

## **Visibility, power and equity: using Aboriginal and Torres Strait Islander data to drive equity in Australia**

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### **Abstract**

This paper arises from a presentation in the Setting the Scene session from the Royal Society of NSW and Learned Academy Forum — Reshaping Australia: Communities in Action. It describes some of the issues and challenges surrounding the collection and reporting of official data on the health and wellbeing of Aboriginal and Torres Strait Islander Peoples in Australia. It emphasizes the importance of accurate and appropriate data for policy planning and decision-making processes highlighting that despite efforts to understand and address the gaps and disparities experienced by these communities, significant challenges persist.

It describes the historical and ongoing impacts of colonisation, which have led to tensions between governments and Aboriginal and Torres Strait Islander people, and some of the effects this has on the data and reporting that pertain to them. It argues for the recognition of Aboriginal and Torres Strait Islander rights to govern their own affairs and shape their own futures. To achieve this, the voices and perspectives of Aboriginal and Torres Strait Islander communities must be respected and included in the governance structures of the nation.

The state of reporting on Aboriginal and Torres Strait Islander health and wellbeing is also discussed, noting the delayed and fragmented approach to data collection and the resulting health and wellbeing reporting. It argues the need for consistent and sustained efforts in this area to bridge the gaps and promote equity. By addressing these issues, policymakers can better understand and address the specific needs and aspirations of these communities, ultimately promoting their health, wellbeing, and self-determination.

### **Introduction**

Official data plays an imperative role in policy planning for health and wellbeing as it provides valuable insights into various aspects of society, including health, economics, and social development. It serves as a foundation for decision-making processes by offering comprehensive understandings of the needs and gaps within communities and populations. However, when it comes to Aboriginal and Torres

Strait Islander Peoples' health and wellbeing, there continues to be issues in official data collections and reporting that require consideration in order to ensure accuracy and appropriateness (Griffiths et al. 2019).

For Aboriginal and Torres Strait Islander Peoples, official data often falls short of being wholly representative. This is in part attributed to historical and ongoing impacts of colonisation whereby Australia's First Nations Peoples continue to advocate for

constitutional recognition and the right to govern their own affairs (McNicol & Haughton 2023). This requires Aboriginal and Torres Strait Islander Peoples to be heard and to have their voices recognised and respected within the governance structures of the nation. Importantly, this requires recognising the inherent rights of Aboriginal and Torres Strait Islander Peoples to govern their own affairs, determine their own priorities, and to shape their own futures. Despite significant investments in understanding the health, social, and economic gaps experienced by Aboriginal and Torres Strait Islander Peoples, disparities persist, with the gap, in many instances, getting wider (Commonwealth of Australia 2022).

Accurate and appropriate reporting of Aboriginal and Torres Strait Islander health and wellbeing is necessary for assessing progress and enabling governments to meet the citizenship rights and needs of these communities. It is a part of the government's responsibility to both identify and address ongoing disparities within society and to ensure routine reporting that reflects the current needs and priorities of Aboriginal and Torres Strait Islander Peoples and communities.

When discussing data in the context of Aboriginal and Torres Strait Islander health and wellbeing, two major points need consideration. The first is the research and reporting efforts dedicated to understanding and documenting the health and wellbeing of this population. These endeavours aim to identify the specific needs and optimize systems, services, and policies accordingly.

The second point revolves around the need for Aboriginal and Torres Strait Islander governance in national administra-

tion and research data collections. Involving and empowering Aboriginal and Torres Strait Islander communities in the collection, management, and interpretation of data concerning their health and wellbeing is critical. This ensures that data reflects Aboriginal and Torres Strait Islander perspectives, priorities, and aspirations, ultimately contributing to more accurate and relevant policy planning.

The historical and contemporary events that have shaped the experiences of Aboriginal and Torres Strait Islander Peoples also have a significant impact on data collection and governance. Recognising and addressing this impact is vital for moving towards reconciliation within Australia. By acknowledging the historical context and involving Aboriginal and Torres Strait Islander Peoples and communities in data used for official reporting, the nation can take a step forward in bridging the gaps and promoting equity for Aboriginal and Torres Strait Islander Peoples.

