

Measuring what counts in Aboriginal and Torres Strait Islander care: a review of general practice datasets available for assessing chronic disease care

Liam McBride Kelly^A , Deborah Wong^{B,*}  and Andrea Timothy^C 

For full list of author affiliations and declarations see end of paper

***Correspondence to:**

Deborah Wong
Yardhura Walani, National Centre for
Epidemiology and Population Health,
Australian National University, Canberra
ACT 2601, Australia
Email: yardhurawalani@anu.edu.au

Received: 3 November 2023

Accepted: 13 June 2024

Published: 9 July 2024

Cite this: McBride Kelly L *et al.* (2024) Measuring what counts in Aboriginal and Torres Strait Islander care: a review of general practice datasets available for assessing chronic disease care. *Australian Journal of Primary Health* **30**, PY24017. doi:10.1071/PY24017

© 2024 The Author(s) (or their employer(s)). Published by CSIRO Publishing on behalf of La Trobe University.

This is an open access article distributed under the Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International License ([CC BY-NC-ND](https://creativecommons.org/licenses/by-nc-nd/4.0/)).

OPEN ACCESS

ABSTRACT

Background. Large datasets exist in Australia that make de-identified primary healthcare data extracted from clinical information systems available for research use. This study reviews these datasets for their capacity to provide insight into chronic disease care for Aboriginal and Torres Strait Islander peoples, and the extent to which the principles of Indigenous Data Sovereignty are reflected in data collection and governance arrangements. **Methods.** Datasets were included if they collect primary healthcare clinical information system data, collect data nationally, and capture Aboriginal and Torres Strait Islander peoples. We searched PubMed and the public Internet for data providers meeting the inclusion criteria. We developed a framework to assess data providers across domains, including representativeness, usability, data quality, adherence with Indigenous Data Sovereignty and their capacity to provide insights into chronic disease. Datasets were assessed against the framework based on email interviews and publicly available information. **Results.** We identified seven datasets. Only two datasets reported on chronic disease, collected data nationally and captured a substantial number of Aboriginal and Torres Strait Islander patients. No dataset was identified that captured a significant number of both mainstream general practice clinics and Aboriginal Community Controlled Health Organisations. **Conclusions.** It is critical that more accurate, comprehensive and culturally meaningful Aboriginal and Torres Strait Islander healthcare data are collected. These improvements must be guided by the principles of Indigenous Data Sovereignty and Governance. Validated and appropriate chronic disease indicators for Aboriginal and Torres Strait Islander peoples must be developed, including indicators of social and cultural determinants of health.

Keywords: Aboriginal and Torres Strait Islander health, big data, chronic disease, clinical information system, electronic medical record, general practice, Indigenous Data Sovereignty, Indigenous health, primary health care.

Introduction

There has been significant success in reducing the fatal burden of disease among Aboriginal and Torres Strait Islander peoples (Australian Institute of Health and Welfare 2022). However, Aboriginal and Torres Strait Islander peoples still experience high rates of chronic disease (Australian Indigenous HealthInfoNet 2024).

There are many sources of population health data reporting on Aboriginal and Torres Strait Islander peoples, including surveys, registries and indicators derived from health system data (Doran *et al.* 2020). Notably, national longitudinal surveys, such as the Mayi Kuwayu Study (Jones *et al.* 2018) and the Longitudinal Study of Indigenous Children (Department of Social Services 2020), provide important information about the relationship between culture, socioeconomic circumstances and wellbeing. However, self-reported surveys are inherently limited in their ability to provide granular insights into how health care is delivered for Aboriginal and Torres Strait Islander peoples. Datasets derived from clinical information systems (CISs) have an important role in filling this gap.

Despite significant improvements being made, chronic diseases, such as cardiovascular disease (CVD), chronic kidney disease and diabetes, are still responsible for much of the morbidity and mortality seen among Aboriginal and Torres Strait Islander peoples (Australian Indigenous HealthInfoNet 2024). Most chronic disease is diagnosed and managed in primary care contexts. As such, access to high-quality primary healthcare data is critical for undertaking quality improvement, service planning and generating evidence-based policy regarding chronic disease. Significant gaps still exist in terms of the indicators of chronic disease screening, assessment and management that are validated and reported nationally. For example, CVD is the leading contributor to the burden of chronic disease among Aboriginal and Torres Strait Islander peoples (Australian Indigenous HealthInfoNet 2024), and yet the national Key Performance Indicators provide only two indicators related to CVD, and no indicator of appropriate CVD management (Australian Institute of Health and Welfare 2020).

