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The Time Has Come: Indigenous Peoples Worldwide Must Now Exercise Their Human Rights and Take Full Control Over Their Data Sovereignty Rights

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ABSTRACT

This article examines the ongoing exploitation of Indigenous Peoples' research data and health data, and the urgent need for Indigenous data sovereignty in Australia. Despite ethical research frameworks, Indigenous Peoples health data continues to be collected, controlled, and used by non-Indigenous institutions, limiting community access and decision-making. Ethical engagement with Indigenous health data is crucial for the success of the Closing the Gap initiatives. Strengthening Indigenous governance over health data, and ethical research practices, is essential for meaningful progress. This paper advocates for policy reforms, Indigenous-led research governance and Indigenous data sovereignty.

The exploitation and unethical use of Indigenous Peoples research data have long-standing historical foundations. For this to be recompensed the path forward calls for a profound commitment to ethical research practices and respect for Indigenous Peoples data sovereignty. The two Aboriginal academic authors have a vested interest in righting this wrong and were compelled to write this discussion paper in support of the United Nations: Expert Mechanism on the Rights of Indigenous Peoples (EMRIP) 2025 call out for inputs: to contribute to the international study on "Indigenous Peoples right to data, including data collection and disaggregation". The United Nations: Declaration on the Rights of Indigenous Peoples [1], Article 31 explicitly recognises the right of Indigenous Peoples to maintain, control, protect, and develop their cultural heritage, traditional knowledge, and intellectual property. Article 31 embodies Indigenous Peoples data sovereignty, which is not only an issue in the Indigenous Australian context, but an ongoing global concern for Indigenous Peoples worldwide.

From first contact, research involving Indigenous Australians has been unethical, dating back to the late 1700s when Sir Joseph Banks accompanied Captain Cook on his voyage. After describing native animals and plants, he observed and described the native Indigenous Peoples, the way they lived, their ceremonies, religion, and language for the curiosity of non-Indigenous audiences [2]. Indigenous communities were unaware they were objects of research, marking the beginning of unethical research practices, thereby making Indigenous Australians a vulnerable population for exploitation [3]. Similar unethical research practices continue to occur globally, with Indigenous Peoples often treated as mere data sources, not giving consent, nor do they benefit from the research being conducted. The unethical research practices by researchers that continue against Indigenous Peoples represent ongoing human rights violations. Although international frameworks like the Nuremberg Code, Helsinki Declaration (1964), and Belmont Report (1979) aimed to establish ethical research practices, they came too late to prevent the historical research exploitation of Indigenous Australians [2]. “Research” has been termed a dirty word by Indigenous Peoples; this is particularly true when research projects have been disengaged from the community's health needs [2].

Today, Indigenous Peoples experience racism worldwide which continues to be a major cause of ill health for Indigenous Peoples of all demographic groups. Scientific research of the past demonstrates the epitome of racism, where in Australia researchers measured the size of Aboriginal Peoples skulls to determine their level of Intelligence/IQ. It is estimated that there are more than 1500 artefacts of Australian Aboriginal human remains held in museums around the world [4]. These ‘human remains,’ remnants of Aboriginal Peoples bodies strongly constitute Indigenous Peoples data, which was collected by researchers in the name of research. This extremely sensitive data must be returned immediately to the Indigenous Peoples and communities from which they were stolen. It could be argued that Indigenous Peoples not being given sovereign rights over their own research data in the present day, has its origins in racist practices of the past, which continues to be a constant barrier to making meaningful progress today.

In the contemporary research context, this aligns with broader discussions on Indigenous Peoples data which encompasses all forms of information, whether written, spoken, or digitally captured, that relates to Indigenous Peoples and communities and has the potential to impact their lives [5]. A particularly important category of Indigenous Peoples data is health data, which is primarily collected by government institutions, universities, and healthcare providers. This data is vast and includes information such as historical data, demographic data, health information, hospital records, vaccination records, and research studies targeting Indigenous health issues and much more [6, 7]. A sizeable portion of this data is government statistics and administrative data about Australian Indigenous Peoples produced from the standpoint of non-Indigenous researchers. This culminates in an absence of health data to which Aboriginal and Torres Strait Islander peoples have access, to make informed decisions about their lives, communities, and health [8].