### **State of events with Aboriginal and Torres Strait Islander health and wellbeing reporting**

Significant investment has been made in recent years to improve our understanding of, and address, the health, social, and economic gaps experienced by Australia's First Nations Peoples. However, the historical context reveals a delayed and fragmented approach to data collection and reporting for Aboriginal and Torres Strait Islander populations.

The first regular collection of Aboriginal and Torres Strait Islander data dates back to 1957 when the Northern Territory Administration started collecting information on infant mortality (Thompson 1997, Smith

1978). However, it took another 16 years until 1973 for the Commonwealth and state and territory health ministers to endorse a policy on collecting national Aboriginal health statistics (Ring & Griffiths 2021). This delayed response reflects a lack of recognition and prioritisation of the health and wellbeing of Aboriginal and Torres Strait Islander Peoples.

Despite the 1967 referendum that recognised Aboriginal and Torres Strait Islander people in the Australian Constitution, there was still a lack of active data collections on Aboriginal and Torres Strait Islander births and deaths until the mid-1980s (Ring & Griffiths 2021). There continue to be challenges, with the under-reporting of Aboriginal and Torres Strait Islander births (Endo 2014, Gibberd et al. 2016). This not only impacts national reporting, but can, at the individual level, impact one's ability to obtain identification and further result in barriers to accessing basic services and programs. Additionally, "semi-national" Aboriginal and Torres Strait Islander deaths data continues to be provided for five of the eight Australian mainland states and territories. This has ongoing implications for measurement and particularly mortality and life expectancy estimates (Australian Bureau of Statistics 2018). This further highlights the need for issues in Aboriginal and Torres Strait Islander data and reporting to be considered and redressed.

Part of the challenge in reporting Aboriginal and Torres Strait Islander health and wellbeing has been the patchy and reactive nature of the efforts. Developments in this area have lacked consistency over time, resulting in gaps and limitations in understanding the needs and priorities

of Aboriginal and Torres Strait Islander Peoples (Ring & Griffiths 2021).

Efforts have been made to improve data collection and reporting, such as the establishment of the Joint Australian Bureau of Statistics (ABS) and the Australian Institute of Health and Welfare (AIHW) Unit, the National Centre for Aboriginal and Torres Strait Islander Statistics, in Darwin in 1996 (Thompson 1997). This unit was tasked with producing biannual publications on the health and welfare of Aboriginal and Torres Strait Islander Peoples. However, it was disbanded after only seven years, indicating a lack of sustained commitment to data collection in this area (Ring & Griffiths 2021).

In 1987, Recommendation 49 of the Royal Commission into Aboriginal Deaths in Custody (RCIADIC) called for a special national survey to be conducted, covering various social, demographic, health, and economic aspects of the Aboriginal population (Nagle & Summerrell 2002). The ABS responded to this recommendation by developing the first national Aboriginal and Torres Strait Islander survey. The purpose of the survey was to provide governments with an information base for planning and measuring progress in meeting the objectives, aspirations, and needs of Aboriginal and Torres Strait Islander Peoples.

However, limited information exists on how the initial purpose of these surveys has empowered Aboriginal and Torres Strait Islander Peoples. While various government departments, committees, and groups have incorporated a focus on Aboriginal and Torres Strait Islander data and its measurement over the years, there has been limited support for Aboriginal and Torres Strait Islander governance. This lack of involve-

ment and consultation with Aboriginal and Torres Strait Islander communities has been a recurring issue that results in a lack of policy relevant data (Kukutai & Walter 2015).

For instance, the development of the 2008 National Indigenous Reform Agreement and the initial Closing the Gap targets faced criticism for being developed without proper consultation with Aboriginal and Torres Strait Islander Peoples (Dept of Prime Minister and Cabinet 2019). There has also been criticism that the focus of these targets has been on the needs of governments rather than the priorities and aspirations of the Aboriginal and Torres Strait Islander communities (Aboriginal Medical Services Alliance Northern Territory 2018).