Large amounts of data are collected about Aboriginal and Torres Strait Islander peoples, but it is often unclear how these data are being used to improve health. In Australia, several large datasets make de-identified primary healthcare data extracted from CISs available for research. These datasets take several forms, including datasets of de-identified patient-level data and centrally held service-level datasets reporting on pre-defined indicators. Patient-level datasets are typically either held centrally by a data custodian (centrally held datasets), or in a distributed fashion by health services and extracted on demand (distributed datasets).

There have long been difficulties accessing healthcare data in Australia (Productivity Commission 2017; Youens *et al.* 2020). The fragmented nature of Australian primary health networks and constrained funding for data management restricts the utility of primary healthcare data for research. Australian data collection arrangements have been criticised for failing to collect adequate patient-level primary healthcare data (Australian Institute of Health and Welfare 2018), and data are often underutilised (Productivity Commission 2017). CIS data are collected primarily for clinical documentation, not research, necessitating robust validation of derived indicators. There are unique difficulties in using these datasets to report on Aboriginal and Torres Strait Islander health care. Some datasets do not adequately record Aboriginal and Torres Strait Islander status (Australian Institute of Health and Welfare 2010) or appropriate indicators of social and cultural determinants of health. This typically reflects a failure to record such data in a readily extractable format.

In Australia, most systematically collected data do not reflect Aboriginal and Torres Strait Islander worldviews or needs. Collected data overwhelmingly reflect a deficits discourse characterised by '5D Data': data that focuses on difference, disparity, dysfunction, disadvantage and deprivation (Walter 2016). The Maïam nayri Wingara Indigenous Data Sovereignty Collective have produced principles addressing

this issue (Maïam nayri Wingara Indigenous Data Sovereignty Collective and Australian Indigenous Governance Institute 2018). It is held that Aboriginal and Torres Strait Islander peoples have a right to Indigenous Data Sovereignty (ID-SOV); that is, a right for 'Indigenous peoples to exercise ownership over Indigenous Data' (Maïam nayri Wingara Indigenous Data Sovereignty Collective and Australian Indigenous Governance Institute 2018). ID-SOV is enacted through Indigenous Data Governance (ID-GOV), a right to 'decide what, how and why Indigenous Data are collected, accessed and used' (Maïam nayri Wingara Indigenous Data Sovereignty Collective and Australian Indigenous Governance Institute 2018). ID-GOV requires that the data ecosystem is controlled by Aboriginal and Torres Strait Islander peoples, that data respect individual and collective interests, are contextualised and disaggregated, are accessible, and empower self-determination (Maïam nayri Wingara Indigenous Data Sovereignty Collective and Australian Indigenous Governance Institute 2018). The extent to which these principles are applied in primary healthcare datasets is unclear.

Prior reviews of national primary healthcare datasets have not focused on Aboriginal and Torres Strait Islander peoples (Canaway *et al.* 2022). Reviews of Aboriginal and Torres Strait Islander health data have not focused on primary care datasets extracted from CISs (Doran *et al.* 2020). Here, we assess all key national primary healthcare datasets for their potential to provide insights into chronic disease care among Aboriginal and Torres Strait Islander peoples, and for their utility in directing quality improvement and service planning. A non-peer-reviewed unpublished report of this study was initially produced for the Australian Government Department of Health (McBride Kelly *et al.* 2021).

Methods

Consultation with Aboriginal and Torres Strait Islander peoples

This work is part of a broader program aiming to develop and implement a contemporary, integrated chronic disease risk assessment approach for Aboriginal and Torres Strait Islander peoples. Given our commitment to collaborative research informed by the needs and priorities of Aboriginal and Torres Strait Islander communities, a process of ongoing consultation with Aboriginal and Torres Strait Islander peoples was undertaken throughout this project. Input was sought at all stages of the project from Thiitu Tharrmay, the Aboriginal and Torres Strait Islander Research reference group, National Centre for Aboriginal and Torres Strait Islander Wellbeing Research. Thiitu Tharrmay members are Aboriginal and Torres Strait Islander researchers, consumers or providers of health care. An interim version of our findings was presented to the First Nations Health Division of the Australian Government Department of Health, with

feedback elicited and acted upon. Findings were provided for circulation to state and territory peak Aboriginal Community Controlled Health Organisations.

Identification of datasets

Datasets were identified by a comprehensive search of PubMed and Google in November 2020, and by personal correspondence with staff of the National Centre for Epidemiology and Population Health (Australian National University, Canberra). Search terms included: 'clinical information system', 'electronic medical record', 'electronic health record', 'personal health record'; 'primary healthcare', 'primary health care', 'general practice' and 'research data'. Datasets were included in our analysis if they collect primary healthcare CIS data, collect data nationally within Australia, and capture data for Aboriginal and Torres Strait Islander peoples.

