Dr Lynne Stuart - Indigenous Nursing Academic Consultant for the Permanent Forum of Indigenous Issues (PFII) – United Nation, New York. I am a descendant of the Mandandanji Aboriginal people of Australia. I hold a PhD in Indigenous Health, Nursing. The content of this Geneva EMRIP submission remains the view of the Indigenous Nursing Academic Consultant and Researcher – Dr Lynne Stuart.

Submission to Geneva (January 2025): Expert Mechanism on the Rights of Indigenous Peoples (EMRIP), Indigenous Peoples and Minority Section, United Nations, Human Rights, Office of the High Commissioner, Geneva, Switzerland.

Call for Inputs: Study on "Indigenous Peoples right to data, including data collection and disaggregation".

Issued By – Expert Mechanism on the Rights of Indigenous Peoples.

Deadline – 31st January 2025.

In Australia, Indigenous Peoples have suffered greatly, they stole the land, they stole the children…now the colonial lens is on stealing Indigenous Peoples research data… An Indigenous Australian Health Research Perspective by Dr Lynne Stuart

In Australia, at first contact Indigenous research commenced, Sir Joseph Banks was a botanist and patron of the natural sciences. He made his name when he took part in Captain Cook's first great voyage in the late 1700's, which included visiting Australia. After describing native animals and plants, he observed and described the native Indigenous Peoples, the

way they lived, their ceremonies, religion, and language (Smith, 2012). His work constituted a pre-ethnography of those sections of Indigenous society which he encountered (Smith, 2012). Obviously the Indigenous Peoples that Banks was researching were unaware that they were being researched over a long period of time or that personal research data surrounding their day to day lives, including cultural practices, sacred ceremonies, and languages, were being documented for the curiosity of non – Indigenous peoples. This was the beginning of unethical research practices in Australia, where non-Indigenous researchers, carried out research on Indigenous Peoples, and if they were mere objects. "Research" has been termed a dirty word by Indigenous Peoples; this is particularly true when research projects have been disengaged from the community's needs (Smith, 2012).

Undeniably, research carried out in the past with Indigenous Peoples of Australia has been mostly unethical. There were no ethical research guidelines then as there are today. Research practices of the past makes Indigenous Australians a vulnerable, marginalised group when it comes to research processes (Liamputtong, 2013). In Australian Universities and research institutions, Indigenous Peoples research data has long been recognised as belonging to the lead researcher. This allows the researcher to pass Indigenous Peoples research data onto others and desegregate the research data for other associated research projects for many years to come. There is no accountability required from the researcher to report if their research findings have contributed to improving the lives and health outcomes of Australian Indigenous Peoples and communities from whom the research data was taken.

In history, the Nuremburg Code – was an attempt to ensure that research carried out by the Nazi Scientists would never happen again. This was followed by the Helsinki Declaration (1964), then the Belmont report in the US (1979). These three documents are referred to as 'landmarks' in establishing a history of ethical research conduct (Smith, 2012). From an Indigenous Australian perspective the Nuremberg Code came too late, the history of research as exploitation was already well under way and continues today. Unfortunately, there have been other vulnerable Indigenous Peoples around the world that have suffered from unethical research practices, and their research data like that of Indigenous Australians has been and continues to be used for unethical purposes, which is a human rights violation.

Changing unethical research by implementing the AIASIS Code of Ethics:

Poorer life outcomes initially began for Indigenous Peoples, in many parts of the world when they were dispossessed from their lands, which is a continued legacy of colonialism today. This makes Indigenous Peoples a vulnerable population when it comes to research and one of the poorest, unhealthiest, and under-educated peoples in the world. These multiple disadvantages experienced by Indigenous Peoples worldwide makes them an easy target for researchers to exploit with regards to unethical research practices.

The *AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research* (The AIATSIS Code, 2020) ensures that research with and about Aboriginal and Torres Strait Islander peoples follows a process of meaningful engagement and reciprocity between the researcher and the individuals and/or communities involved in the research. Professor Michael McDaniel (AIATSIS Council Chairperson 2017 – 2019) said that engaging ethically means many things but ultimately it is about respect and honour...

