



## **Official statistics and Indigenous People – the state of play and recent developments**

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Paper prepared for the 16<sup>th</sup> Conference of IAOS  
OECD Headquarters, Paris, France, 19-21 September 2018

Session 1.E., Day 1, 11:00: Indigenous statistics: Time for an international response

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## Official statistics and Indigenous People – the state of play and recent developments in Europe

DRAFT VERSION 14/09/18

PLEASE DO NOT CITE

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International Association of Official Statisticians (IAOS)  
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## **ABSTRACT**

This paper examines the low level of information available on Indigenous peoples, with focus on Europe and Scandinavia and some recent initiatives in response.

Keywords: Indigenous Peoples, IDS, Sweden, Norway, GDPR,

Indigenous Peoples are present on all continents of the world. In scientific articles and reports their total number varies between 300 and 370 million individuals and this variation is partly due to a combination of crude definitions and rough estimates. There is no universal definition of “Indigenous People” definitions are outcomes of and linked to nation states histories. That means that for statistical purposes, definitions of Indigenous People are often described as complex and contested. In many countries Indigenous Peoples are invisible in the statistical systems or the systems in place are prejudiced or corrupt and built to serve other purposes than portraying the statistical lives of Indigenous Peoples in the best way possible (1, 2, 3).

The history of European and New World states and their development into modern states often goes hand in hand with census taking and attempts to categorize “the other”. The census and its division into identity categories, such as “ethnicity” or “race”, have been displayed as one important tool for exercising power. The census sets its goal as that of objectively assessing the state of subjective identities and thereby creating social reality. For Indigenous Peoples the census is a historical remnant and constant reminder of colonisation.

Nevertheless, despite being fully aware of the shortcomings of national population statistics, the last decade the UN, the WHO, parts of academia together with Indigenous Peoples have called for improved statistics (4). The reason being that the ability of the census to statistically identify Indigenous peoples and their conditions is crucial to contemporary Indigenous issues. This view is based on the rationale that there is a need to identify and address the shared position of socio-economic and cultural and political marginalisation that all Indigenous people experience (3,5).

International governing instruments such as the United National Declaration of the Rights of Indigenous Peoples (UNDRIP) introduced in 2007 and eventually adopted by 148 countries has the potential to make states engage with Indigenous People in meaningful ways to change the current state of affairs. For instance, article 18 states that:

“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 institution”

In this respect, has anything happened lately?

In the first global Indigenous and Tribal Peoples health study (3), 15 of 22 countries reported health and social data on Indigenous Peoples in their national systems. The analyses clearly showed that inequities persist, with generally poorer social and health outcomes for Indigenous peoples relative to benchmark populations. The diversity of the circumpolar north was also evident. For instance, the life expectancy at birth of Inuit was 12.5 years less than the Canadian population while the gap in life expectancy for Norwegian Sami was much lower at just 1.6 years. Swedish Sami data were lacking but served as an example of a country with great potential for improvement. It was obvious that the CANZUS countries maintained the best possibilities to accumulate a variety of data on Indigenous People based on the system of self-definitions in censuses. However, the report concluded that data was a general concern and that “National governments should develop targeted policies for Indigenous and tribal health that address issues of health service delivery and the development of high-quality Indigenous data systems” (3)

Based on the “Ethnicity Counts database (eCount)” Mullane Ronaki (2017) investigated Indigenous Peoples recognition in censuses globally and could show that less than half of all Indigenous people are still not recognised by the state. For those that are part of the censuses the different system for identification ranged from fixed categories to self-identification. In other words, there is plenty of room for improvement.

The problem of identification in states statistical systems is not only a concern for Indigenous People it is tied in with broader discussions of definitions of ethnic groups. In Europe and especially in some welfare state countries (Scandinavia) with excellent registry data, the laws surrounding official statistics have made data with any form of ethnic marker illegal or very problematic to collect. So instead there is nothing. When a state doesn't know who are indigenous or not, it is tremendously hard to make plans and develop policy to support better and healthier lives. If policies for example to improve health are designed without association to relevant data, it is impossible to track and follow if they were appropriate or not. Sweden alongside of most European countries does not allow for ethnic or racial data to be collected in official statistics.

However, the work done against discrimination is leading the way in the discussions on collecting data on race or ethnicity in a European context. There are reports stating that Finland now has the best practice for data collection on equality that includes the Indigenous Sámi population (6). However, to my knowledge there have been next to nothing published using that data in Finland.

Why is Europe “behind”? History also learnt that census data can be used in the most devastating way to

target ethnic groups. One of the most horrific examples is how the Nazi used demographic records to identify and locate Jews and then deport them to concentration camps. This we know. We also know that racial biology used demographic records to separate races, and to identify those that was thought to soon die out. Is it in the light of this history that most European states alongside the European Union's Eurostat, are hesitant to support the development of ethnicity as a category in official statistics?

