Research, Sovereignty and Action: Lessons from a First Nations–Led Study on Aging in Ontario

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Abstract

First Nations in Ontario are building capacity to leverage health services data in Ontario to provide robust, First Nations–driven health evidence. Beyond providing evidence, population health research processes must involve diverse First Nations' perspectives, collective capacity building and translation of research findings into action through integrated and community engaged knowledge translation and exchange (KTE) approaches. Suggested ways include integrating stories and traditional knowledge, prioritizing gatherings and establishing an enduring commitment to action. To effectively support First Nations' self-determination and sovereignty, First Nations' principles of ownership, control, access and possession (OCAP®) in research could be expanded to include "action" (OCAPA).

Key Points

- While vital to the realization of data sovereignty and the generation of First Nations–centred knowledge, research that is OCAP®-aligned does not necessarily lead to community action and uptake.
- It is important to actively share findings from First Nations health research in ways that align with communities' preferred formats, venues and information sources.
- There is a need to reframe conversations around knowledge translation and exchange (KTE) for First Nations health research. Effective KTE should support self-determination and sovereignty.

Introduction

Over the past 10 years, Chiefs of Ontario (http://chiefs-of-ontario.org/) has been working with ICES to leverage the extensive, routinely collected health services data in Ontario to answer research questions that are relevant to First Nations. These initiatives – including reports on cancer (Chiefs of Ontario et al. 2017), diabetes (Green et al. 2019; Slater et al. 2019; Walker et al. 2020), opioid prescriptions (ICES 2017), COVID-19, aging (Walker et al. 2019) and mental health (ongoing) – provide robust, First Nations–driven health evidence. The research teams – which include representatives from Chiefs of Ontario, First Nations community members and health practitioners – focus on knowledge translation and exchange (KTE) strategies that meet the needs of First Nations, their epistemologies and their inherent understanding of well-being. Yet, for many reasons, research findings may not be taken up by First Nations. Beyond providing evidence, research processes must facilitate the translation of findings into action through integrated and community-engaged KTE (Graham et al. 2006). This shift is critical to support First Nations' sovereignty and self-determination through research. In response to these issues, we evaluated the impact of KTE products from the First Nations Aging Study (Walker et al. 2019). Our findings highlight the importance of sharing research findings in ways that support First Nations' sovereignty, self-determination and action.

First Nations' Data Governance and Sovereignty

In Canada, First Nations have been explicitly asserting data sovereignty rights since the early 1990s with the articulation of a set of core principles that establish First Nations' ownership, control, access and possession (OCAP®) over First Nations data (First Nations Information Governance Centre 2014). In response to direction from the elected First Nations leadership in Ontario in 2009, Chiefs of Ontario established a strong relationship with ICES, leading to a formal *Data Governance Agreement* in 2012 and linkage with the federal Indian Register (Pyper et al. 2018; Walker et al. 2017, 2018a).

Research conducted using First Nations data at ICES is different from other projects, in that Chiefs of Ontario must provide permission before any First Nations data is accessed and used. Research applications are considered by a First Nations Data Governance Committee appointed by the Ontario Chiefs Committee on Health. Approaches to data governance are highly community-engaged and unique to each project and partner. Engagement usually includes the involvement of First Nations health directors or coordinators, Elders and people with lived experience (see, for example, Walker et al. 2018b). Research questions come from communities, analysis is guided by communities and results are collaboratively interpreted by communities. The resulting information is shared in ways that are accessible and policy-relevant for communities. These processes are critical to First Nations' self-determination and sovereignty.

What We Did: First Nations Aging Study (2015–2019)

Using the above-mentioned approach, we recently completed the First Nations Aging Study (FNAS) funded by the Canadian Institutes of Health Research. The project was co-created and co-led by a First Nations university-based researcher and Chiefs of Ontario, with other researchers with expertise in qualitative methods, aging and frailty and health services. The initial grant strengthened research capacity at Chiefs of Ontario by funding a partial short-term position at Chiefs of Ontario, which transitioned to an ongoing position when the funding ended. This is an example of how project-specific funding can seed and build sustained capacity.

The project included ongoing engagement with First Nations policy makers and brought together a Knowledge Circle that included First Nations people who were older adults, frontline health workers serving older First Nations adults, First Nations language speakers and Elders. These individuals were not employed by a university or by Chiefs of Ontario, so we provided honoraria for their participation. This was not a closed circle; some individuals came and went, while others stayed for the whole project. Mindful of shifting community priorities, we were flexible in our interactions, which included individual visits and phone calls before and after larger group meetings, integration in group meetings and enabling knowledge holders to join for parts of the project. This flexibility allowed us to build one-on-one relationships, as well as a comfortable space for Elders to share their teachings and thoughts on their own terms. When Elders could not attend large group meetings due to health challenges or shifting priorities, others stepped in to open and close the meetings and offer their guidance and perspectives on the research.

Many findings from the FNAS were policy relevant and shared at five of the Chiefs of Ontario's First Nations Health Forums from 2016 to 2021 and with the Standing Committee on Indigenous and Northern Affairs (https://www.ourcommons.ca/Committees/en/INAN). We completed the final report in fall 2019, integrating qualitative findings from conversations with Anishinaabemowin language speakers and older Anishinaabeg on Manitoulin Island, ON, with quantitative findings from ICES data and the First Nations Regional Health Survey (Walker et al. 2019). Once reviewed by Chiefs of Ontario and health directors from First Nations organizations across Ontario, we shared the report at the February 2020 First Nations Health Forum just weeks before the COVID-19 pandemic began to affect Ontario. These findings informed models prepared for First Nations leadership in the early days of the pandemic. We found that First Nations people had multiple chronic conditions and frailty with a higher prevalence and at younger ages than other people in Ontario, placing them at risk for severe COVID-19 outcomes. However, from a strengths-based perspective, these individuals also tended to report feeling a sense of emotional, physical, spiritual and mental balance.