In Australian Universities and research institutions, Indigenous Peoples research data has long been recognised as belonging to the lead researcher and the research institution. This permits the researcher to pass Indigenous Peoples research data onto others and desegregate the research data for other associated research projects. To compound this, there is no accountability required from researchers to report any of their research findings to the Indigenous Peoples and communities from which the research data was taken, which needs to be urgently redressed. The time has come to challenge the unethical research practices surrounding Indigenous Peoples data usage, which have unfortunately been widespread practice in the role of our past and contemporary researchers.

It could be envisaged that if Indigenous Peoples data were given to its rightful owners, allowing them to control and build upon, they could then use this data towards addressing the Closing the Gap targets, in turn, health outcomes for all Indigenous Australians will start to improve. The Closing the Gap initiative aims to help close the gap in life expectancy between Indigenous Peoples and non-Indigenous Australians, which is currently 8.8 years for Indigenous males and 8.1 years for Indigenous females [9], and to track and improve health outcomes for Indigenous Australians [10]. Without clear policies and access frameworks, the potential for Closing the Gap health data to contribute to meaningful progress remains redundant. Priority Reform Four of the National Agreement on Closing the Gap emphasises the importance of “shared access to data and information at a regional level” [11]. Additionally, recent policy and legislative developments in Australia provide commitments to Indigenous data sovereignty known as ID-Sov [5]. Despite the government's commitment to sharing data and empowering communities, this has not translated into the intended benefits of greater data access and control for Australian Indigenous Peoples.

The vast amount of health data collected through initiatives like Closing the Gap raises several important questions regarding data ownership, access, and usage. Specifically, the locations where this data is stored, who has access to it, how long it remains stored, and who holds ownership of this information. Data is not easily accessible to the very communities it belongs to, creating a significant barrier for Indigenous Peoples seeking to understand and use their own health data for better health outcomes. Undeniably, the vast amounts of health data collected have not significantly contributed to Closing the Gap up to 2025 [10], which report significant failures towards meeting the Closing the Gap targets. Without Indigenous Peoples involvement in the governance and interpretation of their own health data, creating effective and culturally appropriate policies and interventions becomes increasingly difficult [6]. Greater transparency, accountability, and adherence to Indigenous-led data governance principles are required to ensure that these data and research inform and contribute to Indigenous Peoples health needs and promote Indigenous data sovereignty.

The *AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research* [12] and the National Health and Medical Research Council (NHMRC), *Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders* [13], ensures that research with and about Aboriginal and Torres Strait Islander peoples follows ethical protocols. With Indigenous and non-Indigenous researchers adhering to the AIATSIS Code of Ethics [12] and NHMRC [13] guidelines that promote ethical research practices, things are beginning to improve. Empowering Indigenous Peoples and communities to have control over their health data will lead to more culturally appropriate health interventions and better health outcomes [6].

For sustainable progress, more needs to be done within these agendas to include education and support for Indigenous Peoples and communities to have a full understanding of their sovereign rights to their research data, including data collection and disaggregation of data. For rapid progress to be made, the World Health Organisation focal point on Indigenous Peoples health research data needs to be developed with an expert advisory and consultation with Indigenous Peoples and communities worldwide. This expert advisory group should consist of global Indigenous Peoples representatives and key stakeholders who have a professional background specifically in Indigenous

Peoples health. The WHO needs to work in partnership with the United Nations EMRIP and the United Nations Permanent Forum on Indigenous Issues to widely disseminate information about research data policies and protocols related specifically to Indigenous Peoples and communities' data. This approach would help address historical injustices and ensure research data collection processes maintain high ethical standards.

All steps from 2025 onwards need to involve extensive community consultation with Indigenous Peoples and communities, Indigenous health organisations and programs worldwide. The Aboriginal authors of this paper are a part of a collective of millions of Indigenous Peoples voices worldwide and want research data returned to its rightful owners. This vital step needs to be taken to expedite Closing the Gap and acknowledge Indigenous Peoples data sovereignty and human rights.

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Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data that support the findings of this study are openly available in UniSC Research Bank at https://research.usc.edu.au/esploro/.

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