Development of dataset assessment framework

A framework was developed to evaluate datasets for their usefulness for quality improvement, and capacity to provide indicators related to chronic disease assessment and management. A rapid scoping review of frameworks designed to evaluate datasets and indicators was undertaken. Two relevant existing frameworks were identified: the Updated

Guidelines for Evaluating Public Health Surveillance Systems (German *et al.* 2001) and the Information Quality Framework (Canadian Institute for Health Information 2017). These resources were used to develop a dataset assessment framework (Table 1).

Our assessment of adherence to ID-SOV principles was based on the communique produced at the 2018 Indigenous Data Sovereignty Summit (Maia *nayri* Wingara Indigenous Data Sovereignty Collective and Australian Indigenous Governance Institute 2018). In the late stages of preparation of this manuscript, a further communique was produced at the 2023 Indigenous Data Sovereignty Summit (Maia *nayri* Wingara Indigenous Data Sovereignty Collective *et al.* 2023).

Assessment of datasets

Identified datasets were assessed against the assessment framework based on information published on the websites of dataset providers, or in academic literature. Where required, additional information was obtained by email interviews undertaken between May and November 2021. Informed consent was obtained prior to all interviews. All participants were de-identified with a random pseudonym to maximise participation. A preliminary version of our review was circulated to participants for feedback.

Table 1. Evaluation of identified datasets against assessment framework.

	D1	D2	D3	D4	D5	D7
Representativeness						
Substantial number of Aboriginal and Torres Strait Islander patients captured	✓	?	✓	✓	×	✓
Data collected across all states and territories	✓	×	×	×	×	✓
Data collected across various health services (mainstream services, Aboriginal Community Controlled Health Organisations)	×	×	×	×	×	×
Insights into chronic disease						
Dataset includes indicators relating to chronic disease	✓	✓	×	✓	✓	✓
The dataset is able to provide insights into social and cultural determinants of health	×	✓	×	✓	×	✓
Timeliness						
Dataset is current and holds records for at least the past 5 years	✓	×	✓	✓	✓	✓
Usability						
The process of accessing data for research purposes is clearly laid out and publicly published	×	×	×	✓	✓	✓
Information about the dataset and/or the data dictionary is easily accessible	✓	×	✓	×	✓	✓
Information on how to use the data is available and/or training is provided for data users	×	✓	×	×	✓	✓
Data quality						
Completeness of Aboriginal and Torres Strait Islander status data	✓	?	✓	✓	×	✓
Aboriginal and Torres Strait Islander status data is recorded in compliance with best practice guidelines	✓	✓	✓	✓	✓	✓
Adaptability						
Adaptations can be made to dataset, data collection processes and indicators captured for future research	×	✓	✓	✓	✓	✓
Indigenous Data Sovereignty						
Dataset adheres to Indigenous Data Sovereignty and Governance protocols and principles	×	×	✓	×	×	×

Datasets are scored as satisfied (✓), unsatisfied (×) or unable to assess (?) against each criterion.

All datasets were also assessed for their capacity to report on the screening, disease control monitoring and management of CVD. CVD was selected for this analysis, as it is the leading contributor to the burden of chronic disease among Aboriginal and Torres Strait Islander peoples (Australian Indigenous HealthInfoNet 2024).

Ethics

The study was approved by the Australian National University Human Research Ethics Committee (Protocol Number: 2020/618). Consent was obtained from all participants.

Results

Seven datasets were identified (D1–D7), and all data providers consented to interview. Following their consideration of our preliminary review, D6 asked to be excluded from this study. D7 did not respond to our interview request, but later provided detailed feedback on the preliminary report. Of the six datasets analysed, four provide centrally held de-identified patient-level data (D3, D4, D5 and D7), one provides distributed de-identified patient-level data (D2) and one provides service-level indicators (D1). As D2 is not a data custodian, some criteria could not be assessed, as this would require interrogation of the underlying patient records. Table 1 provides a summary of the assessment of the datasets, and Table 2 provides a summary of the indicators available from each dataset reporting on CVD.

Representativeness

Most datasets capture a significant number of Aboriginal and Torres Strait Islander peoples. Notably, D1 captures approximately 100% of Aboriginal and Torres Strait Islander peoples in the Northern Territory, and between 23% and 43% in other states and territories. D5 captured the lowest proportion of Aboriginal and Torres Strait Islander peoples, with just 1.64% of patients in the dataset identified as Aboriginal and/or Torres Strait Islander.

