



Indigenous health data and the path to healing

The health disadvantages of Indigenous peoples around the world have their roots in colonisation and discrimination and are related to a loss of autonomy over lands and culture. This history has profoundly affected social determinants of health, such as poverty and marginalisation, and contributed to higher rates of communicable and non-communicable diseases in Indigenous people, and life expectancies that are typically 5 or more years lower than in non-Indigenous populations.^{1,2} Despite persistent health inequities, Indigenous peoples are determining the path to healing their communities.³

Reports often portray Indigenous health as only a problem and overemphasise negative findings,⁴ rather than highlight progress that has been made in certain areas (eg, smoking rates, cardiovascular deaths, vaccine coverage).⁵ To document progress, Indigenous communities need accurate data to measure

determinants of health, access to health services, and the burden of important diseases and their complications. But major gaps remain in the availability and adequacy of data on Indigenous health.^{1,2}

Indigenous peoples have long claimed sovereignty over their culture and lands and are now making this claim over health data, believing this will empower communities and guide them in advocating for better health and health care.⁶ Article 24 of the United Nations Declaration on The Rights of Indigenous Peoples asserts the right to achieve the highest attainable health.⁷ However, it does not provide guidance on governance of the data that are needed to measure progress towards this goal. Greater efforts are needed to track the health of Indigenous peoples, and address concerns about the ways in which data are gathered and the political ends to which they might be used.²

The landscape of health data is changing with increasing access to diverse sources, including health-system encounters, health payment claims, disease registries, vital statistics, prescriptions, and community care services. The value of these routinely collected data is enhanced if they can be linked securely and anonymously at the level of the individual to create longitudinal records. In several countries, routinely collected data include Indigenous identifiers, or can be linked to files that include this information.

In Australia, the Commonwealth (federal) government has responsibility for primary health care through Medicare and Indigenous identity can be registered when enrolling for coverage. However, enrolment in Medicare is incomplete, as is Indigenous self-identification.⁸ The linkage of Medicare to other administrative and registry data to investigate the health and care of Indigenous peoples first occurred in 2005 in Western Australia⁸ but has not progressed at the national level. By contrast, Aotearoa/New Zealand has had mandatory collection of ethnicity data, including Māori identity, since the 1990s.⁹ Ethnicity is collected as part of public health surveillance and surveys, and national and administrative data collections. Ethnicity data are used to address health inequities, inform health priorities, and monitor Treaty of Waitangi obligations to Māori. One initiative links de-identified individual-level data from health datasets with data from the census and other administrative

Panel: Governance processes for use of routinely collected health data with Indigenous identifiers at the Institute for Clinical Evaluative Sciences in Ontario, Canada

- 1 Access to, and use of data with Indigenous identifiers are approved by data governance committees organised and populated by the relevant Indigenous organisations.*
- 2 Linked datasets with Indigenous identifiers are not routinely available to researchers and analysts, who must make specific application, and seek approval from the relevant data governance committee before they can access them.†
- 3 Researchers are required to discuss their projects with Indigenous community representatives, who may collaborate in the planning conduct and reporting of the studies.
- 4 Researchers and staff at ICES participate in ongoing initiatives to orient them to Indigenous worldviews, research principles, and historical and social contexts.
- 5 Staff at ICES are working with representative organisations to build capacity among Indigenous organisations and communities to train Indigenous analysts and epidemiologists.
- 6 Study results are co-interpreted with the communities and their representatives, who have a lead role in deciding how the results will be communicated more widely.

*We describe the governance of First Nations data; similar arrangements have been established with the Métis Nation of Ontario for analysis of data that identify Métis individuals. †Indigenous persons are routinely included in analyses of the whole province, or regions, but are not identified separately in the results. These analyses do not require clearance by the governance bodies. ICES=Institute for Clinical Evaluative Sciences, Ontario, Canada.

systems, including education, income tax, social services, and justice.¹⁰ Meanwhile, in Canada, the federal government shares responsibility with the provinces and territories for providing health care to Status Indians (First Nations persons), who are registered under the Indian Act. This register is proving useful for the identification of community members on and off reserve¹¹ and contains details that are linkable to a wide range of routinely generated datasets. However, no national agreements exist on the governance of these data in Australia, Aotearoa/New Zealand, or Canada.