What We Did: Evaluating, Learning and Building Capacity

Our team built and strengthened relationships with First Nations communities throughout the project. Nonetheless, we were left with several questions: What was the impact at a community level? Did the report support First Nations in decision making, prioritization and sovereignty?

In 2020, members of the research team, Chiefs of Ontario and the Knowledge Circle reconvened to answer these questions. As a starting point, we implemented a survey at the 2021 First Nations (virtual) Health Forum (Chief of Ontario Assembly Center 2021). Our intent was, firstly, to continue raising awareness about the FNAS, as the initial release coincided with the onset of the COVID-19 pandemic, when communities were necessarily shifting their focus to pandemic preparedness and prevention. Secondly, we wanted to understand and acknowledge opportunities for improvement in the way we reported the findings. This would help us understand if the results reached the intended audience and were useful to them. It would also provide constructive feedback for future projects.

All 341 registrants for the 2021 First Nations Health Forum were invited to participate in the survey, which asked about uptake of the FNAS report and preferences for sharing knowledge gained from research. As an incentive, survey respondents were offered the opportunity to win $300 credits for training in research, KTE or aging. This capacity-building element is central to the principle of reciprocity that is embedded in First Nations' research methodologies. Participants were also asked if they would be willing to be interviewed to provide more in-depth information.

The semi-structured follow-up interviews explored themes of research sovereignty, processes for decision making and research communication to inform a framework for putting First Nations health research into action. A First Nations undergraduate student conducted, recorded, transcribed and analyzed data from the interviews under the mentorship of members of the broader research network. This mentorship was another way to strengthen First Nations' research capacity and sovereignty. Analysis of interview data was done using NVivo and is ongoing. It will be presented elsewhere.

In First Nations research, both individual and collective consent from the community are critical. To establish the collective consent that is embodied in OCAP®, we followed the terms of the *Data Governance Agreement* between ICES and Chiefs of Ontario. In addition, all survey and follow-up interview participants were asked to provide informed individual consent, which they agreed to.

Our team met monthly for nine months. The reflections in our meetings influenced our interpretation of the findings. According to the Indigenous research paradigm described by Shawn Wilson (2008): "If research doesn't change you as a person, then you haven't done it right" (p. 135). In First Nations' research methodologies, researchers and community members reflect on, change and influence research while doing it. Notably, in this project, our discussions made us active influencers of our collective interpretation of the findings regarding impact and action. This was key to our relational approach to patient and community engagement and our relational accountability to First Nations people across Ontario.

What We Learned: The Importance of Stories and Sharing

In all, 29 of the 341 attendees at the 2021 Health Forum responded to our survey. This response rate reflects the challenges of engaging participants at virtual conferences. The respondents were mostly clinicians and health directors and were almost exclusively employed by a First Nations band council. Despite persistent efforts to engage with First Nations community members throughout the FNAS, only three of the 29 respondents reported having seen the report at the previous First Nations Health Forum, and only one had read it. This is a strong indication that the report did not receive wide community uptake. It also made it challenging to directly evaluate how helpful the report was.

We also asked respondents how they like to receive information and how to make research findings useful in their work. A strong majority indicated that stories (97%), traditional teachings or knowledge (90%) and research evidence (86%) were key sources of information. Community gatherings and social media were the preferred venues for finding and receiving information. While we assumed that infographic formats were important KTE tools, only 41% preferred infographics, 69% preferred reports and 62% wanted PowerPoint slides. This suggests that people are thinking of ways to share the findings from the start. Unsurprisingly, academic journals were the least preferred medium.

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What We Learned: Challenges of Engagement and the Importance of Action

One of the biggest challenges we faced was difficulty in engaging Elders in this follow-up project. We discussed this extensively and attempted to problem-solve this gap. This challenge was heightened by the additional demands and stresses that people faced through the COVID-19 pandemic, as well as difficulties associated with virtual meetings (e.g., interest, familiarity and bandwidth or hardware limitations). Engagement was also limited due to the uncovering of gravesites at former residential school sites and the resulting collective grief in First Nations communities. We had to respect that Elders had many other responsibilities and commitments beyond our project.

The involvement of the Chiefs of Ontario and front-line First Nations health professionals has transformed our learning in this follow-up to the initial research project. We prioritized their questions about transferring knowledge to change agents in communities and facilitating the translation of knowledge to action. We saw that OCAP® principles are effective guides to data governance and the generation of First Nations–centred knowledge. But, for research to support sovereignty and self-determination, we need a new principle of action. In our discussions, we have begun to change our language and to refer to OCAPA – collective First Nations ownership, control, access, possession *and* action in research. From a First Nations' perspective, knowledge is intended to be shared. And we have a collective responsibility to act on that knowledge.

Conclusion

Much of the current research and associated KTE with the First Nations data at ICES have been OCAP®-aligned. However, that has not necessarily led to action and community uptake, as we found with the FNAS report. The findings of this study underscore the importance of thinking strategically about sharing findings from First Nations health research. Supportive ways may include integrating stories and traditional knowledge, prioritizing gatherings and social media and establishing an enduring commitment to change, improvement and action based on findings. We need to shift our thinking to include a reciprocal responsibility for research that builds capacity, is strongly community engaged and supports First Nations' sovereignty and self-determination. This is a shift from OCAP® to OCAPA. Findings from the quantitative and qualitative phase of this project will be combined in a research-to-action framework that will facilitate these processes. In this way, research can embody sovereignty over research and data, as well as action based on that data. HQ

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