Table 2. Availability of indicators from each dataset for the screening, disease control monitoring and management of cardiovascular disease.

Dataset	Cardiovascular disease		
	Screening	Disease control monitoring	Management
D1	✓	×	×
D2	✓	✓	✓
D3	×	×	×
D4	✓	✓	✓
D5	✓	✓	✓
D7	✓	✓	✓

Datasets are scored as having the ability to report relevant indicators (✓), or not capturing the required data to generate relevant indicators (×).

All datasets had excellent coverage of either mainstream general practice (GP) clinics (D2, D4, D5, D7) or Aboriginal Community Controlled Health Organisations (D1, D3), but no dataset had substantial coverage of both. Only D1 and D7 collected substantial data across all states and territories. D2 was unable to comment on the number of Aboriginal and Torres Strait Islander peoples captured due to the distributed nature of the dataset.

Insights into chronic disease care

All datasets have the potential to provide insight into chronic disease. D3 did not collect data related to chronic disease, but reported plans to consider capturing this information in the future. D1 reported on several pre-defined service-level chronic disease indicators.

D2, D4, D5 and D7 collected patient-level data on chronic diseases allowing a multitude of indicators to be created. The key limitation for these datasets is the extent to which information is entered in a readily extractable format. For example, information entered as free text in the CIS may only be extracted with the application of significant technical resources, whereas information entered in drop-down menus is more easily extractable. D5 and D7 have tools that can parse free text and generate flags for limited conditions.

No dataset captures cultural determinants of health, and only D4 captures broad social determinants of health. D2 and D7 have the capacity to include this data if captured by the CIS. An area-level socio-economic indicator is currently provided by D7. D2 has the capacity to deploy patient surveys at the point of care, which could be used to capture such data.

D2, D4, D5 and D7 all have the capability to provide indicators related to CVD screening, disease control monitoring and management. Screening indicators were typically related to the proportion of patients for whom absolute CVD risk was calculable, monitoring indicators captured the recency of measurement of key parameters, such as blood pressure, among people with known CVD, and management indicators were typically related to appropriate statin prescribing. D1 does not record the data needed to generate any disease control monitoring or management indicators related to CVD, and D3 does not capture chronic disease indicators.

Timeliness

All datasets hold records for at least the prior 5 years, except D2. Due to the distributed nature of D2, the timespan over which longitudinal records exist was not clear. All datasets are updated frequently (D1, 6 monthly; D2, daily; D3–5, weekly; D7, monthly).

Usability

The most useable datasets for third parties were D5 and D7. Both have a clear process for accessing data, a data

dictionary and training materials available. Both have implemented the Observational Medical Outcomes Partnership Common Data Model (Hripcsak *et al.* 2015), for which several training tools exist online.

D1–3 did not provide sufficient information publicly to understand how data access requests were assessed. D4 provides detailed public information on how to access data, although requests for access can take up to 12 months. D1, D3, D5 and D7 make data dictionaries readily available, D2 only provides one after researchers sign a confidentiality agreement, and D4 declined to provide one for research. D1 and D3 provide no training for researchers, D4 and D5 had limited training, whereas D2 had a full set of online training.

Data quality

All datasets complied with best practice guidelines for collecting Aboriginal and Torres Strait Islander status data (Australian Institute of Health and Welfare 2010). Most datasets had high rates of completeness of Aboriginal and Torres Strait Islander status (D1, 100%; D3, >90%; D4, 99.1%; D7, 81.1%). Notably, D5 recorded status data for just 28% of patients, and D2 was unable to provide this statistic.

Adaptability

Most datasets can be used to generate new indicators from existing data or can adapt data collection arrangements to answer new questions. The key exception is D1, who stated that adding new indicators is a 'lengthy and very expensive process'. D2, D4, D5 and D7 extract almost all information held in the CIS as de-identified patient-level data, so essentially any indicator can be generated that can be derived from CIS data. D3 extracts information about a limited set of conditions only, but have the intention to expand data collection.

D2 and D7 routinely assist researchers in the development of new indicators from existing data and can collect new patient-level data as required. D5 can significantly adapt the data collected, as they developed the program used for data extraction.

