

“Nothing About Us, without Us.” How Community-Based Participatory Research Methods Were Adapted in an Indigenous End-of-Life Study Using Previously Collected Data

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RÉSUMÉ

La recherche en santé autochtone au Canada a été négligée dans le passé et qualifiée de problématique, notamment en raison du manque de collaboration avec les peuples autochtones. *L'Énoncé de politique des trois Conseils sur l'éthique de la recherche avec des êtres humains* décrit au chapitre 9 la conduite éthique de la recherche axée sur les Premières nations, les Inuits et les Métis. Les principes PCAP® des Premières nations (propriété, contrôle, accès et possession) soulignent l'importance majeure de l'engagement et de la gouvernance autochtones. En vue d'assurer que les buts et les activités de la recherche développée soient réalisés en partenariat complet et significatif avec les peuples et les communautés autochtones, il est possible de faire appel à des méthodes de recherche participative communautaire (RPC) intégrant leur plein engagement. Les recherches utilisant des ensembles de données secondaires, telles que les données administratives sur la santé recueillies en routine, ne devraient plus être exclues de cette approche. Notre objectif était de décrire comment notre équipe de chercheurs universitaires, alliée à un organisme national de santé autochtone, a adapté les méthodes de RPC dans le cadre d'un projet de recherche utilisant des données recueillies antérieurement pour examiner les lacunes dans la prestation de soins de fin de vie aux peuples autochtones en Ontario. Nous décrivons le processus d'élaboration de ce partenariat de recherche et expliquons comment l'intégration des principes de base et des processus de formation du savoir autochtones ont guidé cette collaboration. Notre partenariat de recherche, qui implique l'adaptation de méthodes de RPC, illustre un processus d'engagement qui pourrait guider d'autres chercheurs désirant mener des recherches en santé autochtone à l'aide de données déjà recueillies. Nous faisons aussi état d'une entente de recherche transparente, négociée équitablement entre un organisme national de santé autochtone et des chercheurs, qui pourrait servir de cadre pour des collaborations de recherche similaires. Il est essentiel de s'assurer que les perspectives autochtones soient au cœur des processus de recherche et qu'elles soient reflétées dans ceux-ci lorsque des données administratives sur la santé sont utilisées.

ABSTRACT

Indigenous health research in Canada has a chequered past and has been identified as problematic and lacking in appropriate collaboration with Indigenous people. *The Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans*, Chapter 9 describes ethical conduct of research regarding First Nations, Inuit, and Métis Peoples. First Nations Ownership, Control, Access, and Possession (OCAP®) Principles highlight the necessity of Indigenous engagement and governance. To ensure that the aims and activities of the research being developed are in full and meaningful partnership with Indigenous peoples and communities, community-based participatory research (CBPR) methods provide a process in which full engagement is possible. Research utilizing secondary data sets, such as routinely collected health administrative data, should no longer be excluded from this approach. Our aim was to describe how our research team of academic researchers and a national Indigenous health organization adapted CBPR methods in a research project using previously collected data to examine end-of-life health care service delivery gaps for Indigenous people in Ontario. We describe the process of how we developed our research partnership and how grounding principles and Indigenous ways of knowing guided our work together. Through the adaptation of CBPR methods, our research partnership illustrates a process of engagement that can guide others hoping to conduct Indigenous health research using previously collected data. We also present a transparent research agreement negotiated equally by a national Indigenous health organization and research scientists, which can also be used as a framework for others wishing to establish similar research partnerships. Ensuring that Indigenous perspectives are central to and reflected in the research process is essential when using health administrative data.

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We call upon the federal government, in consultation with Aboriginal peoples, to establish measurable goals to identify and close the gaps in health outcomes between Aboriginal and non-Aboriginal communities...

Truth and Reconciliation Commission (2015)

Background

Among the 94 calls to action in the 2015 *Truth and Reconciliation Commission Report* (TRC), published reports on health indicators are identified as a necessity to measure and achieve equity in Indigenous¹ health (Truth and Reconciliation Commission of Canada, 2015). Recent adoption of the United Declaration on the Rights of Indigenous Peoples (UNDRIP) by the Canadian government also highlights the rights of autonomy and ownership over the design, delivery, and evaluation of health services by which policies are developed (United Nations, 2007). However, the legacy of research being completed without respectful engagement with Indigenous communities is a growing concern (Tobias, Richmond, & Luginaah, 2013), and has been identified as problematic and lacking in appropriate collaboration with Indigenous groups (Erasmus & Dussault, 1996; MacDonald, Stanwick, & Lynk, 2014; Mosby, 2016; Schnarch, 2004). For Indigenous health statistics to be meaningful, the collection and analysis of data must be performed in partnership with

Indigenous peoples, organizations, and government agencies (Smylie & Firestone 2015).

