Walking the Path Together: Indigenous Health Data at ICES

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Abstract

Indigenous data governance principles assert that Indigenous communities have a right to data that identifies their people or communities, and a right to determine the use of that data in ways that support Indigenous health and self-determination. Indigenous-driven use of the databases held at the Institute for Clinical Evaluative Sciences (ICES) has resulted in ongoing partnerships between ICES and diverse Indigenous organizations and communities. To respond to this emerging and complex landscape, ICES has established a team whose goal is to support the infrastructure for responding to community-initiated research priorities. ICES works closely with Indigenous partners to develop unique data governance agreements and supports processes, which ensure that ICES scientists must work with Indigenous organizations when conducting research that involves Indigenous peoples.

The Issue

In Canada, colonization and discrimination toward Indigenous peoples have undoubtedly impacted determinants of health, with resulting widespread health inequities (Truth and Reconciliation Commission of Canada 2015). The increased recognition of this inequity, coupled with the pervasiveness of data in our everyday lives, suggests that now, more than ever, the inherent rights of Indigenous peoples must be present in discussions of how data are used to report on their health (Kukutai and Taylor 2016). A global Indigenous data sovereignty movement has emerged with the goal of asserting the right of Indigenous communities to use Indigenous data to tell the stories that support their movement toward health and healing (Kukutai and Taylor 2016; Walker et al. 2017). In Canada, for example, the First Nations' principles of ownership, control, access and possession (OCAP®) of First Nations' data have formed a strong foundation for understanding the pathways to ethical collection, use and reporting of this data (First Nations Information Governance Centre 2014).

While this movement necessitates the shifting of power and decision-making to Indigenous peoples and communities, there remains a role for centralized data collection and analysis of routine data and the potential to learn from existing data expertise and infrastructure (Kukutai and Taylor 2016; Walker et al. 2017). The Institute for Clinical Evaluative Sciences (ICES) is a not-for-profit research institute encompassing a community of research, data and clinical experts, and a secure and accessible array of Ontario's health-related data. The ICES Data Repository consists of record-level, coded and linkable health data sets, and includes population-based health surveys and anonymous patient records, as well as clinical and administrative health and social services databases. For several years, ICES has been working closely with First Nations, Inuit and Métis partners to conduct Indigenous-driven analyses using ICES' data holdings.

In collaborating with Indigenous partners, the biggest challenge for ICES has not been recognizing the importance of this work but rather determining how best to operationalize it. The United Nations Declaration on the Rights of Indigenous Peoples emphasizes the right to participate in decision-making and to determine and develop priorities and strategies for exercising the right to development (UN General Assembly 2008). Moreover, Chapter 9 of the Tri-Council Policy Statement 2 (TCPS-2) on Research Involving the First Nations, Inuit and Métis Peoples of Canada serves as a framework for the ethical conduct of research involving Indigenous peoples (Canadian Institutes of Health Research et al. 2014). Chapter 9 has provided guidance for ICES on collaboration and engagement, as well as on building and maintaining respectful relationships at all stages of the research process. Crucial for ICES has been and will continue to be balancing the holding of data that has great value for research and policy with ensuring that there is a robust layer of protection against the use of Indigenous data without sufficient and appropriate engagement. As a result, and to respect the aforementioned guiding principles, ICES' approach to partnerships, processes and agreements needs to be unique when dealing with Indigenous data and identifiers.

The Approach

ICES' ongoing commitment to the Indigenous-driven use of ICES data is rooted in its ongoing partnerships with diverse

Indigenous organizations and communities. Indigenous governance and the requirement for Indigenous engagement at ICES extend to the use of any data element or analytic approach that identifies Indigenous people or communities. ICES works closely with Indigenous partners to develop unique data governance and data sharing agreements, as well as supporting processes that must be respected for each project that may identify Indigenous peoples or communities. Inherent to these processes is the recognition that data governance landscapes are nuanced and often evolving. Thus, a key component of ICES' approach is being responsive and adaptive to diverse Indigenous partners. For example, ICES is working with the Chiefs of Ontario (COO) and other First Nations communities and organizations to ensure that First Nations' data sovereignty is upheld in decisions regarding the use of First Nations identifiers in data held at ICES. COO is a forum for collective decision-making, action and advocacy for the 133 First Nations communities in Ontario. In 2012, COO initiated the transfer of the federal Indian Register (IR) to ICES from Indigenous and Northern Affairs Canada and the linkage of the IR data to ICES' data holdings. A data governance agreement between COO and ICES ensures that First Nations govern IR data at ICES, in accordance with OCAP® principles. Proposals to use the data to conduct Ontario-level analyses are received and approved by a First Nations Data Governance Committee that has members appointed by the Ontario Chiefs' Committee on Health. This process is complemented by a separate governance agreement with the Kenora Chiefs Advisory and an agreed process with Grand Council Treaty #3, each of which applies to data identifying their members or communities within their respective regions.

In a parallel relationship, ICES has been working closely over many years with the Métis Nation of Ontario (MNO), having linked the MNO Citizenship Registry for a series of studies on chronic diseases. In 2016, ICES and MNO signed a data governance and data sharing agreement that has enabled linkage to an updated version of the MNO Citizenship Registry and ensures that any use of data identifying Métis people aligns with the collective priorities of the MNO. Requests and consultations involving the use of data identifying Métis people are addressed through a joint ICES–MNO Data Governance and Partnership Committee.