Indigenous Data Sovereignty and Governance

D3 is the only dataset assessed meeting all ID-SOV principles (Maiam nayri Wingara Indigenous Data Sovereignty Collective and Australian Indigenous Governance Institute 2018). A key goal of D3 is to assist Aboriginal and Torres Strait Islander people to undertake self-determined quality improvement of health services. The organisation responsible for the dataset has an Aboriginal and Torres Strait Islander-led governance structure, and is committed to supporting ID-SOV principles. Surveillance reports are provided to health services, and they plan to offer traineeships to Aboriginal and Torres Strait Islander peoples to facilitate self-determination.

Other datasets incompletely implement ID-SOV principles. D1 adopts a governance structure that includes Aboriginal and Torres Strait Islander health sector representatives. Both D1 and D4 regularly report data regarding Aboriginal and Torres Strait Islander patients back to services. However, D1 ties service funding to data provision.

Among the other data providers, there was little evidence of the implementation of ID-SOV principles. There was no evidence of reporting data disaggregated by Aboriginal and Torres Strait Islander status to services. We found no public information explicitly referencing ID-SOV for D2, D5 and D7. Many data providers highlighted the requirement for ethics approval to be obtained prior to accessing data; however, this is not itself sufficient to demonstrate adherence to ID-SOV principles.

Discussion

We sought to review all national primary care datasets in Australia that could be used to provide insights into chronic disease among Aboriginal and Torres Strait Islander peoples (McBride Kelly *et al.* 2021). All reviewed datasets had the potential to provide such insights. However, there is significant scope to improve the quality and usability of this information, both at the level of the data collected in primary health care and dataset governance arrangements.

The key driver for the quality of data held in primary healthcare datasets is what and how information is entered and stored in the CIS. CISs are primarily a tool for clinical documentation, not research. The lack of standardisation of CISs in Australia, absence of national standards for the representation of medical information (Youens *et al.* 2020; Canaway *et al.* 2022) and difficulties extracting information from 'free text' fields all contribute to data quality issues. Fortunately, Aboriginal and Torres Strait Islander health services often record chronic disease data in a readily extractable format (Davis *et al.* 2015).

Some datasets reported low rates of completion of Aboriginal and Torres Strait Islander status data, reflecting a failure of clinicians to record this information in a readily extractable manner. Aboriginal and Torres Strait Islander people are frequently under-identified in health records (Australian Institute of Health and Welfare 2010), and such misclassification is non-randomly distributed (Briffa *et al.* 2010; Thompson *et al.* 2012). Analysis of datasets with low rates of Aboriginal and Torres Strait Islander status completeness may be susceptible to selection bias.

Important contextual data, including social and cultural determinants of health, patient-reported outcome measures and patient-reported experience measures, are not routinely recorded by clinicians in CISs. Most health services, apart from some specialised Aboriginal and Torres Strait Islander-specific organisations, do not routinely collect data related

to social and cultural determinants of health. This is reflected in our finding that data related to social and cultural determinants of health are sparse among the datasets reviewed. Capturing this information would require significant changes to the data collected by clinicians, and changes to CISs, so that these data can be stored and extracted appropriately. Structured approaches exist for the collection of these data, but they are incompletely implemented and not currently linked to CIS data. Templates have been developed for the Aboriginal and Torres Strait Islander Peoples Health Assessment (Medicare Benefits Schedule item 715) that facilitate the collection of data related to social and cultural determinants of health (Royal Australian College of General Practitioners 2020). Similarly, the Mayi Kuwayu Study developed a detailed survey including items on culture, health and wellbeing, sociodemographic factors, and family connections, and has sought consent from participants to link responses to morbidity and mortality datasets (Jones *et al.* 2018). Further, the Australian Bureau of Statistics collects patient-reported experience measures through the annual Patient Experience Survey (Australian Bureau of Statistics 2022), as do many health services through various surveys. The incorporation of these data into CISs, and integration into primary healthcare datasets, would significantly expand opportunities for patient-centred quality improvement.

Almost all primary health datasets in Australia are not designed specifically for the needs of Aboriginal and Torres Strait Islander peoples. Only two of the datasets reviewed included a significant proportion of Aboriginal and Torres Strait Islander people, captured chronic disease data, and collected data nationally. The primary healthcare provider for 36% of Aboriginal and Torres Strait Islander peoples is an Aboriginal and Torres Strait Islander-specific health service (Australian Bureau of Statistics 2019). Despite this, no dataset was identified that captured a significant number of both mainstream GP clinics and Aboriginal Community Controlled Health Organisations, with all datasets either overrepresenting one or the other.

