

# Better Policy

ICES is working with First Nations, Inuit and Métis partners across Ontario to apply principles of Indigenous data sovereignty and forge a path to Indigenous-led population health research.

## The Problem

Data about the health of Indigenous (First Nations, Inuit and Métis) people in Canada have historically been produced, stored and used without regard for the sovereignty of those data within Indigenous populations. The recognition of Indigenous data sovereignty is in accordance with the rights set out in the UN Declaration on the Rights of Indigenous Peoples, necessary to the calls to action from the Truth and Reconciliation Commission of Canada, and fundamental to the OCAP® Principles for First Nations research. But until now, data about health services use have not been accessible to Ontario's Indigenous peoples.

## The Research

ICES has worked closely for several years with diverse Indigenous partners to develop unique data governance and data sharing agreements for Indigenous-driven analyses using administrative health data. In October 2017, ICES formalized an Indigenous Portfolio with dedicated staff, a scientific lead and a network of scientists.

The portfolio works with Indigenous partners, including the Chiefs of Ontario and the Métis Nation of Ontario, and

with other research institutes. Applying a decolonized lens and using Indigenous models of well-being, the team works with communities to build internal research capacity by training Indigenous researchers. It also collaborates with international researchers to advance the emerging field of Indigenous data sovereignty.

## Recent Impact

- Creation of unique data governance agreements guided by principles of Indigenous sovereignty, using novel methods for data linkage. These advances make possible, for the first time, Indigenous-driven population health research using linked administrative health data. The data now include the largest First Nations cohort in Canada, at 200,000 people.
- Publication of an internationally collaborative paper in *The Lancet* in 2017 detailing the conditions of Indigenous data sovereignty in Canada, Australia and New Zealand.
- Partnering with First Nations groups on two CIHR grants, and continuing to respond to the data needs of First Nations communities, health units and the Chiefs of Ontario.

"Indigenous data governance and engagement are nuanced and complex. Consistently underpinning our work are our key guiding principles and supporting processes, which include ethical relationships, formalized data governance agreements, appropriate methodology and approaches guided by Indigenous perspectives, and models of well-being."

### Jennifer Walker

Scientist and Lead, Indigenous Portfolio

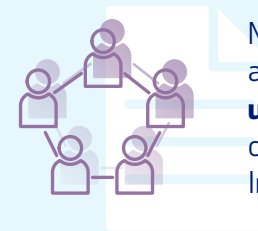
## Impact Highlights



Novel data governance agreements guided by Indigenous data sovereignty principles, **enabling data linkage for Indigenous-led population health research.**



Work with national and international partners to **advance the emerging field of Indigenous data sovereignty.**



Multiple grants, studies, and **partner-led analyses underway** within a year of launching the Indigenous Portfolio.

REFERENCE  
Walker et al. *Lancet* (2017).