One example of harmful research with Indigenous peoples is the nutritional experiments conducted in residential schools during the 1940s and 1950s, in which Indigenous children were malnourished for the "sake of scientific inquiry" (Mosby, 2016). The Royal Commission Report on Aboriginal People (1996) recognized the problematic use of Indigenous data without the consent of Indigenous people. First Nations communities, in particular, have felt that they have been "researched to death" and have gained very little benefit as a result (Schnarch, 2004). It is no surprise that a lack of trust in research is common among Indigenous people. For this reason alone, it is essential to establish trusting relationships when conducting Indigenous research projects.. To ensure that the aims and activities of the research being developed are in full and meaningful partnership with Indigenous peoples and communities, community-based participatory research (CBPR) methods provide a process in which full engagement is possible. CBPR advocates for the community of study to be a full partner in the research (Israel, Shultz, Parker, & Becker, 1998). Research utilizing secondary data sets, such as routinely collected health administrative data, should no longer be excluded from this approach, as it is essential to engage Indigenous communities and organizations as full participants in the research process.

The Tri-Council Policy Statement on the Ethical Conduct of Research Involving Humans (TCPS-2), Chapter 9 describes ethical research behaviour when conducting research with First Nations, Inuit, and Métis peoples (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada Government of Canada, 2014). These research ethical guidelines align with CBPR in that they highlight the importance of reciprocity when conducting research involving First Nations, Inuit, and Métis people. Historically, research involving First Nations, Inuit, and Métis communities has been primarily conducted by non-Indigenous scholars. As such, concern for empowering the community to attain research skills may not have been an objective of the research process in the past. TCPS-2 states that there is an obligation by researchers to give something back to the community during the research process. In honouring the principle of reciprocity, non-Indigenous researchers would ideally conduct research alongside of Indigenous researchers. In an even more ideal world, Indigenous research would be led by Indigenous community needs. Respectful engagement with Indigenous communities from the outset of the research project is stated as an essential requirement, and a collaborative and participatory research process is encouraged. Participatory action research is defined by TCPS-2 as a process of collaboration from the design of the research project, to the collection and analysis the data, to the production of a final product to an action based on the results. TCPS-2 describes this research process as being “based on respect, relevance, reciprocity and mutual responsibility.”

First Nations’ principles of data governance are specified by the First Nations Information Governance Centre (FNIGC) in Ownership, Control, Access, and Possession (OCAP®) Principles. These research ethical principles assert that First Nations data must be owned, controlled, accessed, and possessed by First Nations. The first principle refers to a First Nations community’s right to own their own information, whether that be cultural knowledge or data. The second principle attests that First Nations control the research process from its inception to the finalization. The third principle indicates how and when First Nations people can access their own information and data. The fourth and final principle of possession refers to data stewardship and refers to “the physical control of the data” (First Nations Information Governance Centre, 2014). It is important to note that OCAP principles may not necessarily apply when the study population represents either Métis, Inuit, or a mix of all the Indigenous groups.

Engagement of First Nations, Inuit, and/or Métis communities in the ways described can mitigate the harms of research involving Indigenous peoples that have been

noted in the past, such as disregard for Indigenous ways of knowing, misinterpretation of the truth, further stigmatization, and marginalization (Schnarch, 2004). The risk of such harms can be even greater when conducting research involving secondary analysis of routinely collected health administrative data, which in most cases were collected in the absence of collaboration or consultation with Indigenous people. In the case of conducting research using routinely collected health administrative data, in which individual identity is erased and data are anonymized using encrypted health card numbers, it is not possible to identify a community with which to engage in the way that is intended using community-participatory research methods. For these reasons, it may be challenging to apply CBPR methods as described in TCPS-2, Chapter 9 in these situations in which research is conducted using previously collected data. OCAP principles may be relevant for conducting primary research with First Nations communities and organizations, but require adaptation when using previously collected data.

Formal agreements between Indigenous communities/ organizations and non-Indigenous institutions have been developed to describe the oversight, decision making, legislation, policies, procedures, protocols, and practices that define the management of data. The formal agreements in the form of data governance agreements may also be intended to ensure that, “regardless of where data is stored...it is protected and provides meaning and value” to First Nations groups (Mustimuhw Information Solutions Inc., 2015). Data governance agreements have gained acceptance in recent years (Bruhn, 2014), particularly between government agencies and Indigenous communities and organizations (Dudgeon & Kristjanson, 1995; Government of Newfoundland and Labrador, 2007; Tripartite Project Coordination Team, 2016). Despite the recognition that applying the research ethics principles in TCPS-2, along with the First Nations OCAP Principles, is essential when conducting Indigenous health research (Campbell, 2014), how to operationalize the concept of data governance and research ethical principles when data were previously collected may pose a challenge to researchers.

