal health issues
- Oral health issues
- Rheumatic Heart Disease
- Youth health
- Hearing health
- Alcohol and other Drugs
- Sexual health
- Injuries

5. What, if any, are your most important data or information needs, including what is currently not available? Please rate the list of topics (including any additions you identify) by level of importance as part of a data collection. 1 = High importance through to 5 = Low importance.

	1	2	3	4	5
Health status (eg. self-assessed health)	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Health conditions (eg. asthma, kidney disease etc)	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Health-related actions (eg. seeing a GP or Health Worker)	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physical measures (eg. height, weight, blood pressure)	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Health risk factors (eg. overweight, smoking etc)	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nutrition (eg. diet)	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physical activity	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social topics (eg. education, employment, income, cultural identity etc)	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Closing the Gap and other government reporting	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Other (please use the box below)

QAIHC recommend the National Closing the Gap Agreement priority reforms *and* targets are included.

QAIHC also recommend the need for data collection and reporting across specific and agreed age brackets (life stages), to ensure consistency of data use and ability to address age specific health issues.

6. Do you have any other comments on the survey topics?

The survey topics included are important, however there are some deficits in the context. For example, to evaluate nutrition, the survey asks about servings of vegetables consumed per day etc., but it does not query whether people feel they have access to vegetables. Likewise, for attending health providers, particularly oral health providers, it does not query the reason behind not attending the service. QAIHC feels that this one-dimensional data can mis-lead policy design. Additionally, collecting incomplete data is not useful from research and data management perspectives.

The survey has not included topics such as access to aged care, palliative care, and the NDIS services. QAIHC's view is that all these topics should be included and queried.

QAIHC notes that mental Health and behavioural disorders are covered under one topic. We recommend they should be separated in two different topics (they have traditionally reported on depression, anxiety and 'other behaviour and emotional disorders'). If data are collected as per the existing survey, it will not provide an indication of the prevalence of Autism specifically, or for other behavioural disorders such as Attention Deficit Hyperactivity Disorder (ADHD).

Furthermore, collection of more culturally relevant data related to mental health should be included. Reporting the prevalence of anxiety and depression will not be beneficial if data is based on the significant numbers of false negatives. Evidence shows that depression is often being missed because of how it is defined. For example, the *Getting it Right* investigators identified seven key features of depression in Indigenous men that were not covered by the PHQ-9: anger, weakened spirit, homesickness, irritability, excessive worry, rumination, and drug and alcohol use. This finding has raised the need to re-conceptualise the depression diagnosis, moving beyond the traditional core features of depressed mood or anhedonia as defined for Western populations.

7. Which other topics would you like to give feedback on?

- Biomedical Collection
- Data Integration
- Both

BIOMEDICAL COLLECTION:

16. How important is it for Aboriginal and Torres Strait Islander people to participate in a voluntary biomedical collection as part of the health survey? Why?

- Extremely important
- Very important
- Somewhat important
- Not so important
- Not at all important

QAIHC recognise the value of Aboriginal and Torres Strait Islander peoples' participation in a voluntary biomedical collection however, we have concern regarding the collection, storage and analysis of the samples with respect to ensuring peoples' privacy and confidentiality are protected. QAIHC recommends that the biomedical collection must focus on ensuring data sovereignty and governance for Aboriginal and Torres Strait Islander peoples.

17. What potential benefits or risks are there to Aboriginal and Torres Strait Islander peoples from analysis of biomedical data?

Benefit: Increased understanding and accessibility to evidence of health issues, to inform decision making, policy development and resourcing.

Risk: Privacy and confidentiality including safe handling of the samples.

18. Please select the tests you think should be included? (Tests conducted in 2012-13 are listed in the attached document, for information)

- Cardiovascular Disease tests - Cholesterol, Triglyceride, HDL, LDL, ApoB
- Diabetes - Glucose, hbA1c
- Kidney Disease - Albumin, eGFR, Creatinine
- Liver Function - ALT, GGT
- Nutrition - Folate, B12, Sodium, Potassium, Vitamin D, Iodine, Iron
- Environmental hazards exposure tests (eg PFAS - fire retardant chemical)
- Other, please suggest any other tests or add comments about the above tests

Rheumatic Heart Disease

19. What ethics, consent or governance processes are needed for a survey, including a biomedical collection, to occur in a culturally appropriate way?

