

## **Critical Public Health**



ISSN: 0958-1596 (Print) 1469-3682 (Online) Journal homepage: https://www.tandfonline.com/loi/ccph20

# A decolonizing method of inquiry: using institutional ethnography to facilitate communitybased research and knowledge translation

Melody E. Morton Ninomiya, Natasha Hurley & Jack Penashue

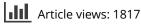
To cite this article: Melody E. Morton Ninomiya, Natasha Hurley & Jack Penashue (2020) A decolonizing method of inquiry: using institutional ethnography to facilitate communitybased research and knowledge translation, Critical Public Health, 30:2, 220-231, DOI: 10.1080/09581596.2018.1541228

To link to this article: <u>https://doi.org/10.1080/09581596.2018.1541228</u>



Published online: 16 Nov 2018.

Submit your article to this journal 🖸





View related articles



View Crossmark data 🗹



Citing articles: 7 View citing articles 🗹

#### RESEARCH PAPER



Check for updates

### A decolonizing method of inquiry: using institutional ethnography to facilitate community-based research and knowledge translation

Melody E. Morton Ninomiya D<sup>a,b</sup>, Natasha Hurley<sup>c</sup> and Jack Penashue<sup>d</sup>

<sup>a</sup>Institute for Mental Health Policy Research, Centre for Addiction and Mental Health, London, Canada; <sup>b</sup>Well Living House, St. Michael's Hospital, Toronto, Canada; <sup>c</sup>Innu Nation, Sheshatshiu, Canada; <sup>d</sup>Charles J. Andrew Youth Treatment Centre, Sheshatshiu, Canada

#### ABSTRACT

This paper describes how a study using institutional ethnography (IE) was used as a decolonizing method of inquiry in a rural Indigenous community in Canada. IE honors lived experience, reveals institutional and colonial practices, provides clear empirical evidence, and can offer clear recommendations that can benefit Indigenous communities. At the heart of decolonizing research is the task of shifting whose knowledge is privileged - from those with power (often researchers) to those who are being researched (those subject to the effects of colonization). To highlight how IE can be used as a decolonizing method of inquiry, the authors of this paper (a) point out common pitfalls of academic research and knowledge translation (KT) practices in Indigenous health; (b) highlight decolonizing research principles and how IE can be a decolonizing method of inquiry; and (c) share an example to illustrate how IE was used in a decolonizing health study in a First Nations community context. This paper also outlines critiques of mainstream research and KT practices. highlights principles for conducting research with Indigenous people in Canada, and further discusses how IE is well positioned to facilitate both decolonizing research and strategic KT.

#### **ARTICLE HISTORY**

Received 17 June 2017 Accepted 21 October 2018

#### **KEYWORDS**

Institutional ethnography; decolonizing research; indigenous health; knowledge translation; community-based research

#### Introduction

Indigenous community-driven research is an important and valuable facet of Indigenous people's self-determination in Canada (ITK, 2016). Health researchers and the broader research community are implicated in the colonization that continues to negatively affect the health of Indigenous communities (Smith, 2012; Smylie, 2011; TRC, 2015). Increasingly, researchers are re-orienting methodologies to include a decolonizing paradigm. Decolonizing research is about collaboration, centering self-determination, engaging in researcher self-reflexivity, changing power dynamics, and privileging community knowledge (de Leeuw, Cameron, & Greenwood, 2012; Smith, 2012; Smylie et al., 2015). Decolonizing research requires an epistemological shift in what constitutes scientific knowledge, who controls research design, and how knowledge is gathered and shared (Kendall, Sunderland, Barnett, Nalder, & Matthews, 2011; Stanton, 2013).

Knowledge translation (KT) is an integral part of the scientific process and is about using research to inform change (CIHR, 2012; Grimshaw, Eccles, Lavis, Hill, & Squires, 2012). Research funders recognize that well-articulated KT strategies are more likely to 'translate' knowledge during and from research, into action in an effort to increase the relevance and positive impact on health

outcomes. Too often, academic health research and KT materials report on Indigenous health issues void of historical or cultural context (King, 2015; Smylie, Williams, & Cooper, 2006). Neglecting to acknowledge and explain Indigenous contexts has led to research dissemination that emphasizes deficits: Indigenous lives and communities are often depicted as desperate, bleak, and sick. This narrative is stigmatizing and perpetuates negative stereotypes (Browne, Smye, & Varcoe, 2005). Widely accepted forms of research and KT practices have been criticized for reproducing colonial ways of knowing and doing (Estey, Kmetic, & Reading, 2010; Smylie, Olding, & Ziegler, 2014). In short, epistemological assumptions for health research KT are intertwined with non-Indigenous concepts of evidence-based medicine (Graham et al., 2006; Greenhalgh & Wieringa, 2011).

The idea for this paper came from the lead author's (MMN) experience with collaborative research in a First Nations community in Atlantic Canada. This paper aims to (a) point out common pitfalls of academic research and KT practices in Indigenous health; (b) highlight decolonizing research principles and how institutional ethnography (IE) can be a decolonizing method of inquiry; and (c) share an example to illustrate how IE was used in a decolonizing health study in a First Nations community context. The main purpose of this paper is to demonstrate how IE research that integrates community-based methods and community-identified KT initiatives can be a decolonizing method of inquiry.