Multiple datasets would need to be combined to represent the whole healthcare system used by Aboriginal and Torres Strait Islander peoples. However, this is a costly and technically complex process owing to a lack of standardisation in the way that GP data is extracted, stored and represented, with most datasets having their own non-standardised coding systems. Encouragingly, two datasets (D5 and D7) implemented the Observational Medical Outcomes Partnership Common Data Model, which translates each element in the dataset into a standardised vocabulary and data schema (Hripcsak *et al.* 2015). Further standardisation of primary healthcare datasets would expand opportunities for datasets to be used in combination.

Only one dataset assessed was adherent with ID-SOV principles. The collection of the medical information of Aboriginal and Torres Strait Islander peoples into research datasets could be seen as an example of the violation of

ID-SOV (Renehan 2018). This is unsurprising given the focus on a top-down approach of imposing data collection arrangements on health services, a lack of substantial engagement with Aboriginal and Torres Strait Islander peoples (The Centre of Research Excellence in Aboriginal Chronic Disease Knowledge Translation and Exchange 2020), and limited opportunities for data to remain within the control of Aboriginal and Torres Strait Islander peoples. Data providers must act to implement ID-SOV principles, empowering Aboriginal and Torres Strait Islander peoples to exercise self-determination in this domain. Only then will collected data reflect the worldviews and visions of Aboriginal and Torres Strait Islander peoples.

There is significant scope for improving the accessibility and utility of primary healthcare datasets. Although many data custodians provide surveillance reports to health services, these reports are often not disaggregated by Aboriginal and Torres Strait Islander status. As such, the potential for quality improvement related to Aboriginal and Torres Strait Islander patients is limited. Further reporting specific to the needs of Aboriginal and Torres Strait Islander patients, and expanding dataset access would support self-determination. Indeed, healthcare services report these data are of assistance in quality improvement, funding applications and identifying gaps in service delivery (Australian Institute of Health and Welfare 2020).

This study's key strength is that interviews were undertaken with those responsible for the relevant datasets, hence providing insight into capabilities that may not be publicly available. The interim report was circulated to data providers for their review. A positive outcome of this feedback process was that one data provider welcomed suggestions on how principles of ID-SOV could be applied to their ways of working: including Aboriginal and Torres Strait Islander representation in their governance structure, and Aboriginal and Torres Strait Islander-specific reporting. One limitation of our approach is that we did not obtain access to the underlying data held in the reviewed datasets. It is likely that further dataset capabilities and limitations would become apparent with access to the underlying data, particularly limitations regarding dataset interoperability.

Conclusion

This study is the first review of the capacity of national, CIS-derived primary healthcare datasets to provide insights into the health care of Aboriginal and Torres Strait Islander peoples. It is critical that more accurate, comprehensive, and culturally meaningful Aboriginal and Torres Strait Islander healthcare data are collected. Improvement of these datasets must be led by the principles of ID-SOV, enabling public health policy to be directed by community priorities and self-determination. Key steps include developing national

policy for the implementation of ID-SOV principles in these datasets, sponsoring Indigenous traineeships in data science to ensure data remains in Indigenous hands, and developing governance structures that support ongoing health data collection and use by Aboriginal and Torres Strait Islander peoples. Further, validated and appropriate national indicators for chronic disease assessment and management among Aboriginal and Torres Strait Islander peoples should be developed, including indicators for social and cultural determinants of health. This work would be significantly supported by implementing standardised tools for capturing social and cultural determinants of health, patient-reported experience measures, and patient-reported outcome measures in CISs and GP datasets.