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 considered as a key principle.

Privacy and confidentiality principles are also fundamental issues that are connected to data sovereignty. Clear legal and regulatory methods must be in place to ensure the privacy and confidentiality of data are managed effectively, especially biomedical samples. QAIHC's view is that an individual's biomedical sample must be collected, analysed and stored; and report is shared in line with the ethical standards set by the National Statement on Ethical Conduct in Human Research.

Furthermore, Aboriginal and Torres Strait Islander researchers have advocated that decisions about these processes should be informed by prior research and must consider Strong and ongoing community engagement is paramount:

1. Plan for a lengthy engagement, informed consent and recruitment process;
2. Borrow on the strengths of Indigenous understandings of the basic principles of genetics and genetic research, and their enthusiasm to learn more;
3. Aboriginal leadership should be visible across every line. Consider forming an Aboriginal Governance Committee (AGC) with the right to veto;
4. Ensure clear, regular and, ideally, face-to-face communication among the multidisciplinary team.

(Lessons learned in genetic research with Indigenous Australian participants. Steven YC Tong, Heather D'Antoine, Melita McKinnon, Kyle Turner, Maui Hudson, Ngjare Brown, Jonathan R Carapetis and Dawn C Bessarab Med J Aust 2020; 212 (5): 200-202.e1. || doi: 10.5694/mja2.50499)

20. How important is it for children to be included in the collection of biomedical samples (blood or urine or saliva) for testing? Why?

- Extremely important
- Very important
- Somewhat important
- Not so important
- Not at all important

It is important that children be included in the collection of biomedical samples because the results can inform the policy and decision-making processes. Sampling an early developmental stage of life will enable the identification of potential health risk factors which could influence policy design, enabling those risk factors to be addressed early.

21. Should sample storage under appropriate governance be considered, to allow for future tests? Please provide your reason.

Yes

No

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*”.

For this reason, QAIHC's recommendation is that sample storage should consider appropriate governance mechanisms led by Aboriginal and Torres Strait Islander experts to ensure Aboriginal and Torres Strait Islander peoples' sovereignty.

22. Should consent for sample storage allow an option for genomic testing, under appropriate governance? Please provide your reason.

Yes

No

Genetic testing does have value, however QAIHC suggests at this early stage there is a greater need of raising community awareness/understanding and acceptance about genomic testing before starting using biomedical samples for the purpose. If genetic testing is incorporated, is paramount that consideration is given to any cultural concerns around the storage and disposal of genetic samples, especially if the individual is deceased.

23. Do you have any other comments on biomedical collection?

Yes

No

DATA INTEGRATION:

24. If the National Aboriginal and Torres Strait Islander Health Survey (NATSIHS) data was integrated with the Multi Agency Data Integration Project (MADIP), how useful is it likely to be for you, your community or work? Why?

- Extremely important
- Very important
- Somewhat important
- Not so important
- Not at all important

In QAIHC's view, data quality is key to efficient data integration and its ongoing utility.

25. Do you have any concerns about NATSIHS data being integrated with the MADIP? Please elaborate on any concerns you have.

- No concerns
- A little concerned
- Very concerned

Other (please use the box below)

QAIHC's concern is that data integration must maintain Aboriginal and Torres Strait Islander peoples' data sovereignty through safe handling of data. A rigorous process must be established to de-identify individuals to protect privacy and confidentiality. The ABS must implement data governance procedures effectively to ensure data are protected and used lawfully.

26. What potential benefits are there to Aboriginal and Torres Strait Islander peoples from the integration of data?

Data integration will support researchers and policy makers to better understand relationships between health and the socio-economic determinants of health. Understanding these relationships is important when developing policies to improve the health and wellbeing outcomes of Aboriginal and Torres Strait Islander peoples.

27. Do you have any topics that you think would be important to research? Please provide your reason.

Yes

No

N/A

28. Could data integration help with data gaps that you are aware of? Please provide your reason.

Yes

No

N/A

29. Do you have any other comments on data integration?

No



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