#### Common pitfalls of research and KT in indigenous health

Decolonizing research is possible when those who have been colonized are in a position to determine how and what research is practiced (Smith, 2012; Tuck, 2013). Conducting research on or with Indigenous people is frequently framed as understanding and proposing solutions to Indigenous problems (Porsanger, 2004). Academic research on Indigenous people has largely been conducted and interpreted by non-Indigenous researchers who benefit professionally, politically, or economically (Bishop, 2003; Smith, 2012). Meanwhile, Indigenous peoples and communities continually experience being misrepresented, passive objects of research, and excluded from discussions about research designs and findings (Hanson & Smylie, 2006; Rikhy, Jack, Campbell, & Tough, 2008; Smith, 2012). Despite efforts to redress health inequities among Indigenous peoples in Canada and other settler states, major health disparities remain (Malcolm King, Smith, & Gracey, 2009; Mitrou et al., 2014).

In the same way Indigenous people have rights to self-determination, access to culturally safe services, and respect for Indigenous knowledge and practices, Indigenous communities have a right to decide *how* and *what* research is conducted within their community. Leading Indigenous scholars have argued that KT strategies with Indigenous peoples must be re-conceptualized and evaluated (Estey, Kmetic, & Reading, 2008; Estey, Smylie, & Macaulay, 2009; Hanson & Smylie, 2006; Ranford & Warry, 2006; Smylie et al., 2014). While Canada's federal health funding agency distinguishes Indigenous KT from general population integrated and end-of-grant KT approaches (Table 1), there are no consistent mechanisms or resources for Indigenous communities to hold researchers accountable for adhering to Indigenous KT principles. Similarly, researchers and community stakeholders are not always clear about how to put guiding principles into research practice (Morton Ninomiya & Pollock, 2017).

#### Decolonizing research principles and IE

#### Decolonizing research principles

Decolonizing research has several main tenets including recognizing and building on communityspecific Indigenous worldviews, ensuring that research processes and findings are contextually relevant holding researchers accountable to communities, and lastly, resisting, critiquing, or

Table 1.	KΤ	definitions	for	health	research.
----------	----	-------------	-----	--------	-----------

Guide to knowledge translation planning at CIHR (Canadian Institutes for Health Research, 2012)	Institute for Aboriginal Peoples' Health (Estey et al., 2009)		
Institutes for Health Research, 2012) Integrated KT (iKT) Researchers and research users collaborate throughout research – from development to dissemination. End-of-Grant KT Research findings get disseminated to 'knowledge users'; range from publications, tailored messages for target audiences, and commercialization.	<ul> <li>Institute for Aboriginal Peoples' Health (Estey et al., 2009)</li> <li>Indigenous KT</li> <li>Draw and build on Indigenous practices, knowledge sharing, and concepts of health and well-being.</li> <li>Practice the 4R's of research (respect, reciprocity, relevance, and responsibility).</li> <li>Follow ownership, control, access, and possession (OCAP) principles.</li> <li>When doing <i>integrated KT</i>, utilize the multiple types of knowledge and ways of knowing.</li> <li>When doing <i>end-of-grant KT</i>, consider how to get messages out in partnership with community members,</li> </ul>		
	Aboriginal/Indigenous community-based organizations, and Aboriginal/Indigenous leaders/elders.		

emancipating power structures that are responsible for social inequities (Brown & Strega, 2005; Kovach, 2009; Smith, 1997, 2012). Decolonizing health research draws on critical theory by arguing that dominant research pedagogies must be replaced with local Indigenous ways of knowing and doing (Denzin, Lincoln, & Smith, 2008). The challenge often lies in creating and navigating an 'ethical space' where researchers and Indigenous communities members must learn about each other's ways of knowing to determine the goals and process of research (Ermine, Sinclair, & Jeffery, 2004). In decolonizing research, Indigenous communities not only decide how and what research to be involved with, but also determine how research can dismantle or challenge colonial policies and practices within institutions. Researchers in Indigenous health must be reflexive as they navigate tensions between community and academic institutional priorities (de Leeuw et al., 2012; Kobayashi, 2003; Morton Ninomiya & Pollock, 2017).

In Canada, a national research policy statement with a specific section on research involving Indigenous people sets out the foundational ethics of health research involving Indigenous peoples (Secretariat on Responsible Conduct of Research, 2014). Indigenous health research frameworks have several common values which are often applied in context-specific ways. The core elements of these frameworks generally include: local control, reciprocity, respectful communication, trauma-informed approaches, and the use of research methodologies that serve and benefit Indigenous communities (Hart, 2010; NHMRC, 2009; Kovach, 2009; Taylor & Kukutai, 2016; Weber-Pillwax, 2001; Wilson, 2008). Such frameworks are largely built on scholarship and policy work related to Indigenous self-determination, knowledge systems, and values in research (Australian Government, 2014; Hudson, Milne, Reynolds, Russell, & Smith, 2010; Secretariat on Responsible Conduct of Research, 2014).

KT approaches and activities are also an essential component of decolonizing research practices. Estey et al. (2010) suggested four important activities for researchers in the context of planning KT with Indigenous peoples across Canada. First, clarify what KT means to both Indigenous communities and researchers. Second, acknowledge past negative research experiences between Indigenous research participants and researchers and discuss how similar experiences can be mitigated. Third, reach consensus on what 'doing KT' will look like for the project. And last, discuss and agree on stakeholder roles and responsibilities in KT activities.