References

- Australian Bureau of Statistics (2019) National Aboriginal and Torres Strait Islander Health Survey, Australia, 2018–19. (Australian Bureau of Statistics: Canberra, ACT, Australia) Available at <https://www.abs.gov.au/statistics/people/aboriginal-and-torres-strait-islander-peoples/national-aboriginal-and-torres-strait-islander-health-survey/2018-19> [Verified 7 September 2023]
- Australian Bureau of Statistics (2022) Patient experiences, 2021–22 financial year. (Australian Bureau of Statistics: Canberra, ACT, Australia) Available at <https://www.abs.gov.au/statistics/health/health-services/patient-experiences/latest-release> [Verified 7 September 2023]
- Australian Indigenous HealthInfoNet (2024) Overview of Aboriginal and Torres Strait Islander health status. (Australian Indigenous HealthInfoNet: Perth, WA, Australia) Available at <https://healthinfonet.ecu.edu.au/learn/health-facts/overview-aboriginal-torres-strait-islander-health-status> [Verified 1 June 2024]
- Australian Institute of Health and Welfare (2010) National best practice guidelines for collecting Indigenous status in health data sets. (Australian Institute of Health and Welfare: Canberra, ACT, Australia) Available at <https://www.aihw.gov.au/reports/indigenous-australians/national-guidelines-collecting-health-data-sets/summary> [Verified 7 September 2023]
- Australian Institute of Health and Welfare (2018) Australia's Health 2018. (Australian Institute of Health and Welfare: Canberra, ACT, Australia) Available at <https://www.aihw.gov.au/getmedia/7c42913d-295f-4bc9-9c24-4e44eff4a04a/aihw-aus-221.pdf.aspx?inline=true> [Verified 7 September 2023]
- Australian Institute of Health and Welfare (2020) Review of the two national Indigenous specific primary health care datasets: the Online Services Report and the National Key Performance Indicators. (Australian Institute of Health and Welfare: Canberra, ACT, Australia) Available at <https://nla.gov.au/nla.obj-2497074289/view> [Verified 7 September 2023]
- Australian Institute of Health and Welfare (2022) Australian Burden of Disease Study: impact and causes of illness and death in Aboriginal and Torres Strait Islander people 2018. (Australian Institute of Health and Welfare: Canberra, ACT, Australia) Available at <https://www.aihw.gov.au/reports/burden-of-disease/illness-death-indigenous-2018/summary> [Verified 7 September 2023]
- Briffa TG, Sanfilippo FM, Hobbs MST, Ridout SC, Katzenellenbogen JM, Thompson PL, Thompson SC (2010) Under-ascertainment of Aboriginality in records of cardiovascular disease in hospital morbidity and mortality data in Western Australia: a record linkage study. *BMC Medical Research Methodology* 10, 111. doi:10.1186/1471-2288-10-111
- Canadian Institute for Health Information (2017) CIHI's information quality framework. (Canadian Institute for Health Information: Ottawa, ON Canada) Available at https://www.cihi.ca/sites/default/files/document/iqf-summary-july-26-2017-en-web_0.pdf [Verified 7 September 2023]
- Canaway R, Boyle D, Manski-Nankervis J-A, Gray K (2022) Identifying primary care datasets and perspectives on their secondary use: a survey of Australian data users and custodians. *BMC Medical Informatics and Decision Making* 22, 94. doi:10.1186/s12911-022-01830-9
- Davis S, Reeve C, Humphreys J (2015) How good are routinely collected primary healthcare data for evaluating the effectiveness of health service provision in a remote Aboriginal community? *Rural and Remote Health* 15, 2804. doi:10.22605/RRH2804
- Department of Social Services (2020) A decade of data: findings from the first 10 years of footprints in time. (Department of Social Services: Canberra, ACT, Australia) Available at https://www.dss.gov.au/sites/default/files/documents/05_2021/19667-dss-footprints-time.pdf [Verified 1 June 2024]
- Doran C, Potts B, Langham E, Begg S, Bryant J, Hardie-Boys N, Bainbridge R (2020) Evaluation of the Australian Government's Investment in Aboriginal and Torres Strait Islander Primary Health Care through the Indigenous Australians' Health Programme: quantitative data feasibility assessment. (Allen and Clarke Consulting: Melbourne, Vic, Australia) Available at https://web.archive.org/web/20220709170213/https://www.iahpyarnes.com/wp-content/uploads/2018/03/IAHP-Yarnes-DFA-Report_Final_18Jun2020.pdf [Verified 7 September 2023]
- German RR, Lee LM, Horan JM, Milstein RL, Pertowski CA, Waller MN (2001) Updated guidelines for evaluating public health surveillance systems. (Centers for Disease Control and Prevention: Atlanta, GA, USA) Available at <https://www.cdc.gov/mmwr/preview/mmwrhtml/rr5013a1.htm> [Verified 7 September 2023]
- Hripesak G, Duke JD, Shah NH, Reich CG, Huser V, Schuemie MJ, Suchard MA, Park RW, Wong ICK, Rijnbeek PR, van der Lei J, Pratt N, Noren GN, Li YC, Stang PE, Madigan D, Ryan PB (2015) Observational Health Data Sciences and Informatics (OHDSI): opportunities for observational researchers. In 'MEDINFO 2015: eHealth-enabled Health'. (Eds IN Sarkar, A Georgiou, P Mazzoncini de Azevedo Marques) pp. 574–578. (IOS Press: Amsterdam, Netherlands)
- Jones R, Thurber KA, Chapman J, D'Este C, Dunbar T, Wenitong M, Eades SJ, Strelein L, Davey M, Du W, Olsen A, Smylie JK, Banks E, Lovett R, Mayi Kuwayu Study Team (2018) Study protocol: *Our Cultures Count*, the Mayi Kuwayu Study, a national longitudinal study of Aboriginal and Torres Strait Islander wellbeing. *BMJ Open* 8, e023861. doi:10.1136/bmjopen-2018-023861
- Maiam nayri Wingara Indigenous Data Sovereignty Collective, Australian Indigenous Governance Institute (2018) Indigenous Data Sovereignty Communique. (Maiam nayri Wingara Indigenous Data Sovereignty Collective) Available at <https://www.maiamnayriwingara.org/s/Communique-Indigenous-Data-Sovereignty-Summit-x5Rk.pdf> [Verified 7 September 2023]
- Maiam nayri Wingara Indigenous Data Sovereignty Collective, Australian Indigenous Governance Institute, Lowitja Institute (2023) Indigenous Data Governance Communique. (Maiam nayri Wingara Indigenous Data Sovereignty Collective) Available at <https://www.maiamnayriwingara.org/s/Indigenous-Data-Governance-Communique-2023.pdf> [Verified 7 September 2023]
- McBride Kelly L, Timothy A, Wong D, Paige E, Douglas K, Agostino J (2021) A review of general practice datasets available for assessing coverage of chronic disease risk assessment and management for Aboriginal and Torres Strait Islander peoples. Report to the Australian Government Department of Health. National Centre for Epidemiology and Population Health, Canberra, ACT Australia.
- Productivity Commission (2017) Data availability and use: overview & recommendations. (Productivity Commission: Canberra, ACT, Australia) Available at <https://www.pc.gov.au/inquiries/completed/data-access/report/data-access-overview.pdf> [Verified 7 September 2023]
- Renehan C (2018) Indigenous Data Sovereignty Summit. (Tribal Wave Regional Alliance Mid North New South Wales: Port Macquarie, NSW, Australia) Available at https://web.archive.org/web/20200311004154/https://tribalwave.org.au/wp-content/uploads/2019/08/TWA_Aboriginal_DataSovereignty_RPT_Jul18.pdf [Verified 7 September 2023]
- Royal Australian College of General Practitioners (2020) Resources to support health checks for Aboriginal and Torres Strait Islander people. (Royal Australian College of General Practitioners: Melbourne, Vic, Australia) Available at <https://www.racgp.org.au/the-racgp/faculties/atsi/guides/2019-mbs-item-715-health-check-templates> [Verified 7 September 2023]
- The Centre of Research Excellence in Aboriginal Chronic Disease Knowledge Translation and Exchange (2020) Aboriginal Community Controlled Health Organisations in practice: sharing ways of working