For me, it is yindyamarra, a Wiradjuri concept which means to act with honour and respect, wisdom, to go slowly and act responsibly, be gentle and polite and honest with each other, be careful of the words and actions you put out to the world and understand the impact they have…

There are many similar examples within Indigenous knowledge traditions that articulate how to act in the right spirit, with integrity and with respect for Country and for all living things. With the help of Indigenous and non-Indigenous researchers adhering to the AIATSIS Code of Ethics, (AIATSIS, 2020) ethical research and building trusting and respectful relationships with Indigenous Peoples and communities, things are starting to change for the better. There are multiple Indigenous Peoples health research agendas in Australia, therefore more needs to be done within these agendas to include education and support for Indigenous Peoples to have a full understanding of their rights to their own data, including data collection and disaggregation" of their data.

Key Points:

Institutional racism continues today and it is a barrier for Indigenous Peoples to have rights to their own data and to manage their research data. Today, racism is experienced by Indigenous Peoples worldwide and 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. In the Australian context the research area of craniology measured the size of Aboriginal peoples Human Skulls to determine the level of Intelligence/ IQ. The Scientists were generally of European heritage, their research subjects were generally Indigenous Peoples. It is estimated that there are thousands of specimens of Australian Aboriginal human remains held in museums around the world (The Telegraph, 2010). These 'human remains' of Aboriginal men, woman and children kept for the purposes of being curiosity objects for archaeological education strongly constitutes Indigenous Peoples data. This highly sensitive data should be returned immediately to the Indigenous Peoples and communities from where they were stolen, so they can start to grieve from the trauma and loss. For example, the British government holds 382 sets of Aboriginal remains in 18 institutions, and uses these human remains in part for educational purposes (The Telegraph, 2010). The collected data of Aboriginal human remains examined and kept by non – Indigenous researchers in the name of research.

For rapid progress to be made the World Health Organisation (WHO) focal point on Indigenous people's health research data needs to be developed up with an expert Indigenous advisory and consultation with Indigenous peoples and communities worldwide. This expert group should consist of key stakeholders that have a background specifically in Indigenous Peoples health and wellbeing. The WHO should work in partnership with EMRIP to disseminate information about research data policies and protocols surrounding "Indigenous Peoples right to data, including data collection and disaggregation".

All steps from 2025 onwards, need to involve extensive community consultation with Indigenous Peoples, and Indigenous health organizations and programs worldwide. Noting the six research values important to Indigenous Peoples in Australia, Spirit and Integrity,

Reciprocity, Respect, Equality, Survival and Protection, Responsibility (National Health and Medical Research Council, 2005). Researchers in Indigenous health who are working with Indigenous Peoples and communities need to have a good understanding of these values, 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 (Australian Government, 2022). Speaking for all Indigenous Peoples of Australia, yes – we want our research data back and we want the right to our data and to have input on data collection processes and be informed about how our data is being used. Most of all, as Sovereign Indigenous Peoples of the planet, we want our human rights respected!

References

Australian Government, 2022. Chronic disease support for Aboriginal and Torres Strait Islander people 2022, Date accessed 31/01/2025.
Chronic disease support for Aboriginal and Torres Strait Islander people | Australian Government Department of Health and Aged Care

Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) 2020, Guidelines for ethical research in Indigenous Studies, Australian Institute of Aboriginal and Torres Strait Islander studies, Canberra. Date accessed: 31/01/2025.
https://aiatsis.gov.au/research/ethical-research

Liamputtong, P. 2013, Research Methods in Health: Foundations for evidence-based practice, 2nd ed. Oxford University Press.

National Health and Medical Research Council, 2003, Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research, Commonwealth of Australia, Canberra.

National Health and Medical Research Council, 2005, Keeping on Track: A guide for Aboriginal and Torres Strait Islander peoples about health research ethics.

Smith, L. 2012, Decolonizing Methodologies: Research and Indigenous Peoples. London: Zed.

The Telegraph, 2010, Government urges Aboriginal skull return. Date accessed: 31/01/2025.
http://www.telegraph.co.uk/news/worldnews/australiaandthepacific/australia/7544943/Prince-William-pledges-to-help-return-Pemulwuys-head-to-Aborigines.html