Objectives

Our research partnership formed to identify gaps in end-of-life health care service delivery to Indigenous people who received provincially funded home care services in Ontario, Canada. It is well known that most people prefer to die at home or in their communities (Dudgeon & Kristjanson, 1995; Fraser, 2016; Habjan, Prince, & Kelley, 2012), but the extent to which these end-of-life preferences are actually experienced by Indigenous peoples in Ontario on a population

level is not known. The objectives of our research study were to describe end-of-life places of care and places of death for Indigenous people in Ontario who received provincially funded home care services, through the analysis of routinely collected health administrative data held at The Institute for Clinical Evaluative Sciences (ICES). This article will illustrate how our research team adapted community-based participatory research methods to conduct research using routinely collected data from health administrative databases in a population-level research project examining end-of-life care for Indigenous peoples in Ontario, Canada.

We will detail our steps of engagement, including the involvement of a national Indigenous health organization. Through this process, our research team adapted some of the well-known guidance documents and principles to guide our partnership agreement, which could support the goals of the research while protecting the rights and knowledge of Indigenous communities. By setting us on a good path, this partnership agreement provided a frame for working together to answer our research questions.

Creating a Collaborative Framework and Research Agreement

Dilemma Using Previously Collected Data: Who is the "Community" with Which to Collaborate?

Our research partnership was initiated by an academic research team, including two First Nations researchers who reflected on the need to involve an Indigenous organization that had a mandate for First Nations, Inuit, and Métis collective priorities in relation to palliative care and home care. As a result, a relationship with the Canadian Indigenous Nurses Association (CINA) emerged based on our mutual interests in the area of palliative care. A formal partnership was then established to meaningfully reflect both academic and Indigenous-led research priorities, values, and ways of knowing. CINA identified a need for this research to support their work in addressing frontline and health policy issues related to providing quality end-of-life care for Indigenous peoples in Canada.

Our partnership was formalized via a research partnership agreement. The first process of creating the research partnership agreement took eight months, from initial draft in September 2016 to signing the final version (see Figure 1). In February of 2017, following a tobacco offering (a traditional gesture when making a request from a respected Knowledge Holder) to the CINA Research Committee chair by one of the academic First Nations researchers, the research agreement was signed at a face-to-face



Figure 1: Timeline of engagement, first introduction to ethics approval

meeting at the Wabano Centre of Aboriginal Health in Ottawa, Ontario. The research team then applied for ethics clearance, which was received in May of 2017.

Establishing Guiding Principles

Prior to conducting the research, we spent a great deal of time establishing the guiding principles that would underpin our research and the ways in which the research partners would work together. As research partners, we determined that our relationship and project should be grounded in UNDRIP (United Nations, 2007). UNDRIP describes the rights of Indigenous people in 41 articles, several of which apply to health, which are to be recognized by states of the world. UNDRIP recognizes the rights of Indigenous people to establish their own priorities and improve their own health. For us, this meant that our research objectives and questions would reflect the priorities of Indigenous people as represented by CINA as full and equal partners in the research process.

The principle of *two-eyed seeing* was another important principle that guided how we would work together. This principle recognizes the importance of respecting both Indigenous and Western ways of knowing (Bartlett, Marshall, & Marshall, 2012). For us as research partners, this meant that all researchers in the partnership had something important to contribute and that Western approaches were not viewed as superior to Indigenous ways. All members of the research team were considered equal, and decisions were made based on consensus. Both of these guiding principles were explicitly stated in our research partnership agreement.

Adaptions of CBPR, TCPS-2, and OCAP

Our research process was guided by CBPR and TCPS-2, which require researchers to collaborate with “the community under study” from the inception of the research project. According to the TCPS-2, community is described as a collective group of individuals or organizations with mutual interests, which is what our partnership was based on. Prior to conducting the research, the research partnership agreed on objectives and research questions, which were then formalized in the research agreement. As this study was a population-level study using routinely collected health administrative data housed at ICES, the academic researchers arranged for the epidemiological analysis of the data. Once the analysis was complete, the research partnership met to review the results. Long discussions were had about how to interpret the data. Ways to mitigate any stigmatization of Indigenous people were agreed upon. The importance of understanding the limitations of the data was raised and discussions were had on how to best present these limitations. Final products of the project were collaboratively created (i.e., conference poster presentations, oral presentations, and journal manuscripts). No materials were disseminated outside

the research partnership without the awareness and agreement of all parties. There has yet to be a situation in which consensus by verbal agreement could not be achieved.

OCAP principles informed our research partnership, however, as we were not doing primary data collection, we only specified ownership in our research partnership agreement. We interpreted ownership as referring to the results and products of the research project. Within our agreement, we formalized what we meant by ownership. As a partnership, we agreed that we would co-own all products of the research.

Details of the Research Partnership Agreement

We based our research partnership agreement on the now-archived *Canadian Institute of Health Research (CIHR) Guidelines for Health Research Involving Aboriginal People* (Canadian Institutes of Health Research, 2007), which contained a research agreement template that provided the structure that our research partnership used. This structure contains sections regarding the parties to the agreement between the researchers and the community involved in the research; the purpose, scope and methods of the research project; a description of how researchers will interact with the community during the research process; specifics about data collection, sharing, distribution, ownership and storage; and funding, benefits, and commitments.