Principles of good governance of Indigenous data have been defined by the emerging data sovereignty movement. As described by Snipp¹² they must ensure: “(1) that Indigenous peoples have power to determine who should be counted among them; (2) that data must reflect the interests and priorities of Indigenous peoples; and that (3) tribal communities must not only dictate the content of data collected about them, but also have the power to determine who has access to these data.”¹²

These conditions map well to the principles of Ownership, Control, Access and Possession (OCAP®) established by Canadian First Nations in 1998.¹³ Three of us (CJ, JW, and DH) were guided by these principles when linking the Indian Register to all routinely collected provincial health administrative data for 201678 First Nations individuals in the province of Ontario, Canada. These data are held at the Institute for Clinical Evaluative Sciences in Toronto.¹¹ The principles that underpin this work are summarised in the panel. These were developed during negotiation of several data governance and data-sharing agreements. Following these arrangements Indigenous organisations and communities put forward questions that came from communities and representative organisations, such as cancer survival rates, child wellbeing indicators, neonatal abstinence syndrome rates, prevalence and outcomes of prescription opioid use, and health-care trajectories for those with diabetes. Research questions are enriched through discussions with methodologists and clinician scientists. The communities have a sense of ownership of the research, which improves implementation of important findings. Research with large linked administrative and registry datasets is cost-effective, and enables Indigenous organisations to commission studies that would not otherwise be feasible or affordable. But the true potential can only be realised if appropriate governance processes are put in place.

We hope our experience will stimulate wide discussion of these issues, and welcome engagement from other groups.

Jennifer Walker, Ray Lovett, Tahu Kukutai, Carmen Jones,

*David Henry

School of Rural and Northern Health, Laurentian University, Sudbury, ON, Canada (JW); Institute for Clinical Evaluative Sciences, Toronto, ON, Canada (JW, DH); Aboriginal and Torres Strait Islander Health Epidemiology for Policy and Practice, National Centre for Epidemiology and Population Health, College of Health and Medicine, Australian National University, Canberra, Australia (RL); Te Para One E Tū Mai Nei: Māori and Indigenous Futures, National Institute of Demographic and Economic Analysis, The University of Waikato, Hamilton, New Zealand (TK); The Chiefs of Ontario, Toronto, Canada (CJ); and Centre for Research in Evidence-Based Practice, Bond University, Gold Coast, QLD, Australia (DH) dhenry@bond.edu.au

JW is Lead and DH is former Lead for Indigenous Data at the Institute for Clinical Evaluative Sciences. We declare no other competing interests.

- 1 Gracey M, King M. Indigenous health part 1: determinants and disease patterns. *Lancet* 2009; **374**: 65–75.
- 2 Kirmayer LJ, Brass G. Addressing global health disparities among Indigenous peoples. *Lancet* 2016; **388**: 105.
- 3 Kirmayer LJ, Dandaneau S, Marshall E, Phillips MK, Williamson KJ. Rethinking resilience from indigenous perspectives. *Can J Psychiatry* 2011; **56**: 84–91.
- 4 Cochran PA, Marshall CA, Garcia-Downing C, et al. Indigenous ways of knowing: Implications for participatory research and community. *Am J Pub Health* 2008; **98**: 22–27.
- 5 Commonwealth of Australia. Aboriginal and Torres Strait Islander health performance framework 2017 report. 2017. <https://www.pmc.gov.au/sites/default/files/publications/2017-health-performance-framework-report.pdf> (accessed Sept 21, 2017).
- 6 Kukutai T, Taylor J. Data sovereignty for Indigenous peoples: current practice and future needs. In: Kukutai T, Taylor J, eds. *Indigenous data sovereignty. Research monograph no 38*. Canberra: Australian National University Press, 2016: 1–18.
- 7 UN General Assembly. United Nations Declaration on the Rights of Indigenous Peoples: resolution adopted by the General Assembly, 2 October 2007, A/RES/61/295. 2007. http://www.un.org/en/genocideprevention/documents/atrocities-crimes/Doc.18_declaration%20rights%20indigenous%20peoples.pdf (accessed Aug 16, 2017).
- 8 Thompson SC, Woods JA, Katzenellenbogen JM. The quality of Indigenous identification in administrative health data in Australia: insights from studies using data linkage. *BMC Med Inform Decis Mak* 2012; **12**: 133.
- 9 Cormack D, McLeod M. Improving and maintaining quality in ethnicity data collections in the health and disability sector: Te Rōpū Rangahau Hauora a Eru Pōmare. Wellington School of Medicine and Health Sciences, University of Otago (Wellington). 2010. <http://www.otago.ac.nz/wellington/otago600098.pdf> (accessed Aug 18, 2017).
- 10 Integrated Data Infrastructure—statistics New Zealand. Data in the IDI. July, 2017. http://www.stats.govt.nz/browse_for_stats/snapshots-of-nz/integrated-data-infrastructure/idi-data.aspx#health (accessed Aug 18, 2017).
- 11 Walker J, Jones C. First Nations data sovereignty in action: creation of the largest First Nations health research study cohort in Canada. Nov 3, 2016, Australian National University. <http://rsph.anu.edu.au/news-events/first-nations-data-sovereignty-action-creation-largest-first-nations-health-research> (accessed Aug 16, 2017).
- 12 Snipp CM. What does data sovereignty imply: what does it look like? Indigenous data sovereignty. Research monograph no 38. Canberra: Australian National University Press, 2016.
- 13 First Nations Information Governance Centre. The First Nations Principles of OCAP®. <http://fnigc.ca/ocap.html> (accessed Aug 18, 2017).