### **Developments in international and national Indigenous data capabilities**

The International Group for Indigenous Health Measurement has played a significant role in highlighting important considerations in data, information, and reporting pertaining to Indigenous Peoples worldwide. This group brings together Indigenous data and measurement experts from around the globe to engage in discussions with official statistics bodies, governments, and international agencies like the United Nations (UN) and the Organisation for Economic Cooperation and Development (OECD).

One of the key rights recognized for Indigenous Peoples is the right to be counted and have their values reflected in the data and information that pertains to them (United Nations General Assembly 2008). The known invisibility of Indigenous Peoples in official data collections, stemming from historical marginalisation and exclusion, had led to a call for national statistical agencies globally to improve efforts

in collecting Indigenous data and ensure the inclusion of Indigenous Peoples in official statistics (Madden et al. 2016). The discussions have also highlighted the importance of human rights in relation to the right to be counted as Indigenous Peoples and emphasized the need for high-quality information to accurately report on Indigenous populations at the international and national levels (Kukutai & Walter 2015, Madden et al. 2016, Griffiths et al. 2019).

Within the Australian context, three overarching issues have particular significance. Firstly, there is the question of who is counted, which involves considerations regarding the definitions of Aboriginal and Torres Strait Islander Peoples and how these definitions are operationalised (Griffiths et al. 2019). Australia has made progress in this area, with the development of the Commonwealth definition in 1978 and the subsequent implementation of a standard indigenous question in 1996. However, capturing the heterogeneity of indigeneity remains a challenge, as demonstrated by the significant increase in Indigenous identification during the 2016 Census, particularly on the east and south coasts (Australian Bureau of Statistics, 2023a). This increase indicates that individuals are embracing their Aboriginal and/or Torres Strait Islander identities, but it also highlights the diversity of lived realities within the Aboriginal and Torres Strait Islander population, including those who have recently identified as Aboriginal and/or Torres Strait Islander. This diversity needs to be considered when measuring outcomes, such as mortality or life expectancy estimates.

Census changes can also have an impact upon funding allocation and service provision. For example, the distribution of

Commonwealth funds to state, territory and local governments including the Goods and Services Tax (GST) entitlements is based on census counts (Australian Bureau of Statistics 2022). Any changes in Aboriginal and Torres Strait Islander identification patterns will have implications regarding where these funds go (Biddle 2014).

The second issue relates to how many people are counted and encompasses concerns about the completeness and accuracy of enumeration (Griffiths et al. 2019). National statistical agencies must address undercounts and overcounts and employ appropriate methodologies to ensure the accuracy of the data. The ABS uses post-enumeration surveys to address undercounts and overcounts in the census. Other enhancement methods such as data linkage are employed to improve Indigenous status in other datasets, such as hospitalisations and deaths data (Australian Bureau of Statistics 2023b). However, the sharing of Aboriginal and Torres Strait Islander data also raises legal and ethical considerations that require careful attention (Griffiths 2019).

The third issue pertains to what is counted and measured, involving the development of indicators and measures that encompass Aboriginal and Torres Strait Islander Peoples' states of events, values, and understandings (Griffiths, 2019). Aboriginal and Torres Strait Islander Peoples are to lead in the development of these measures. Furthermore, to enable policy relevance within colonial systems, processes that support Aboriginal and Torres Strait Islander ways of being, knowing, and doing are required to be valued. In recent years, there have been significant advancements in measuring Aboriginal and Torres Strait

Islander health and wellbeing. Projects such as the What Matters study (Howard et al. 2020) and the Mayi Kuwayu study (Jones et al. 2018), led by Aboriginal and Torres Strait Islander people, have provided culturally relevant and evidence-based approaches to better support and address the health and wellbeing of Aboriginal and Torres Strait Islander Peoples and communities. However, these initiatives currently rely on research funding rather than being fully supported as government programs, posing challenges to their continuity and sustainability.