ICES is also working with Tungasuvvingat Inuit, an Inuit-specific provincial health services provider, to formalize a partnership through a shared statement of values. The primary purpose of the statement is to enable Inuit-specific research in Ontario in a manner that is grounded in Inuit Qaujimajatuqangit, a body of knowledge which encompasses Inuit worldviews and is guided by six principles: *Pijitsirniq* (serving), *Aajiiqatigiingniq* (consensus decision-making), *Pilimmaksarniq* (skills and knowledge acquisition), *Piliriqatigiingniq* (collaborative relationships or working together for a common purpose), *Avatimik Kamattiarniq* (environmental stewardship) and *Qanuqtuurunnarniq* (being resourceful to solve problems) (Tagalik 2012). These guiding principles form the foundation for our relationship.

A primary vehicle for Indigenous-led analyses of Indigenous data is our ability to respond, with funding from the Ontario Ministry of Health and Long-Term Care, to questions from Indigenous organizations about the health of their people and communities. This can range from a simple query from a single community to a widespread collaborative research project involving many First Nations communities. A second approach is researcher-driven, collaborative and participatory research with Indigenous partners that is funded by research grants. Most of these studies use mixed methods and explicitly integrate Indigenous perspectives and ways of knowing through processes such as the involvement of Elders and Knowledge Keepers.

The Framework

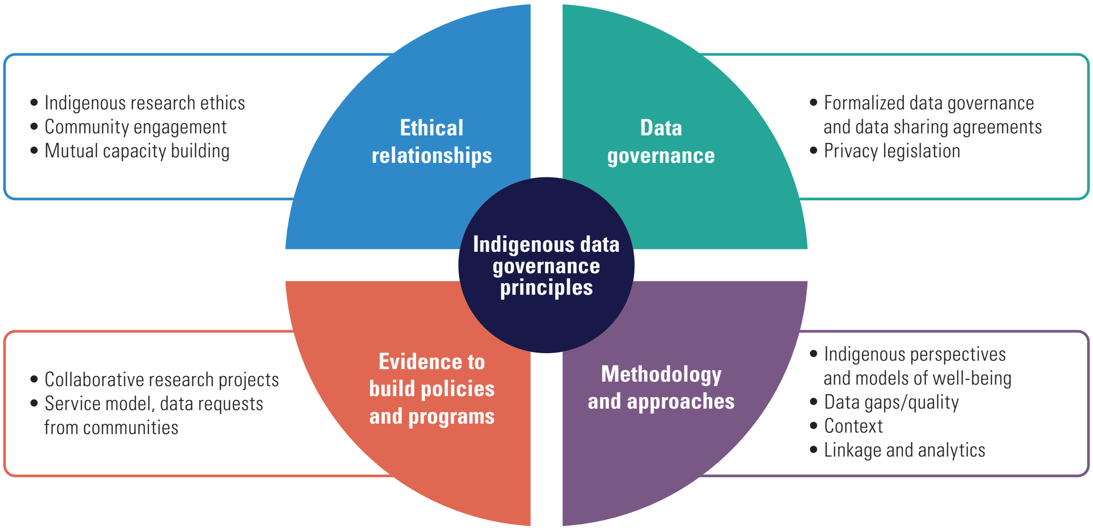
Collaboration with the Chiefs of Ontario working with First Nations data has informed an overall framework for working with Indigenous data (Figure 1). Central to this framework are Indigenous data governance principles, such as OCAP®, and Inuit Qaujimajatuqangit principles.

Our work with Indigenous data is guided by four components: (1) ethical relationships, (2) data governance, (3) methodology and approaches and (4) evidence to build policies and programs. The elements within each of these four domains demonstrate how grounding work in Indigenous data governance principles has implications across roles and departments at ICES – from privacy processes to data analysis, capacity building and knowledge translation and exchange activities.

The Results

Using the framework to guide ICES' work with Indigenous partners has resulted in new and strengthened partnerships, as well as research that has an impact. Current projects using data from the Indian Register examine cancer surveillance, diabetes, prescription opioid use, chronic conditions and aging. ICES also uses geographic identifiers to answer critical questions from First Nations communities about the health of their populations. ICES and the MNO collaborated for several years on the Chronic Disease Surveillance Project, completing reports on diabetes, respiratory cardiovascular and kidney diseases and musculoskeletal conditions, using Métis Citizenship Registry data. At present, these data, linked at ICES, are being used by the MNO to study the mental health of Métis people.

FIGURE 1.
Framework for working with Indigenous data



Adapted from the model developed with Chiefs of Ontario (Lovett, Walker and Jones 2016).

With a growing number of partners and projects, the formalization of an Indigenous Portfolio at ICES connects the many people involved in this work: a core team of dedicated ICES staff, a network of ICES scientists, an extended team of representatives from departments across ICES, and our First Nations, Inuit and Métis partners and Indigenous health services providers in Ontario.

The Path Forward

The goal of the ICES Indigenous Portfolio is to be a trusted partner of Indigenous organizations, scholars and communities by supporting their information needs. Through mutual capacity building and respect for Indigenous knowledge, the Indigenous Portfolio aims to foster relationships, while providing the infrastructure for answering community-initiated research questions. Guided by our Indigenous partners, ICES is moving forward on a path toward Indigenous-driven data usage to promote well-being, healing and effective policy for Indigenous peoples in Ontario.

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