Initially, we needed to adapt the template provided by CIHR, as it was created for projects that involved primary data collection between a First Nations, Inuit, or Métis community and an outside organization, and did not reflect the nuances when using previously collected data. Sections of our research agreement were adapted to allow for appropriate wording changes when referencing academic researchers (“research scientists”) and research partners within CINA (“leadership, research chair/knowledge holder/knowledge user”). The following sections were included in our research agreement: intent of the document (details of the project and the terms of collaboration); parties to the document (details about what the research agreement pertains to); ownership; ethics approval process; and funding, benefits, and commitments (See Appendix).

Intent of the Document

This is an opening section that described who the research partners are and the intent of the agreement, which lay the foundation of how the research team would conduct the study (i.e., incorporate principles of two-eyed seeing, TCPS-2, and OCAP).

Parties to the Document

This section describes the members of the research partnership. It also declared that the parties agreed to conduct the research in a collaborative partnership and through processes of consensus. This section also included how the research team agreed to conduct the research project, and listed what the understandings of this conduct would be. For example, this section described the project, its methods, anticipated outcomes, and approvals. This section also described the participation of research team members. For example, partners agreed to ensure that Indigenous perspectives would be considered in all aspects of the research, from the cultural appropriateness of data gathering to the interpretation of results to identifying potential harms and the co-development of mitigation strategies. The research team also worked together to approve the research protocol, identify additional research questions, and embed wherever possible and plausible the practices and protocols of Indigenous peoples. Additional important details of the research agreement included a disclaimer indicating that each step of the research would ensure that the concerns raised by Indigenous partners were addressed, and that recommendations were incorporated. Rules for information sharing and knowledge translation of the research and research outcomes, such as how the research team would communicate with media and how publications would be managed, were also outlined.

Ownership

This section specifies the co-ownership of the research and research results by all members of the partnership. Ownership, in these contexts referred to the translation of knowledge and information, including conference presentations and manuscripts.

Ethics Approval Processes

The processes to obtain ethics approval through the academic and health care institutions were described in this section.

Funding, Benefits, and Commitments

This section describes issues commonly associated with academic research, including the naming of the Ministry of Health and Long-Term Care (Ontario) and CIHR as funders of the project, and the statement that no financial contributions were required by the Indigenous organization.

Benefits

Benefits specific to academic team members and the Indigenous organization were described in this section.

Benefits to the research team included peer-reviewed publications and conference presentations. Benefits to the Indigenous organization included those related to the work and outcomes of the study: using results as a basis for development of health education resources, authorship in associated reports and manuscripts, and collaboration with scientists using large databases, as well as possibilities for future research collaborations.

Commitments

Commitments by both the research team and the Indigenous organization were also described in this section. Indigenous organization commitments included support for community engagement, culturally relevant and appropriate interpretation of data (as appropriate), co-authorship of publications and oral presentations, the inclusion of Indigenous perspectives and interpretation of findings, and expertise in relation to culturally specific knowledge and information regarding study outcomes.

Research team commitments included informing CINA about the progress of the study; ensuring First Nation, Inuit, and Métis Elder/Knowledge Holders were acknowledged as was determined appropriate through the CINA Research Committee; and sharing opportunities for CINA to contribute to the knowledge translation and exchange of research outcomes.

Being that our study analysed health administrative data housed at ICES, the technical aspects of the study, such as epidemiological data analysis, were done by data analysts employed at ICES. Data analysts then supplied researchers with tables of results. Because the connection to ICES was primarily via the academic researchers, it was their commitment to the research partnership to keep CINA apprised of the progress of the analysis. When results were made available, the entire partnership met to review and interpret the results and CINA offered valuable insight into how to best interpret and document the findings.

This section also declared under what circumstances the research team might agree to interruption of the research, such as a decision by team members to withdraw their support or a conflict whereby culturally appropriate processes of consensus building could not be reached.

Discussion

In order to operationalize research ethical principles in the TCPS-2 and OCAP, we opted to adapt CBPR processes. We did so because CBPR is a well-established research method that recognizes the community as an equal partner in the research process. It is simple to conceptualize the CBPR process when thinking of studies involving specific Indigenous communities, in which the research in question is addressing a community concern,

particularly in qualitative research. For example, over the last few years, Six Nations of the Grand River has completed some community projects with the Centre for Community Based Research (CCBR) designed to improve health services in their First Nation community (Botschner & Lomotey, 2002; Fruch, Monture, Prince, & Kelley, 2016). These studies describe how the First Nations community was a full partner in the project from inception to finalization. One study (Fruch et al., 2016) examined how to improve palliative care services in the community. The study describes how the need for this study was community driven and how academic researchers supported the community to conduct the research. The study was led by a community advisory committee, and the research was facilitated by a community member and resulted in a successful palliative care program in the community. This study illustrates the importance of reciprocity in the research process, through which researchers are giving something back to the community and not simply conducting research to advance their own academic futures.