#### Institutional ethnography

IE is a method of inquiry that developed from sociology and has commonalities with critical anthropology. IE has been used to understand the social organization of health work – through, by, and within health care institutions. Rather than generating or testing theory, IE aims to produce

evidence that maps how peoples' activities and labor are invisibly coordinated by institutional texts. *Institution* in IE refers to any organization that functions to coordinate or organize peoples' activities, often from a distance and invisible to the people being coordinated (Smith, 1999). *Ethnography* comprises detailing everyday experiences of people through descriptions of their surroundings, circumstances, and activities – through observation, interviews, and/or detailed textual documentation of experiences.

Smith (2013) argues that people rarely see how lived experiences are connected to institutional practices. Researchers using IE aim to reveal how particular peoples' everyday experiences are connected to observable social relations that are mediated by institutional work. In short, IE studies make visible a concept called *ruling relations* that form a constellation of social relations. IE studies reveal (a) how power is built into the way institutions are organized to accomplish particular goals, as opposed to the individuals who *do* the organizational work (Foucault, 1979); and (b) material conditions that inform how and what people can produce (Marx & Engels, 1976). Researchers using IE are tasked with mapping the ways in which particular experiences are coordinated by *ruling relations* that are driven by institutional texts. Ruling relations are typically embedded in policies, forms, procedures, and other regulations activated by employees, who are often far removed from the original setting. For example, there are ruling relations between parents who advocate for supports for their children, school staff that follow administrative protocols for assessments and documentation, boards of education members who follow decision-making policies, and provincial government employees that adhere to protocols for determining funding based on eligibility criteria.

IE has the capacity to make visible how health, economic, environmental, and other policies are linked to large health disparities between Indigenous and non-Indigenous populations (Frohlich, Ross, & Richmond, 2006; Richmond & Ross, 2009). By teasing apart how non-Indigenous policies and practices are applied in Indigenous contexts, IE can illustrate how institutional work, despite best intentions, often serves to further disadvantage Indigenous peoples.

#### Decolonizing aspects of IE

Three aspects of IE position it as a decolonizing method of inquiry: methodological flexibility, the empirical commitment and attention to institutional texts, and the ability to facilitate KT through contact with people who work at multiple institutional levels. Each of these aspects are discussed in turn.

#### Methodological flexibility

Many IE studies are based on interviews, observations, and document analyses completed by a single academic researcher (Travers, 2016). In our view, IE offers an emancipatory method of inquiry due to its methodological flexibility. For example, IE has the ability to involve community members and stakeholders in all aspects of the study including development, data collection, analysis, and dissemination of the results. In the study development stage of research, community collaborators can share knowledge about community history, culture, and relationships with non-Indigenous institutions. Similarly, as data collection tools are being developed, community stakeholders can be involved in reviewing and adding questions that, while not critical to IE research questions, may serve to generate relevant and valuable knowledge for the community. At the dissemination of findings stage of research, community leaders and stakeholders may advise and be involved in the presentation of findings to different populations such as Chief and Band Council, health directors, regional health authorities, other outside government representatives, and the academic community.

#### Empirical commitment and attention to institutional texts

The empirical nature of IE can serve Indigenous communities and non-Indigenous institutional staff well. IE data analysis is usually focused on mapping how institutional texts organize people's lives. In other words, findings from IE studies include showing how people's actions are guided by text,

224 👄 M. E. MORTON NINOMIYA ET AL.

by people working *within* institutions as well as people who are 'served' by institutions. Similar to a conflict resolution motto, 'focus on the problem, not the person', an IE researcher's gaze is focused on institutional work, not individual people. This focus can make institutional stakeholders more willing to participate in interviews, engage in discussions about findings, and get involved in recommendations. We suggest that focusing on texts and institutional work rather than individuals enables productive discussions of colonizing practices and policy.

#### Effective KT through contact with people at multiple institutional levels

An integrated KT approach aims to engage key stakeholders and target audiences throughout the research lifecycle. By building stakeholder investment in research results, KT maximizes the potential uptake of research findings. In IE, researchers document how local accounts of everyday lived experiences are directly linked to institutions that regulate those experiences as well as document institutional work done by *translocal informants*, informants that are far removed from the first and local informants. Translocal informants play an important role in creating, deciding on, or enforcing governing texts such as institutional forms, protocols, and policies. In short, IE studies often include informants that are also stakeholders that can play an important role in the uptake of research findings and recommendations. Scholarship in Indigenous health research suggests that having champions and engaging influential stakeholders is necessary to making research credible and useful to communities (Ranford & Warry, 2006; Smith, 2012; Smylie, 2011). Effective KT strategies often include identifying and building strategic relationships with target audiences, particularly policy and decision-makers (Canadian Health Services Research Foundation, n.d.; Canadian Health Services Research Foundation, 2001; Ross, Lavis, Rodriguez, Woodside, & Denis, 2003) and IE is well positioned to facilitate this naturally.

#### How an IE study in an Indigenous community came to be

Sheshatshiu Innu First Nation (SIFN) is a rural Indigenous community in northeastern Canada with a population of approximately 1300 (Statistics Canada, 2017). The Sheshatshiu Innu are historically a nomadic people whose traditional territory covers parts of Labrador and Quebec. Today, the Labrador Innu have a land claim that includes 5000 square miles of land in Labrador (Olthuis Kleer Townshend, 2018). With increased numbers of settlers and forestry developments in the early 1900s came decreased numbers of caribou and other sources of food that permanently changed the way of life for the Innu. By the 1960s, Innu families lived year-round on a settlement and sent their children to school. The cumulative effects of colonization through settlement, church-based schooling, child welfare, racism, and loss of subsistence living, have played a large role in the use of alcohol as a coping mechanism for some people in the community.