There has been significant investment in Australia regarding whole-of-population data that impacts Aboriginal and Torres Strait Islander research and reporting. This includes the establishment of the Office of the National Data Commissioner to build and support the legislation and infrastructure for the sharing and use of official data collections (Office of the National Data Commissioner 2023). There is also a range of emerging developments and initiatives within the Australian Public Service and official statistical agencies. This includes the development of the Data and Digital Government Strategy to support insightful data-driven policies and to deliver easy, accessible and secure services for people and businesses (Australian Government 2023); the National Collaborative Research Infrastructure Strategy (Department of Education 2022); and the historical Health Services Principle Committee and the Australian Institute of Health and Welfare, National Health Information Strategy (National Rural Health Alliance 2020) to make better use of research and health data.

These advancements have an important role in enabling and implementing health equity approaches within Australia. Fur-

thermore, to ensure the rights and needs of Aboriginal and Torres Strait Islander Peoples are met, there is an explicit requirement for governments and organisations to be led and guided by Aboriginal and Torres Strait Islander Peoples regarding the collection, storage and use of Aboriginal and Torres Strait Islander Peoples' data.

### **Towards appropriate and accurate Aboriginal and Torres Strait Islander reporting**

The enduring effects of colonisation on the health and wellbeing of Aboriginal and Torres Strait Islander communities continue to reverberate throughout society, impacting both individuals and communities. These extend far beyond immediate health outcomes into the intricate dynamics between Aboriginal and Torres Strait Islander Peoples and governing bodies. To truly understand and address these impacts, it is essential to recognize and rectify the issues surrounding data collection and representation for Aboriginal and Torres Strait Islander communities.

Accurate and comprehensive data collections play a pivotal role in informing policies, resource allocation, and healthcare interventions. However, the identification of individuals, the accuracy of population counts, and the metrics used for assessment have historically been plagued by limitations and challenges in the context of Aboriginal and Torres Strait Islander communities. The complexity of Aboriginal and Torres Strait Islander identities and the diverse nature of these communities often pose difficulties when applying conventional data collection methodologies. These issues currently contribute to inaccurate and incomplete representations of the health and wellbe-

ing of Aboriginal and Torres Strait Islander Peoples.

Actively involving, consulting, and supporting Aboriginal and Torres Strait Islander communities in shaping and building data collections can also support reflective reporting that pertain to them. By doing so, data collections can align with Aboriginal and Torres Strait Islander aspirations and goals. Furthermore, Aboriginal and Torres Strait Islander priorities, knowledge systems and practices provide valuable insights into the determinants of health and holistic wellbeing. It must be acknowledged that these may not be captured adequately by the existing health measures currently reported.

By addressing the limitations of official data collection for Aboriginal and Torres Strait Islander Peoples, this will ensure more accurate and empowering representation. This requires ongoing efforts to enhance data collection methodologies, develop culturally relevant frameworks, and establish robust quality assurance mechanisms. This must also be addressed jointly with any legal or ethical issues that may arise. Collaborative partnerships between Aboriginal and Torres Strait Islander communities, researchers, policymakers, and data custodians are instrumental in co-designing data collection processes that respect Indigenous rights, privacy, and sovereignty.

Moreover, supporting the development of Indigenous data governance is vital for achieving better policy outcomes and effectively allocating resources. Indigenous data governance recognises the rights of Aboriginal and Torres Strait Islander Peoples to control and manage their data, ensuring that data collection processes are conducted ethically and in alignment with

community values (Kukutai & Taylor 2016). By empowering Aboriginal and Torres Strait Islander communities to govern their data, decision-makers can gain insights into the specific needs, strengths, and aspirations of these communities. This, in turn, enables the formulation of policies and interventions that are tailored to address the priorities and needs of Aboriginal and Torres Strait Islander Peoples, ultimately contributing to improved health, wellbeing, and self-determination.

To address these impacts comprehensively, it is critical to actively involve and support Aboriginal and Torres Strait Islander communities in shaping official data collection and reporting processes. By striving for more accurate and inclusive representation, while also supporting Indigenous data governance, we can advance policy outcomes, allocate resources more effectively, and ultimately promote the health, wellbeing, and self-determination of Aboriginal and Torres Strait Islander Peoples throughout Australia.

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