In our project using previously collected data, we had to creatively adapt CBPR methods. We built our partnership around the principles of “respect, relevance, reciprocity and mutual responsibility” (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada, 2014). In terms of respect, our research partnership recognized the unique skills each of us had to bring to the project. It should be noted that there is a risk when not partnering with Indigenous organizations (or communities) when conducting research using previously collected data, as it is unlikely that the research, discussion, or conclusion would reflect Indigenous perspectives. Non-Indigenous partners in these endeavours must understand the subject matter in order to ensure that research results have meaning for the needs and concerns of Indigenous peoples. For others thinking of conducting this type of research, when pursuing a research partner, it would be ideal that the partner represents the voice of the Indigenous groups identified in the study and understands the subject matter, that the area of research is meaningful to the partner, and that the partner can help disseminate the findings through its communication channels.

As an example, in our study, an “aboriginal” flag in the home care base was used, and for this reason a partnership with CINA, an Indigenous health organization, was sought to provide First Nations, Inuit, and Métis perspectives about data analysis in the end-of-life care study for Indigenous peoples. Possessing an understanding of Indigenous statistics and end-of-life and home care-related issues for Indigenous peoples, CINA was able to pose important research questions for the

study that could then uncover how home care services and places of death for Indigenous peoples differ from the services provided for non-Indigenous peoples. Recognizing that the results of this study may support further work leading to changes in health policy, CINA, as the national representative body for Indigenous nurses across Canada, may best inform the changes needed to improve end-of-life care for Indigenous communities.

In terms of relevance, CINA was the community with which academic researchers partnered. CINA became involved early on in the process, which enabled them to shape the research objectives and questions. As our research project focused on end-of-life health care use and places of death, inclusion of CINA in the research partnership allowed for the community perspective of providing end-of-life care to Indigenous people, particularly as it related to home care nursing and allied health services. CINA partners also contributed to analysis and interpretation of the results, advising us how best to reduce any potential stigmatization of Indigenous peoples.

In terms of reciprocity, all members of the research partnership gained knowledge regarding gaps in end-of-life care for Indigenous people in Ontario who received provincially funded home care services. One limitation of our study in not embracing all principles of CBPR was the result of the technical requirement of having the epidemiological data analysis performed by data analysts employed at ICES. Future studies using previously collected Indigenous health data could consider a mechanism whereby Indigenous research partners gain skills in such data analysis. Organizations engaged in such types of data analysis may even consider training and employing Indigenous people. Such efforts would work to address additional TRC calls to action.

Whether one is conducting community-based research or using Indigenous identifiers in health administrative databases, it is essential that the research and outcomes are reflective of Indigenous needs and challenges. One way to identify these needs and challenges is through equitable and meaningful partnerships with Indigenous organizations. By enabling Indigenous organizations to inform the processes for respectful engagement in research, all parties can benefit from the work. Research agreements, developed in partnership with Indigenous organizations/communities may then outline research processes that respect the principle of self-determination by Indigenous peoples through meaningful involvement in all stages of the work, and that avoid further potential stigmatization and harm of Indigenous peoples via the research, its processes, or its outcomes. By adhering to these principles, research partnerships can ensure mutual responsibility to each other and to the results of the research.

The use of routinely and/or previously collected data (e.g., survey data from the Canadian Community Health Survey, First Nations Information Governance Centre Regional Health Survey, health administrative data linked to Indigenous registries) can be used to identify health care gaps in elder care and end-of-life care for Indigenous people. Never before has there been a time where this has been more important, as the Indigenous population in Canada is estimated to age at a faster rate than the general population. It is estimated that by 2031, the proportion of Indigenous seniors will triple (Caron Malenfant & Morency, 2011). In using these previously collected data sets in this way, the research world can contribute to the TRC calls to action and identify health care gaps. However, this research world must no longer consist of non-Indigenous researchers conducting research on Indigenous people. Instead, researchers must recognize that harm and further stigma can unintentionally occur if Indigenous perspectives are not included in the research, and that the best way to avoid harm is to involve Indigenous organizations/communities as equal partners as early in the research project as possible. Through collaborative processes, research questions can be designed that are both culturally sensitive and that do not further stigmatize Indigenous peoples. Also, early collaboration also means that Indigenous groups can shape the research to best address their community and/or health policy concerns.

Conclusions

Engaging Indigenous communities and organizations is essential to research studies focusing on Indigenous health that utilize previously collected data, such as those routinely collected in health administrative databases, as this ensures that Indigenous cultural perspectives are central to and reflected in the research process.