The issue of fetal alcohol spectrum disorder (FASD) became public and gained media attention in the early 2000s when a pediatric geneticist assessed many children in the community for FASD. After a number of children in the community were diagnosed, a FASD Coordinator staff position in SIFN was created to work in the area of FASD prevention and diagnostic referrals.

Following a large provincial forum in 2008 on the state of FASD services in Newfoundland and Labrador, the lead author (MMN) contacted stakeholders across the province to ask what FASD research questions they wanted answered. A nurse in SIFN offered a few FASD research ideas that led to a meeting with key community stakeholders in 2009. MMN was unsure if the process for initiating this study would be seen as reproducing colonial ways of conducting research since she approached community members to ask if a study on FASD might be valuable to the community rather than being approached by the community.

FASD is a medical diagnosis for neurodevelopmental disabilities resulting from prenatal alcohol exposure. By definition, FASD links disabilities with birth mothers, which can lead to 'mother-blame' and stigmatizing women who drink alcohol in their reproductive years. In the early stages of discussing the idea of doing research related to FASD in SIFN, three points became clear. First,

several community leaders were keen to talk about how research could address community concerns about FASD. At the same time, other community leaders expressed concern about how research might further stigmatize families and the community. These discussions took place in the context of an unofficial moratorium on research in the community, the result of extensive experiences with projects that offered little or no benefit to the community, causing harm in some cases. Several Innu people shared stories of past researchers who publicly shared findings without community permission. Others described how media portrayed FASD as an 'Indigenous problem' in part due to FASD studies undertaken in Indigenous communities in disrespectful ways.

After 18 months of conversations with community stakeholders, we decided to go forward with the study. At the start, there was no formal process for community-research licensing. The methods used were iterative and focused on a relational approach to community consent. We assessed potential community benefits from a FASD study, discerned how the research could be undertaken without stigmatizing individuals or the community, discussed the relevance of MMN as a foster parent to a child with an FASD diagnosis, and decided who would be involved in the project. The study was endorsed by the SIFN Band Council, approved by the Innu Education Board of Trustees, and licensed by the Newfoundland and Labrador Health Research Ethics Authority (#12.110). The research process is described elsewhere (Morton Ninomiya & Pollock, 2017). Our objective was to make the work of caregivers, community resources, and institutions visible using IE and to reveal points of tension where assumptions of what was happening was at odds with peoples' lived experiences.

SIFN requested a strength-based research approach be used to minimize the likelihood that the results would stigmatize the community. Research methods and the dissemination plan were jointed determined to reduce the risk of misinterpretation and harm to the community. Throughout this study, community stakeholders demonstrated a strong commitment to relationship building with MMN and other stakeholders from outside the community. MMN and other key community stakeholders intentionally engaged with people of diverse perspectives and worked collaboratively to mitigate and address community concerns as they arose.

#### Decolonizing practices: adaptations made at different stages of research

There was no clear guidance on how to marry Indigenous and decolonizing research principles with IE. Prior to this study, we were only aware of one other IE study that explicitly involved Indigenous people and chose IE for its attention to colonial ruling relations. Using IE, Restoule et al. (2013) examined how post-secondary educational institutions both supported and hindered Indigenous student enrolment and experiences of success after entering programs. Our study was different from Resoule et al (2013) in that ours was situated in a specific Indigenous community that was also involved in the study design from the outset.

Key stakeholders in SIFN were supportive and interested in a study that could improve supports for children, youth, and adults living with FASD, inform key community stakeholders, and avoid further stigmatization of the community or of individuals living with FASD. In the following sections, we highlight adaptations that were made at the development, data collection and analysis, and dissemination phases of the study.

#### Research development phase

In the research development stage, MMN and community stakeholders jointly held two face-toface group meetings to explore what kind of FASD research was needed to address FASD-related community concerns. The group meetings were in addition to 10 consultation meetings between MMN and community leaders, influential community members, and institutional stakeholders in health, education, and child welfare. The first group meeting provided limited direction. When questions were reframed to ask what the community wanted to see happen, stakeholders called for more information on how to better support and advocate for people living with FASD, with or without a diagnosis. MMN outlined proposed research questions and used a visual illustration to

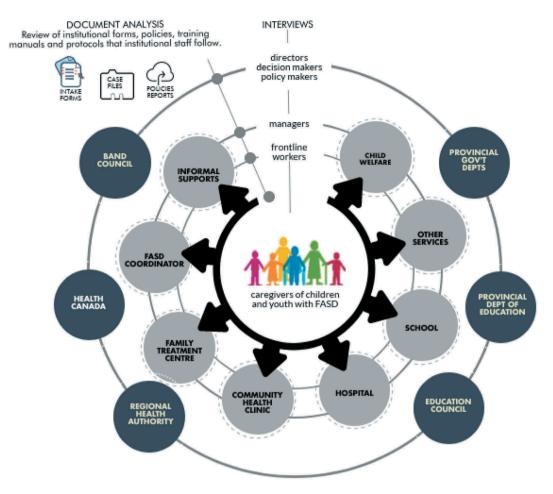


Figure 1. Diagram of the IE study design on FASD.

describe an IE research study design to show how the questions would be answered (Figure 1). A community-research agreement was created and outlined how MMN would consult and share updates with identified community leaders and stakeholders throughout the data collection and analysis stage. The agreement outlined how research data was owned, stored, and accessed by the community as well as how permission would be granted for disseminating research findings outside of the community. One community stakeholder emphasized the importance of using a strengths-based approach to counter and prevent community stigma.