- from the ACCHO sector. (South Australian Health and Medical Research Institute: Adelaide, SA, Australia) Available at https://sahmri.blob.core.windows.net/communications/ACCHO_Interactive_Resource2020.pdf [Verified 7 September 2023]
- Thompson SC, Woods JA, Katzenellenbogen JM (2012) The quality of Indigenous identification in administrative health data in Australia: insights from studies using data linkage. *BMC Medical Informatics and Decision Making* 12, 133. doi:10.1186/1472-6947-12-133
- Walter M (2016) Data politics and Indigenous representation in Australian statistics. In 'Indigenous data sovereignty: toward an agenda'. (Eds T Kukutai, J Taylor) pp. 79–97. (Australian National University Press: Canberra, ACT, Australia)
- Youens D, Moorin R, Harrison A, Varhol R, Robinson S, Brooks C, Boyd J (2020) Using general practice clinical information system data for research: the case in Australia. *International Journal of Population Data Science* 5(1), 1099. doi:10.23889/ijpds.v5i1.1099

Data availability. The de-identified data that support this study will be shared upon reasonable request to the corresponding author.

Conflicts of interest. The authors declare no conflicts of interest.

Declaration of funding. This work was supported by funding from the Australian Government Department of Health and Aged Care – First Nations Health Division. The funder had no role in the study design, data collection and analysis, decision to publish or preparation of the manuscript.

Acknowledgements. The authors thank the data providers who participated, alongside Dr Jason Agostino, Dr Ellie Paige, Professor Kirsty Douglas and Dr Rosemary Wyber.

Author affiliations

^ASchool of Medicine and Psychology, Australian National University, Canberra, ACT 2601, Australia.

^BYardhura Walani, National Centre for Epidemiology and Population Health, Australian National University, Canberra, ACT 2601, Australia.

^CCentre for Health Systems and Safety Research, Australian Institute of Health Innovation, Macquarie University, Sydney, NSW 2109, Australia.