Notes

- ¹ "An inclusive and international term to describe individuals and collectives who consider themselves as being related to and/or having historical continuity with 'First Peoples.'" (Allan & Smylie, 2015). Often used to refer to the First Nations, Inuit, and Métis people as a collective.
- ² Bartlett, C., Marshall, M., & Marshall, A. (2012). Two-eyed seeing and other lessons learned within a co-learning journey of bringing together Indigenous and mainstream knowledges and ways of knowing. *Journal of Environmental Studies and Sciences*, 2(4), 331–340.
- ³ Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada. (2014). Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans.

References

- Allan, B., & Smylie, J. (2015). *First Peoples, second class treatment: The role of racism in the health and well-being of Indigenous peoples in Canada*. Toronto: The Wellesley Institute.
- Bartlett, C., Marshall, M., & Marshall, A. (2012). Two-eyed seeing and other lessons learned within a co-learning journey of bringing together Indigenous and mainstream knowledges and ways of knowing. *Journal of Environmental Studies and Sciences*, 2(4), 331–340.
- Botschner, J., & Lomotey, J. (2002). *Review of primary prevention/ community support: Final report. Prepared for Six Nations of Grand River*. Kitchener, ON: Centre for Research and Education in Human Services.
- Bruhn, J. (2014). Identifying useful approaches to the governance of Indigenous data. *The International Indigenous Policy Journal*, 5(2). doi: 10.18584/iipj.2014.5.2.5
- Campbell, T. (2014). A clash of paradigms? Western and Indigenous views on health research involving aboriginal peoples. *Nurse Researcher*, 21(6), 39–43.
- Canadian Institutes of Health Research. (2007). *Guidelines for health research involving Aboriginal people (2007–2010)*. Retrieved 4 April 2018 from <http://www.cihr-irsc.gc.ca/e/29134.html#7>
- Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada. (2014). Tri-Council Policy Statement: Ethical Conduct For Research Involving Humans, December 2014. Catalogue No: RR4-2/2014E-PDF
- Caron Malenfant, É., & Morency, J.-D. (2011). *Population projections by Aboriginal identity: 2006 to 2031*. Ottawa: Statistics Canada.
- Dudgeon, D., & Kristjanson, L. (1995). Home versus hospital death: Assessment of preferences and clinical challenges. *Canadian Medical Association Journal*, 152(2), 337–340.
- Erasmus, G., & Dussault, R. (1996). *Report of the Royal Commission on Aboriginal Peoples*. Ottawa: Government of Canada.
- First Nations Information Governance Centre. (2014). *Ownership, control, access and possession (OCAP®): Paths to First Nations governance*. Ottawa: First Nations Information Governance Centre. Retrieved 9 March 2018 from http://fnigc.ca/sites/default/files/docs/ocap_path_to_fn_information_governance_en_final.pdf
- Fraser, J. (2016). *Palliative and end-of-life care provincial roundtable report: A report from Parliamentary Assistant John Fraser to the minister of health and long-term care*. Retrieved 11 March 2018 from http://www.health.gov.on.ca/en/public/programs/palliative/pdf/palliative_report.pdf
- Fruch, V., Monture, L., Prince, H., & Kelley, M. (2016). Coming home to die: Six Nations of the Grand River Territory develops community-based palliative care. *International Journal of Indigenous Health*, 11(1), 50–74. doi: 10.18357/ijih111201615303

- Government of Newfoundland and Labrador. (2007). *Government standard for Aboriginal administrative data*.
- Habjan, S., Prince, H., & Kelley, M. (2012). Caregiving for Elders in First Nations communities: Social systems perspectives on barriers and challenges. *Canadian Journal of Aging/La Revue canadienne du vieillissement*, 31(2), 209–222.
- Israel, B., Shulz, A., Parker, E., & Becker, A. (1998). Review of community-based research: Assessing partnership approaches to improve public health. *Annual Review of Public Health*, 19, 173–202.
- MacDonald, N., Stanwick, R., & Lynk, A. (2014). Canada's shameful history of nutrition research on residential school children: The need for strong medical ethics in Aboriginal health research. *Paediatrics*, 19(2), 64.
- Mosby, P. (2016). Administering colonial science: Nutrition research and human biomedical experimentation in Aboriginal communities and residential schools, 1942–1952. *Historie sociale/Social History XLVI*, 91, 615–642.
- Mustimuhw Information Solutions Inc. (2015). Data governance framework: Framework and associated tools. Retrieved 9 October 2018 from <https://www.bcfndgi.com/data-governance>
- Schnarch, B. (2004). Ownership, Control, Access and Possession (OCAP®) or self-determination applied to research: A critical analysis of contemporary First Nations research and some options for First Nations communities. *Journal of Aboriginal Health*. Retrieved 9 October 2018 from <http://old.nswp.org/sites/nswp.org/files/SCHNARCH-OCAP.pdf>
- Smylie, J., & Firestone, M. (2015). Back to the basics: Identifying and addressing underlying challenges in achieving high quality and relevant health statistics for Indigenous populations in Canada. *Statistical Journal of the IAOS*, 31(1), 67–87. doi: 10.3233/SJI-150864
- Tobias, J., Richmond, C., & Luginaah, I. (2013). Community based participatory research (CBPR) with Indigenous communities: Producing respectful and reciprocal research. *Journal of Empirical Research on Human Research Ethics*, 8(2), 129–140.
- Tripartite Project Coordination Team. (2016). *BC First Nations' Data Governance Initiative Strategic Framework*. Retrieved 8 October 2018 from https://static1.squarespace.com/static/558c624de4b0574c94d62a61/t/578d385dff7c501707c3a328/1468872798427/-REPORT_-_BC_FN_DATA_GVERNANCE_INITIATIVE_STRATEGIC_FRAMEWORK_-_EVERGREEN.pdf
- Truth and Reconciliation Commission of Canada. (2015). *Truth and Reconciliation Commission of Canada: Calls to action*. Retrieved 10 March 2018 from http://nctr.ca/assets/reports/Calls_to_Action_English2.pdf
- United Nations. (2007). *United Nations Declaration on the Rights of Indigenous Peoples*.