People leading this study took a relational approach to fulfilling commitments outlined in the community-researcher agreement. This relational approach involved getting to know each other through social activities that were not work related such as visiting each other's homes, getting to know extended family members, and attending community-wide celebrations and memorials. Building authentic relationships was a priority for people leading this study, from the first conversation until data collection was complete three years later.

#### Data collection and analysis phase

Only caregivers who had children with a confirmed FASD diagnosis were included in the study. The FASD Liaison worker identified caregivers who had children with confirmed FASD and invited them to participate in an interview. Key people and institutions responsible for supports and services for

families that had a child with an FASD diagnosis were identified by caregivers during their interview.

The lead researcher (MMN) maintained contact with research informants throughout the data collection phase while she developed a visual map that tracked institutions and institutional processes and texts. As the map of accessed supports and services grew, MMN was able to connect caregivers to service providers that they did not realize existed and more often, connected service providers in one jurisdiction to service providers in another jurisdiction with the same 'clients'. Similarly, MMN's involvement on local, regional, provincial, and national FASD-related committees meant that she could share the latest approaches from other jurisdictions, material resources, and networking connections with stakeholders in SIFN.

One of the areas of concern and interest identified by caregivers and frontline workers during interviews was the lack of opportunities to learn more about FASD. In response, SIFN hired an experienced FASD educator to deliver training in their community. MMN was aware the Nunatsiavut Government (Inuit) in Labrador was trying to secure funding for FASD training. As a result, SIFN collaborated with the Nunatsiavut Government to offer FASD training sessions for front line staff and caregivers from across the region. This initiative led to an ongoing and regional collaboration related to FASD. One of the initiatives that has taken place since this study was completed in 2015 was the development of an Innu-specific FASD educational workshop that people within the community were trained to deliver.

During informant interviews with caregivers, the lead researcher disclosed her personal experience as a foster parent to a child with an FASD diagnosis. To ensure consistency, MMN disclosed information about her identity to participants whenever interviewing caregivers of children with a FASD diagnosis. This was done to convey to other caregivers that this topic was of long-term personal and professional interest, not just connected to a research project. Disclosure also helped create an interview experience that was conversational, demonstrated investment in a potential relationship, and established any distant kinship connections between the researcher's child and people in the community. In the Innu contexts, as with many Indigenous communities, kinship ties are central to building and fostering relationships, and relationships are central to ethical research practices in many Indigenous community contents (Bull, 2010; Morgan & Lamb, 2012; de Leeuw et al., 2012).

When researchers using IE share a similar identity as the informants, they can 'neglect to interrogate and challenge the very language, concepts, notions, and ideas' that are familiar and taken for granted (Bisaillon, 2012, p. 614). This phenomenon of not recognizing implicitly familiar language, concepts, notions, or ideas is called *institutional capture* and can get in the way of critically examining important ruling relations. In this study, MMN was diligent in asking for clarification or explanations on work processes that informants assumed MMN would know or understand. For example, extra probing was used when an informant referenced 'home visits' by a child welfare social worker and when another informant mentioned that their child's teacher 'doesn't get FASD'.

#### End-of-project KT phase

During community presentations, findings and recommendations were discussed. There was substantial overlap in the recommendations that we offered based on the research findings compared with informant recommendations. MMN was invited to serve on an FASD Working Group and submit a research report to inform the FASD Working Group's multi-year work plan. Recommendations from this research were incorporated into the community's health strategy, which was designed by Indigenous leaders in the community. In the three years following the completion of the FASD study, the community has invited MMN to participate on the FASD Working Group to co-develop and help implement a multi-year strategic action plan with the community. Of the 10 action items, a critical one is to develop, implement, and evaluate a community-wide FASD prevention strategy in the two Innu communities in Labrador.

#### Strengths and limitations

To date, this is the first study that used IE in an Indigenous context and integrated OCAP<sup>®</sup> (First Nations Centre, 2007) research principles and ethical frameworks throughout all phases of the study (Morton Ninomiya & Pollock, 2017). As a decolonizing method of inquiry, IE is well positioned to reveal how institutions continue to regulate and colonize Indigenous peoples' lives and communities in insidious ways. One of the strengths of this study was the use of visual maps as a knowledge sharing method. This was an effective way to communicate findings and recommendations with diverse stakeholders IE studies involve tracing and mapping how institutional texts are used to coordinate peoples' activities – starting with the lived experiences of a particular group of people to untangle how institutional work is linked to lived experiences. This process also involves documenting how policies, forms, protocols, training, and other institutional texts coordinate work. In this study, maps and infographics were instrumental in describing and discussing what the study aimed to discover, how data was to be collected, and what was revealed. In community presentations, visual maps were used to:

- (1) discuss the range of services available versus services that were being used;
- (2) show caregivers how institutional intake processes, assessments, referrals, and (the lack of) client data sharing was connected to specific supports and services offered to children with FASD; and
- (3) show service providers how much work and knowledge caregivers were required to do/have in order to secure or demonstrate adequate 'care' for their children. (Morton Ninomiya, 2017).

A limitation of using IE was the challenge of presenting findings in a manner that served the community well. While this IE study produced evidence of colonialist practices and policies within powerful institutions such as the child welfare system, presenting these findings in an academic setting, such as peer reviewed publications did not directly benefit those implicated in the results. Great care was taken by the research team to engage institutional interviewees in the later phases of the study when research findings and recommendations were being discussed and implemented. We recognized that sharing findings could cast a negative light on particular institutions and de-motivate new community 'champions' that were making improvements to the way they were providing supports to families with children with FASD. We suggest that writing critically in a public arena about government organizations who need to be part of the solution may not necessarily motivate individuals within these organizations to make institutional changes. Nor does it foster improved relationships.

Earlier in this paper, we highlighted that IE focuses on institutional texts that guide the work of institutional staff rather than lay blame with individuals within institutions. In addition, IE studies also reveal how assumptions about what is happening – through institutional work – is at odds with what is actually happening. Revealing these points of tension highlight how people working within non-Indigenous institutions may not be aware of how their work is tied to invisible institutional processes and policies, and how work has unintended consequences in the everyday lives of people the institution aims to serve. In this study, institutional informants responsible for local institutional policy and programs were motivated, after hearing key findings of the study, to implement changes but not necessarily 'bite the hand that feeds them'. Changes at the community level were done in small increments as government frontline, managers, and middle management staff are often averse to criticizing institutional policies or challenging their superiors, for fear of losing their job or being reprimanded.

We are not arguing that public critique of colonial actions by institutions be muzzled but rather that *how* institutions are held accountable to Indigenous communities is up to Indigenous communities themselves. In this study's case, the research was aimed at identifying and addressing problematic areas that disserve children with FASD and their caregivers. The research process itself facilitated decision-makers' investment and engagement to start addressing problematic issues that were not previously understood.

#### Conclusion

When implemented in a collaborative and participatory manner, IE can be a decolonizing method of inquiry that honors lived experience, reveals institutional and colonial practices, and provides tangible benefits to Indigenous communities during the research process. Many in the Indigenous research space acknowledge the burden of Western research approaches on communities. Some communities have clarified that their research fatigue is tied to being part of research that they have not requested, benefited from, or had control over.

To address these concerns, community-based research encourages community members to be highly involved in all stages of research. However, high levels of community involvement are not always possible or desirable. In a rural Indigenous community with limited human and financial resources as well as competing urgent priorities, it may not be fair or pragmatic to expect community members to invest a lot of time on research projects. Indigenous communities may choose to advise and be consulted throughout a study *without* being directly involved in the recruitment, data collection and analysis, and sharing of findings (de Leeuw et al., 2012). Researchers must continue to think creatively about using methodologies from various fields – such as IE from sociology – and adapt them to fit the local context while expanding the possibilities for decolonizing research. Just as researchers and Indigenous people involved in research must discuss differing epistemologies, they must also continue to engage in dialogue about how to best conduct decolonizing research that is authentic, respectful, and that serves the interests of communities.

#### Acknowledgements

The authors would like to thank the Innu Minuinniuin Committee and the Innu Health and Healing Asset Map Committee Members for their work on the research that informed this paper. The authors also greatly appreciate Fern Brunger, Nathanial Pollock, and Raglan Maddox for their constructive and helpful feedback on earlier versions of this manuscript.

#### **Disclosure statement**

No potential conflict of interest was reported by the authors.

#### Funding

This work was supported by the Institute of Aboriginal Peoples Health [120450,132340]; Memorial University of Newfoundland [F. A. Aldrich Fellowship];Northern Scientific Training Program; Research and Development Corporation of Newfoundland and Labrador [5404.1440.101].

#### ORCID

Melody E. Morton Ninomiya (b) http://orcid.org/0000-0002-0196-3410

#### References

- Australian Government. (2014). Aboriginal and Torres Strait Islander: Health performance framework 2014 report. Canberra, Australia. Retrieved from https://www.pmc.gov.au/sites/default/files/publications/indigenous/Health-Performance-Framework-2014/aboriginal-and-torres-strait-islander-health-performance-framework-2014-report/ executive-summary.html
- Bisaillon, L. (2012). An analytic glossary to social inquiry using institutional and political activist ethnography. International Journal of Qualitative Methods, 11(5), 607–627.
- Bishop, R. (2003). Culture counts: Changing power relations in education. London: Zed Books.
- Brown, L., & Strega, S. (Eds.). (2005). *Research as resistance: Critical, indigenous, and anti-oppressive approaches*. Toronto: Canadian Scholars' Press.
- Browne, A. J., Smye, V. L., & Varcoe, C. (2005). The relevance of postcolonial theoretical perspectives to research in aboriginal health. *Canadian Journal of Nursing Research*, 37(4), 16–37.

- Bull, J. R. (2010). Research with aboriginal peoples: Authentic relationships as a precursor to ethical research. Journal of Empirical Research on Human Research Ethics, 5(4), 13–22.
- Canadian Health Services Research Foundation. (2001). *Knowledge transfer: Looking beyond health* (Conference report). Ottawa, ON: CHSRF.
- Canadian Health Services Research Foundation. (n.d.). How to be a good research partner: A guide for health system managers and policy makers. Retrieved from http://www.chsrf.ca
- Canadian Institutes for Health Research. (2012). Guide to knowledge translation planning at CIHR: Integrated and endof-grant approaches. Retrieved from http://www.cihr-irsc.gc.ca/e/45321.html
- Castleden, H., Morgan, V. S., & Lamb, C. (2012). "I spent the first year drinking tea": Exploring Canadian university researchers' perspectives on community-based participatory research involving Indigenous peoples. *The Canadian Geographer*, *56*(2), 160–179.
- de Leeuw, S., Cameron, E. S., & Greenwood, M. L. (2012). Participatory and community-based research, indigenous geographies, and the spaces of friendship: A critical engagement. *The Canadian Geographer*, *56*(2), 180–194.
- Denzin, N. K., Lincoln, Y. S., & Smith, L. T. (Eds.). (2008). Handbook of critical and indigenous methodologies. London: Sage. Ermine, W., Sinclair, R., & Jeffery, B. (2004). The ethics of research involving indigenous peoples. Saskatoon, Saskatchewan: Indigenous Peoples' Health Research Centre.
- Estey, E. A., Kmetic, A., & Reading, J. (2008). Knowledge translation in the context of aboriginal health. *Canadian Journal of Nursing Research*, 40(2), 24–39.
- Estey, E. A., Kmetic, A. M., & Reading, J. L. (2010). Thinking about aboriginal KT: Learning from the network environments for aboriginal health research British Columbia. *Canadian Journal of Public Health*, 101(1), 83–86.
- Estey, E. A., Smylie, J. K., & Macaulay, A. (2009). Aboriginal knowledge translation: Understanding and respecting the distinct needs of Aboriginal communities in research. Ottawa: CIHR. Retrieved from http://www.cihr-irsc.gc.ca/e/ 41392.html
- First Nations Centre. (2007). OCAP: Ownership, control, access and possession. Sanctioned by the first nations information governance committee, assembly of first nations. Ottawa: National Aboriginal Health Organization.
- Foucault, M. (1979). Discipline and punish: The birth of the prison. London: Tavistock.
- Frohlich, K. L., Ross, N., & Richmond, C. (2006). Health disparities in Canada today: Some evidence and a theoretical framework. *Health Policy*, *79*(2–3), 132–143.
- Graham, I. D., Logan, J., Harrison, M. B., Straus, S. E., Tetroe, J., Caswell, W., & Robinson, N. (2006). Lost in knowledge translation: Time for a map? *Journal of Continuing Education in the Health Professions, 26*. doi:10.1002/chp.47
- Greenhalgh, T., & Wieringa, S. (2011). Is it time to drop the 'knowledge translation' metaphor? A critical literature review. Journal of the Royal Society of Medicine, 104(12), 501–509.
- Grimshaw, J. M., Eccles, M. P., Lavis, J. N., Hill, S. J., & Squires, J. E. (2012). Knowledge translation of research findings. Implementation Science, 7(1), 50.
- Hanson, P. G., & Smylie, J. K. (2006). Knowledge translation (KT) for indigenous communities: A policy making toolkit. Toronto. Retrieved from http://ahrnets.ca/files/2011/02/KT\_Policy\_Toolkit\_Indigenous\_Communities\_IPHRC.pdf
- Hart, M. A. (2010). Indigenous worldviews, knowledge, and research: The development of an indigenous research paradigm. *Journal of Indigenous Voices in Social Work*, 1(1), 16.
- Hudson, M., Milne, M., Reynolds, P., Russell, K., & Smith, B. (2010). Te ara tika guidelines for researchers and ethics committee members. Wellington, New Zealand. Retrieved from http://www.hrc.govt.nz/sites/default/files/Te%20Ara %20Tika%20Guidelines%20for%20Maori%20Research%20Ethics.pdf
- Inuit Tapiriit Kanatami. (2016). Inuit Tapitiit Kanatami submission to the Naylor Panel for Canada's Fundamental Science Review. Ottawa. Retrieved from https://itk.ca/wp-content/uploads/2017/03/ITK-Submission-to-the-Naylor-Panel-for-Canada%E2%80%99s-Fundamental-Science-Review.pdf
- Kendall, E., Sunderland, N., Barnett, L., Nalder, G., & Matthews, C. (2011). Beyond the rhetoric of participatory research in indigenous communities: Advances in Australia over the last decade. *Qualitative Health Research*, 21(12), 1719–1728.
- King, M. (2015). Contextualization of socio-culturally meaningful data. Canadian Journal of Public Health, 106(6), 457.
- King, M., Smith, A., & Gracey, M. (2009). Indigenous health part 2: The underlying causes of the health gap. *Lancet*, 374. doi:10.1016/s0140-6736(09)60827-8
- Kobayashi, A. (2003). GPC ten years on: Is self-reflexivity enough? Gender, Place & Culture, 10(4), 345-349.
- Kovach, M. (2009). Indigenous methodologies: Characteristics, conversation, and contexts. Toronto: University of Toronto Press. Marx, K., & Engels, F. (1976). The German ideology. Moscow: Progress Publishers.
- Mitrou, F., Cooke, M., Lawrence, D., Povah, D., Mobilia, E., Guimond, E., & Zubrick, S. R. (2014). Gaps in indigenous disadvantage not closing: A census cohort study of social determinants of health in Australia, Canada, and New Zealand from 1981–2006. *BMC Public Health*, *14*(1), 1–9.
- Morton Ninomiya, M. E. (2017). More than words: Using visual graphics for community-based health research. *Canadian Journal Public Health*, *108*(1), 91–94.
- Morton Ninomiya, M. E., & Pollock, N. (2017). Reconciling community-based Indigenous research and academic practices: Knowing principles is not always enough. *Social Science & Medicine*, *172*, 28–36.
- National Health and Medical Research Council (2009). *Australian guidelines to reduce health risks from drinking alcohol.* Canberra, Australia: Author.

- Olthuis Kleer Townshend. (2018). Labrador Innu sign historic land claim, self-government and hydro agreement. Retrieved from http://www.oktlaw.com/labrador-innu-sign-historic-land-claim-self-government-hydro-agreement/
- Porsanger, J. (2004). An essay about indigenous methodology. Nordlit: Special Issue on Northern Minorities, 15, 105– 120.
- Ranford, J., & Warry, W. (2006). Knowledge transfer/translation project summary report. Hamilton, Ontario. Retrieved from http://ahrnets.ca/files/2010/05/IHRDP-Knowledge-Translation-Summary-Report-IHRDP.pdf
- Restoule, J., Mashford-Pringle, A., Chacaby, M., Smillie, C., Brunette, C., & Russel, G. (2013). Supporting successful transitions to post-secondary education for indigenous students: Lessons from an institutional ethnography in Ontario, Canada. *International Indigenous Policy Journal*, *4*, 4.
- Richmond, C. A. M., & Ross, N. A. (2009). The determinants of first nation and Inuit health: A critical population health approach. *Health & Place*, 15(2), 403–411.
- Rikhy, S., Jack, M., Campbell, L., & Tough, S. (2008). Knowledge exchange as a vehicle to improve the health of aboriginal communities. *Pimatisiwin*, 5(2), 107–124.
- Ross, S., Lavis, J., Rodriguez, C., Woodside, J., & Denis, J. L. (2003). Partnership experiences: Involving decision-makers in the research process. *Journal of Health Services Research and Policy*, 8(S2), 26–34.
- Secretariat on Responsible Conduct of Research. (2014). *Tri-council policy statement: Ethical conduct for research involving humans*. Ottawa. Retrieved from http://www.pre.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-eptc2/Default
- Smith, D. E. (1999). Writing the social: Critique, theory, and investigations. Toronto: University of Toronto Press.
- Smith, D. E. (2013, June 20). [Weeklong Intensive Workshop on Institutional Ethnography].
- Smith, G. H. (1997). *The development of Kaupapa Maori: Theory and praxis* (Doctorate Doctoral Dissertation). Auckland: University of Auckland.
- Smith, L. T. (2012). Decolonizing methodologies: Research and indigenous peoples. New York: Zed Books Ltd.
- Smylie, J. K. (2011). Knowledge translation and indigenous communities: A decolonizing perspective. In E. M. Banister,
   B. J. Leadbeater, & E. A. Marshall (Eds.), *Knowledge translation in context: Indigenous, policy, and community settings* (pp. 181–208). Toronto: University of Toronto Press.
- Smylie, J. K., Kirst, M., McShane, K., Firestone, M., Wolfe, S., & O'Campo, P. (2015). Understanding the role of Indigenous community participation in indigenous prenatal and infant-toddler health promotion programs in Canada: A realist review. Social Science & Medicine, 150, 128–143.
- Smylie, J. K., Olding, M., & Ziegler, C. (2014). Sharing what we know about living a good life: Indigenous approaches to knowledge translation. Journal of the Canadian Health Libraries Association, 35(01), 16–23.
- Smylie, J. K., Williams, L., & Cooper, N. (2006). Culture-based literacy and aboriginal health. Canadian Journal of Public Health, 97(2), S21–S25.
- Stanton, C. R. (2013). Crossing methodological borders: Decolonizing community-based participatory research. *Qualitative Inquiry*, 20(5), 573–583.
- Statistics Canada. (2017). Sheshatshiu, Newfoundland and Labrador and Ontario: Census profile. 2016 Census. Retrieved from http://www12.statcan.gc.ca/census-recensement/2016/dp-pd/prof/index.cfm?Lang=E
- Taylor, J., & Kukutai, T. (Eds.). (2016). Indigenous data sovereignty: Toward an agenda. Acton, Australia: Australian National University Press.
- Travers, M. (2016). Book review: Dorothy E. Smith and Susan Marie Turner (eds), Incorporating texts into institutional ethnographies. *Qualitative Research Journal*, 16(4), 480–481.
- Truth and Reconciliation Commission of Canada. (2015). Honouring the truth, reconciling for the future: Summary of the final report of the Truth and Reconciliation Commission of Canada. Ottawa. Retrieved from http://www.trc.ca/ websites/trcinstitution/File/2015/Findings/Exec\_Summary\_2015\_05\_31\_web\_o.pdf

Tuck, E. (2013). Commentary: Decolonizing methodologies 15 years later. AlterNative, 9(4), 365-372.

Weber-Pillwax, C. (2001). Orality in Northern Cree Indigenous worlds. *Canadian Journal of Native Education*, *25*(2), 149–165. Wilson, S. (2008). *Research is ceremony: Indigenous research methods*. Halifax: Fernwood Publishing.