In countries with population registries rather than censuses (Scandinavia, The Netherlands) its more convenient to only register citizenship and country of birth. This is because ethnicity is a "subjective" category – and should thereby be self-reported. Official population registers seem difficult to open up for self-identification. In the Swedish system of population registries self-reporting is not an option. But also, the law of official statistics also signifies that there is a concern that statistics on ethnicity and race are *too* sensitive to be collected in official statistics. The question not answered is: sensitive to whom? If groups such as Indigenous Sami express that they want and need solid demographic data for planning their future, and wants to find ways to collect this information it seems more likely that its more sensitive to the state than the Sami.

## **NEW HORIZONS – INDIGENOUS DATA SOVEREIGNTY AND POPULATION STUDIES**

While the histories of the aftermath of WW2 and racial biology linger and perhaps are reasons for the reluctance to do anything to meet the demands of Indigenous Peoples and ethnic groups that want and need accurate population statistics to plan their future – the call for Indigenous Data sovereignty has grown rapidly. The Indigenous Data Sovereignty (IDS) - network consists of academics, policymakers and activists suggest that the call for improved statistics might be framed a bit different than what has been expressed the last decades.

The IDS has shifted the international conversation beyond data disaggregation, identification and access to consider issues of Indigenous Peoples governance, ownership and control (See Kukutai & Taylor). The discussion also includes data in "all forms" everything from official statistics to Facebook or Ancestry.com. Indigenous data, in any form, should not be about them - but for them. IDS describe the right of Indigenous peoples to control data from and about their communities and lands - articulating both individual and collective rights to data access and to privacy (7).

IDS see that nations where Indigenous data are collected, federal, state, and local governments as well as researchers primarily collect these with limited input from the Indigenous nations, communities, and individuals described. The results has been that Indigenous nations' rely on external data that largely fail to reflect community needs, priorities, and self-conceptions. This data imbalance threatens self-determination,

limits informed policy decisions, and restricts progress toward Indigenous aspirations for healthy, sustainable communities (Likewise, researcher and other governments' reliance on these data limit the robustness of data-driven research and the validity of policy decisions. The inconsistencies and inadequacies of existing Indigenous data systems have led to researchers, data repositories, and data service operations being increasingly aware of the need to understand IDS. The aim is to choose data governance and stewardship mechanisms that better align with Indigenous rights and aspirations and improve data quality and value. IDS has only been operating since 2015 but made an impact on the global agenda of Indigenous Peoples but was clearly left out of the discussion of the European Union, General Data Protection Regulation (GDPR).

The GDPR replaced the Personal Data Act in Sweden in early summer of 2018 but maintained that the processing of data that reveals ethnicity or race is prohibited. This regulation has severely impaired discussion in relation to Indigenous data since its introduction in 1973. Sweden is an example of a welfare state where health equity and equality are advanced and where epidemiology and health statistics are cutting-edge - but where laws surrounding data have resulted in Sweden being unable to provide any significant data to understand the health and social wellbeing of the Sámi, its only Indigenous people. This circumstance also means that there are little data produced by the state that Sámi people can take ownership of. Indigenous data are mainly produced by researchers and guarded by Swedish ethical protocols, that do not take Sámi ownership or control into account. However, things have recently been moving forward due to increased pressure from Sámi society and NGOs that have called for; a truth and reconciliation commission; ethical guidelines for Sámi research, a consultation order for Sámi issues; and enhancing the Sámi Parliaments role and possibilities to collect data. This and the implementation of a Saami Nordic Convention may force the Swedish state to open up for discussions on ownership and governance of data. The IDS agenda has the potential to be crucial (10)

There are other important arenas where change is coming, such as population studies carried out by researchers in close collaboration with Indigenous communities and organizations. However, the range of actors involved presents a coordination challenge and there is further a need to develop guidance involving Indigenous People, communities and organizations on how data collection, ownership and dissemination might proceed in an ethical, culturally sensitive and useful manner. These efforts require long term funding in order to produce comprehensive and longitudinal data. In this ongoing discussion Indigenous research methodologies and ethics are closely intertwined with the actual practice of gathering population data.

One successful example of a population based study is the SAMINOR study led by the Sami Center for

Health research at the Arctic University of Norway (UIT). The SAMINOR is both a questionnaire and a clinical study and has run twice (2003-4 and 2012-14) in selected municipalities in the traditional Sami area of Norway. The SAMINOR study has mainly focused on adults (+18 years) and the clinical studies in the last SAMINOR involved individuals 40-79 years of age. Participants self-identify their ethnic affiliations and answer questions regarding, for example, psychosocial health, discrimination and trust in healthcare systems. The 2012-14 study involved 11600 participants and the 2003-4 version 16865. This is a very unique and valuable health survey for understanding some of the current health issues in Norwegian Sápmi.

In Sweden the government has just decided to fund a similar population based study called HALDI – health and living conditions in Sápmi, Sweden. It will collaborate with the SAMINOR study and for the first time in Sweden the planned HALDI study will be based on the international recommendation of ethnic self-identification. The HALDI and SAMINOR data will also be able to speak with one voice for one Indigenous People divided by two countries.

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