Appendix: Research Agreement

Places of Death and Places of Care at End of life for Indigenous People in Ontario

Intent of the Document

The intent of this agreement between CINA research chair/CINA Indigenous Knowledge Holder and Drs. Funnell, Tanuseputro, Walker is to:

- Describe the project and its objectives
- Clearly define our agreed-upon roles and commitments to the project
- Set out who can use the information that the project produces and how
- Describe ways that Indigenous perspectives will be included

The project team includes First Nations researchers Dr. Jennifer Walker and Dr. Sarah Funnell. Further expertise for this project is being provided through collaborative partnership with the Canadian Indigenous Nurses Association (CINA) via the , the national representative organization of First Nation, Inuit and Métis nurses across Canada. CINA's involvement is viewed as essential to ensuring the project work and outcomes benefit from the cultural knowledge and perspectives of Indigenous nurses and nursing practice in relation to Indigenous end-of-life care issues.

This Research agreement has been developed in keeping with the principles of two-eyed seeing² which recognizes the importance both Indigenous ways of knowing and Western knowledge and works to incorporate both into a meaningful collaboration. Further, the Research agreement is aligned with the principles of the TCPS-2, with specific reference to Chapter 9: Research Involving the First Nations, Inuit and Métis Peoples of Canada³. These documents will be given primary consideration in the development of the project research protocol, and ethics application.

Although not explicitly stated, First Nations principles of OCAP® (ownership, control, access, possession) are imbedded though out this research agreement and were given important consideration during the drafting and revising of this document.

We decided as a group, that we did not require terms of references as all items that would be included in such are also captured within this document.

Parties to the Document

This Research agreement is a binding document specific to the above project that will be carried out in collaborative partnership and through collaborative processes of consensus building between the:

1. CINA research chair/CINA Indigenous Knowledge Holder.

2. Project Research Team comprised of scientific researchers: Dr. Sarah Funnell, Dr. Peter Tanuseputro, Dr. Jennifer Walker.

Research Agreement Pertains to:

The above named researchers and the CINA research chair/CINA Indigenous Knowledge Holder agree to conduct the named research project with the following understanding:

1. Before undertaking the project, the researchers must apply for approval of an ICES PIA.
2. The purpose of this research project, as discussed with and understood by CINA research chair/CINA Indigenous Knowledge Holder and the project research team is 'to describe end-of-life care use for Indigenous decedents in Ontario who have accessed publicly-funded home care services'. Places of care, places of death and intensity of nursing home care services are the main descriptors.
3. The scope of this research project, as discussed and understood by CINA research chair/CINA Indigenous Knowledge Holder is 'to use Health Administrative Data housed at the Institute for Clinical Evaluative Sciences (ICES) to conduct the study'.
4. The hypothesis, determined as 'a health gap will be identified in the analyses of the research data and information and the results of this may be used as evidence to further advocate for improved health equity in end-of-life care'.
5. The methods to be used, as agreed upon by the project research team and CINA research chair/CINA Indigenous Knowledge Holder 'to create a cohort of Indigenous decedents who received publicly funded home care in Ontario over a 5 year period and using encrypted and de-identified health care numbers link to other health administrative databases housed at ICES to determine demographic information (sex, age of death, cause of death, rurality, neighbourhood income, chronic conditions), calculate a multi-morbidity score using the John Hopkins Adjusted Clinical Group System score, and link to administrative databases to identify places of death, places of care, home care services (including physician home visit and palliative care designation) and intensity of nursing home care'.
6. CINA research chair/CINA Indigenous Knowledge Holder agrees to participate in this project through:
 - a. Ensuring Indigenous perspectives are central and reflected throughout the work and outcomes of this study;
 - b. Providing advice with regards to culturally appropriate gathering, use and interpretation of First Nation, Inuit, Métis data and information;
 - c. Identifying any potential harms to First Nation, Inuit, Métis from the research;
 - d. Co-development of mitigation strategies for identified potential harms from the research;
 - e. Approval of research protocols;
 - f. Identifying any additional research questions not found in current protocols; and,
 - g. Ensuring the research team acknowledges the practices and protocols of First Nation, Inuit, Métis groups, communities and organizations involved in the study.

At each step of the process, all attempts will be made to ensure that any concerns by CINA research chair/CINA Indigenous Knowledge Holder are addressed and that recommendations are incorporated into the research plan and activities.

7. Project progress will be communicated to CINA research chair/CINA Indigenous Knowledge Holder via:
 - a. Quarterly teleconferences
 - b. Quarterly or as warranted summary or activity updates
 - c. Email
8. Communication with the media and other parties (including funding agencies) outside the names researchers and CINA Research Chair/CINA Indigenous Knowledge Holder will be handled in these agreed upon ways:

Step 1. Researcher team members and CINA research chair/CINA Indigenous Knowledge Holder work in partnership to develop a plan for manuscript development.

Step 2. CINA research chair/CINA Indigenous Knowledge Holder role and involvement in authorship is determined at planning stages of publication development.

Step 3. CINA research chair/CINA Indigenous Knowledge Holder will be engaged to review manuscript drafts prior to submission for publication, this will include members of CINA considered to be content experts in related areas and/or members of the CINA Research Committee.

Step 4. CINA research chair/CINA Indigenous Knowledge Holder will be acknowledged as appropriate in the final manuscript drafts according to their role in the project and development of the manuscript.

Step 5. CINA research chair/CINA Indigenous Knowledge Holder is required to provide written approval for all related publications from this research study.

Ownership

The process, methods, results and products resulting from this research will be shared and co-owned by CINA and the researchers.

Ethics Approval Process

Under Dr. Tanuseputro's arrangement with the Ottawa Hospital Research Institute (OHRI), research projects with ICES only need to undergo ethics review with ICES. For this reason, this current project will only undergo ethics review with ICES. All parties to this agreement are in agreement with this ethics being reviewed in this manner.

Funding, Benefits & Commitments

Funding

This study will comprise Dr. Sarah Funnell's Masters of Epidemiology research paper requirement.

This study will be a part of a larger end-of-life study being conducted by Dr. Peter Tanuseputro at the Ottawa Hospital Research Institute (OHRI) using health administrative data and requires no additional monetary support from CINA. This larger end-of-life study already has funding from the Ministry of Health and Long-term Care (Ontario) and CIHR, for this reason no additional costs related to analysis of the data is required by CINA.

Where possible, funding will be provided for CINA research chair/CINA Indigenous Knowledge Holder to attend one conference (either two at the same conference or one each at 2 separate conferences) where an abstract related to this project has been accepted and is being presented. Funding will be used to cover conference registration fees, meals, travel and accommodation. *Dr. Funnell is currently applying for a research grant from the College of Family Physicians specifically for this purpose.*

Benefits

Benefits of the project are as follows:

The research team members may benefit from the work and outcomes of this study in the following ways:

- Completed requirements of Dr. Sarah Funnell’s Masters of Epidemiology Research paper requirement
- Scientific peer-reviewed publications
- Conference presentations

CINA may benefit from the work and outcomes of this study in the following ways:

- Related information and understanding to be used as a basis in the development of health education resources
- Authorship in the creation of associated reports and manuscripts
- New collaboration with scientists using large databases
- Possible extension and collaborations of the study with other provinces and researchers

Commitments

CINA research chair/CINA Indigenous Knowledge Holder’s commitment to researchers is to provide expertise and advice in the following areas:

- Community Engagement
- Culturally relevant & appropriate interpretation of data
- Written publications and oral presentations that include Indigenous perspectives or interpretation of findings
- Advisory Capacity in relation to culturally specific knowledge and information regarding study outcomes

The research teams’ commitment to CINA is as follows:

- To inform CINA in an ongoing basis of the progress of the study
- To ensure First Nation, Inuit, Métis elder/knowledge Holders are acknowledged as is determined appropriate through the CINA Research Committee
- To ensure opportunities for CINA to contribute to knowledge translation and exchange processes with regards to the knowledge and information gained as a result of the project

The research team agrees to interrupt the research project in the following circumstances:

- If CINA research chair/CINA Indigenous Knowledge Holder decides to withdraw their support
- A conflict resolution process cannot be determined that is culturally appropriate including the use of a consensus building processes when verbal agreements regarding the study, how it is conducted and how the findings are used and interpreted cannot be reached

Signed by:

Date:	Date:
(Signature of CINA contact person)	(Signature of main researcher)
Name:	Name:
Position:	Position: