Ethical research engagement with Indigenous communities

Jennifer Billan[1] (ORCID)**, Danette Starblanket[1], Sadie Anderson[1],
Marlin Legare[1], Mikayla Caroline Hagel[1], Nathan Oakes[1],
Mackenzie Jardine[1], Gail Boehme[2], Ethel Dubois[2],
Orval Spencer[2], Millie Hotomani[2], Betty McKenna[1] and
Carrie Bourassa[1]**

Abstract

Introduction: Canada's colonial policies and practices have led to barriers for Indigenous older adults' access to healthcare and research. As a result, there is a need for Indigenous-led research and culturally safe practices. Morning Star Lodge is developing a training module to assist AgingTech researchers on ethical, culturally safe ways to engage Indigenous communities. This includes exploring Indigenous health research, community-based partnerships, reciprocal learning, and cultural safety; this is presented through a case study on ethically engaged research.
Methods: Morning Star Lodge developed a research partnership agreement with File Hills Qu'Appelle Tribal Council and established a Community Research Advisory Committee representing the eleven First Nations within the Tribal Council. The work designing the culturally safe training module is in collaboration with the Community Research Advisory Committee.
Results: Building research partnerships and capacities has changed the way the eleven First Nation communities within File Hills Qu'Appelle Tribal Council view research. As a result, they now disseminate the knowledge within their own networks.
Conclusions: Indigenous Peoples are resilient in ensuring their sustainability and have far more community engagement and direction. Developing culturally safe approaches to care for Indigenous communities leads to self-determined research. Culturally safe training modules can be applied to marginalized demographics.

Keywords

Ethically engaged research, ageing, Indigenous community-based research, community-based partnerships, cultural safety

Date received: 29 January 2020; accepted: 6 April 2020

Introduction

Canada's past and current colonial policies and practices have led to barriers for Indigenous older adults' access to healthcare and health research. It is known that contemporary research methods are required to go through a "decolonization" process, where the research objectives, policies, institutions, and methods that are tied to our colonial history must be removed in order for current Indigenous community research methods to be effective.[1] In recent decades, community-based research is gradually involving more participation of community members with the objective to collect accurate data that can be applied in meaningful, relevant ways.[2] With effective methodologies, the disparities of health and access to services may be appropriately addressed. Consequently, this has brought about a need for Indigenous-led research and the development of culturally safe practices. The research team at Morning Star Lodge (MSL), an Indigenous health

[1]Department of Community Health and Epidemiology, College of Medicine, University of Saskatchewan, Regina, Canada
[2]File Hills Qu'Appelle Tribal Council, Fort Qu'Appelle, Canada

Corresponding author:
Jennifer Billan, University of Saskatchewan College of Medicine, 401-2631 28th Ave, Regina, Saskatchewan S4S 6X3, Canada.
Email: jen.billan@usask.ca

research lab is developing a training module to assist AgingTech researchers in engaging Indigenous communities in culturally safe ways. The training module describes the importance of community partnerships, sets out Indigenous research methodologies (IRM), mutually beneficial research, and data stewardship.[3] Implementing cultural safety encourages healing from the trauma of previous, unethical research involving Indigenous Peoples but more importantly it empowers the communities as co-researchers, leaders, collaborators, and the owners of the research.

Researchers must acknowledge the societal structures that have affected the health and wellbeing of Indigenous Peoples, including Canada's colonial history as well as unethical research involving Indigenous Peoples and the lack of control over data and research findings.[4] Utilizing culturally safe research practices and IRM promotes ownership of research and self-determination. Furthermore, knowledge translation (KT) promotes community engagement and meaningful research. Prior to the development of IRM, the Research Ethics Boards were the sole source for ensuring ethical research however, this has historically failed to uphold ethical standards for research involving Indigenous Peoples.[5]

Community-based research is congruent with IRM and places emphasis on forming collaborative relationships with the community and encouraging the participation of community members in the process of creating knowledge; this collaborative approach not only includes all partners in the research process but also recognizes and builds on the strengths and contributions of each member of the research team.[6] In our research projects, a community-based research assistant (CRA) is a local member from the community hired to lead the Community Research Advisory Committee (CRAC) from the community perspective. The CRA works directly out of the File Hills Qu'Appelle Tribal Council office, which is the administration building that represents all eleven First Nations within Treaty 4 Territory.

MSL takes direction from Indigenous research community partners in a variety of ways, including identifying research priorities. Many of the partnerships have been formed over several years. As an Indigenous research lab, MSL promotes community-based health research, training and education, and developing community capacity in Indigenous communities.

Indigenous health research and methodologies

According to the Canadian Institutes of Health Research,[7] Indigenous health research is defined as, "any field or discipline related to health and/or wellness that is conducted by, grounded in, or engaged with, First Nations, Inuit or Métis communities, societies or individuals and their wisdom, cultures, experiences or knowledge systems, as expressed in their dynamic forms, past and present." IRM concerning health research should be uniquely adapted to fit the specific needs of communities, as there is no pan-Indigenous approach for analyzing issues related to Indigenous Peoples. Despite facing challenges as a direct result of colonization and assimilation, Indigenous cultures and communities have remained resilient. Rather than instilling a hopeless narrative on Indigenous Peoples through highlighting health outcome disparities, IRM seeks strength-based approaches that include cultural continuity, which refers to the integration of Traditional Knowledges (TK) and culture(s) within research methods to allow for knowledge transmission and maintenance.[8] The Tri-Council Policy Statement reiterates,

> "Traditional Knowledges is specific to place, usually transmitted orally, and rooted in the experience of multiple generations. It is determined an Indigenous community's land, environment, region, culture and language. Traditional knowledge is usually described by Indigenous Peoples as holistic, involving body, mind, feelings and spirit."[9]

As colonization is not yet a concept of the past, it must be noted that IRM, through the embodiment of TK, address both historical consequences of unethical research and current colonial research practices by including components such as self-determination and capacity building research. Researchers' investment of time and energy into relationship building within the community is critical for both self-determination and ownership of research. In order to build effective, genuine relationships within a community, researchers must ensure that trust is built and respected. Community is included within every aspect of the decision-making process, including developing research priorities, or topics of research pertinent to the community itself.[10] IRM includes cultural protocols and values, such as TKs, ceremonies and guidance from Elders and Knowledge Keepers as integral components of the research process.[10] IRM also includes the assurance that the research is community driven, relevant, and has beneficial results for the community. Forming ethical relationships with communities is a fundamental role within IRM.[11,12] Co-researchers do not solely participate in research, but rather guide and lead the research. At MSL, we are increasing research capacity of community members and ensuring community members are co-researchers in every project.

IRM helps to ensure research is done respectfully and in a culturally safe way to encompass Indigenous ways of Knowing and understanding. The importance of discontinuing a colonial mindset is demonstrated by a commitment to building research capacity in communities by ensuring community members act in leadership roles and have control over their preference of research components. The driving force behind IRM is to create partnerships while building capacity for improved self-determination.

Indigenous Peoples are moving towards their own research methodologies as a means to empower themselves in a field that has sought to make them the subject and not the owner of research. Auger et al.[13] concluded the overall experience trend of 35 urban Vancouver Indigenous co-researchers in a community-based Indigenous research design who identified healing through traditional workshops as crucial to improving self-determination and increased ownership of their holistic wellness and healthcare decisions.[13] In the analysis of the findings in the same article the participants' positive feedback is indicative of the participants' motivation to take their knowledge and experience from being a co-researcher and use it for health improvements, as they explained having access to traditional workshops improved their use and access to both western and traditional healing practices in the urban setting of Vancouver.[13]

It is therefore of the utmost importance that Indigenous Peoples interact with all aspects of the research and be given the space to analyze and respond to data that involves them. Acknowledging the colonial beginnings of research with Indigenous groups while re-centering the ownership, control, and dissemination is one step in decolonizing Western research practices. Utilizing living experiences as a valid form of Indigenous knowledges creates an emancipation on behalf of Indigenous research from the colonial focus of academia. Privileging the voices of Indigenous Peoples can also aid in self-determination within communities. These methods ensure that researchers serve the specific needs of the community and its members while increasing self-determination over the communities' research. Indigenous community-based research is an effective method to form collaborative relationships with communities where trust-building and outreach are required.[14] These pillars should be recognized in research projects involving Indigenous communities.

Community-based partnerships

A research partnership began with the File Hills Qu'Appelle Tribal Council (FHQTC) and MSL in 2015. In partnership with the FHQTC, we established the CRAC representing the eleven First Nations within the Tribal Council to direct the research and help identify research priorities relevant to the community needs. This partnership provides direction from a diverse group of individuals who moves the work forward, giving us the ability to ethically undertake the research.

The CRAC is comprised of Elders, nurses, health directors, and community members. It includes Indigenous individuals who are members of First Nations belonging to the FHQTC including Nekaneet First Nation, Wood Mountain Lakota First Nation, Piapot First Nation, Muscowpetung, Saulteaux Nation, Pasqua First Nation, Standing Buffalo Dakota Nation, Little Black Bear First Nation, Star Blanket Cree Nation, Peepeekisis Cree Nation, Okanese First Nation, and Carry the Kettle Nakoda Nation (CRAC members include Gail Boehme, Nicole Akan, Elder Sylvia Obey, Elder Millie Hotomani, Lorna Breikreuz, Ethel Dubois, Lois Dixon, Lorraine Walker, Judy Sugar, Donna McKay, Freda O'Watch (deceased), Richard Ironchild (deceased), Leona Peigan (deceased), Belinda Whitecap, Rozella McKay, Paulette Gosselin, Natalie Jack, Cindy McArthur, Lorna Audette, Orval Spencer, Glenda Goodpipe, Mindy Koochicum, Rhonda van der Breggen, and Roxanne Quewezance).

This research partnership is beneficial for both parties as the researchers assist with priorities identified by the CRAC members during monthly research meetings. In addition, the CRAC assists MSL in identifying community needs and research expectations. Throughout the years, the CRAC has evolved from attending meetings to fully directing the research and the research team, including determining methods for data collection and data analysis, manuscript writing, presenting research findings at academic conferences and within their respective communities. Using community-based partnerships to increase capacity for communities to decide how they want to complete research projects is a significant outcome of self-determined research. The CRAC has a full understanding of the research projects and the next steps to sustain the work they are doing.

Reciprocal learning and KT

A directive of IRM is not to collect knowledge just for the sake of collecting knowledge but to apply this knowledge in a good way. By achieving full engagement of Indigenous communities in research, community is left with an asset, something they can build on. Any research undertaken should aim to prioritize capacity building and practices that will enhance self-determination. Self-determination is an important aspect involving the autonomy a person holds over

making decisions concerning their life and well-being.[11] Conventional western research is typically done "to" communities, rather than "with" communities. Indigenous community-based research on the other hand, is collective and collaborative, creating a space where reciprocal learning happens.[11] A key component of community-based Indigenous research is to preserve and uphold Indigenous Knowledges through community-driven, self-determined research and respect for the traditions, protocols, and expectations of the community.[10] For example, in some communities, tobacco offerings are given, and a prayer by the Elder or Knowledge Keeper begins the research process, to start off in a good way. It is known that traditional tobacco is used by Indigenous Peoples to open ethical engagement in all traditional and reciprocal social engagements from ceremony to asking a Knowledge Keeper for advice or assistance of any type, including sharing knowledge.[15] These cultural protocols vary from community to community and it is vital researchers are informed on them.

Indigenous KT comprises local languages, conceptualizations, ways of "knowing" and "doing," and practical demonstration of the above. With the aid of our co-researchers, KT can be done ethically and with proper reverence to the community.[16] The goal of ethical KT is to use a community-driven approach to synthesize data and redistribute it to the community, where CIHR believes ethically sound applications of knowledge creates an important opportunity toward improving Indigenous health equity by stimulating transformative change to both Indigenous health and the health system.[17] Neglecting to engage Indigenous communities in KT efforts is unethical research, and there are a set of standards affirming how First Nations data be owned, controlled, accessed, and shared.[18]

In current IRM ethical KT can be achieved with the use of the Collective Consensual Data Analytic Procedure, now adapted to Nanâtawihowin Âcimowina Kika-Môsahkinikêhk Papiskîci-Itascikêwin Astâcikowina and community sharing circle.[19] Key to ethical research is the aspect of reciprocal learning. As co-researchers are sharing their stories, Knowledges, and Traditions, so should everyone involved with the research to create mutual learning. The research article produced in 2008 by Ball and Janyst[15] states, enacting ethical principles in forming co-researcher partnerships with Indigenous communities is fundamental to making research objectives culturally meaningful because the co-researchers influenced an established benefit of positive social change by being involved with the research.[19]

Self-location is also an important part of IRMs and reciprocal learning. Self-location offers space for researchers to locate themselves within the research, reflect on power differentials, as well as possible biases and privileges, and share their experiences with co-researchers; this process helps build reciprocity and trust.[20] Self-location is a necessary means to add relevance to research projects within communities. The process of self-location plays a critical role in achieving ethical research with Indigenous communities and safeguards individual experiences from being misinterpreted and generalized.[21]

Cultural safety

Cultural safety in research is a key component of ethical engagement with Indigenous communities as it ensures the working relationships with Indigenous communities are prioritized and relevant.[22] The overarching term, cultural safety, cannot be fully achieved without including aspects of cultural competency, relevancy, and humility.[23] These facets of cultural safety help to ensure that professionals and academics (particularly in the health field) decolonize perspectives to avoid further perpetuating agents of hegemony when engaging in their respective practices. This process comes through deconstructing the prescribed systems of dominance of thought and ethnocentric viewpoints, which are maintained within the health and research field in Canada and the world at large. There is a need for health providers and researchers to understand Eurocentric bias towards knowledge, data, and medicine in order to actively partake in decolonization. Many western non-Indigenous worldviews hold the biomedical model as the pinnacle of health outcomes, status, and treatment of disease. Although the biomedical model is the most frequently used lens in Canada for examining health research, the devaluation of traditional IK removes legitimacy for Indigenous Peoples to feel valued or connected to health practitioners, research, and researcher(s), limiting the autonomy of Indigenous Peoples. As mentioned in the article produced by Brown[24] in 2018 regarding self-determination and Indigenous health, research with Indigenous communities must be mindful of holistic traditions and be more focused on building relationships rather than prioritizing biased research approaches that exclude community guidance.[24]

In order to accurately understand how to achieve cultural safety within research practices, it is important that a person (researchers and community) first understands what cultural safety is, and the ingredients that build the concept. In general terms, a person is considered to encompass culturally safe practices if they are able to maintain a trusting and reciprocal working relationship with someone from another culture.[25] Rather than evaluating discrimination on a case-by-case basis,

the concept of cultural safety focuses on systemic issues, including colonial-based racism that is ingrained in the medical field. The term "cultural safety" was originally developed in the context of New Zealand nurses caring for the Indigenous Maori population but has since been adapted and applied in any discipline. Although the definition of the term can be easily determined, there are more complex factors and aspects affecting one's ability to truly practice cultural safety in their respective practices as one must be able to undertake a process of self-reflection in their own cultural identity and self-locate any potential conflicts or biases that may arise as a result of cultural differences.

One of the important components to the overarching term of cultural safety is the practice of cultural competency and the adherence to it. This includes re-evaluating skills, knowledge, and attitudes that an individual may possess that apply to the concept of cultural safety. In order to achieve competency in the sense of culture, one is required to look beyond any "taken for granted" biases and power structures while critiquing or criticizing their respective culture.[26] Often, this term may be misconstrued to mean becoming competent in other people's culture, but this misses the importance of self-locating any bias within an individual's unique cultures. The objective of cultural competency is not to highlight differences between the cultures of others, but rather to determine where one may exhibit bias when relating to other people with different cultures. There is a reliance on the ability of researchers to be self-reflective and to critically reflect on this process throughout the research project to achieve cultural safety.

The terms cultural relevancy and humility are also often used alongside cultural competency to describe the different components that help to define the concept of cultural safety.[26] Relevancy relating to culture addresses the issue of determining if programs and services aptly include relevant aspects of values, traditions, beliefs, and practices. For example, in Canada, governmental policy, which fails to incorporate cultural relevance regarding Indigenous culture and traditions within their policies results in the continuation of systemic racism, drawing upon the need for culturally safe practices and policies. Cultural humility in relation to safety involves internal self-reflection of personal bias while being able to humble yourself immersing or understanding the cultures of other people.[26] Focusing too narrowly on achieving cultural competency, relevancy, and humility in practice may take away from the larger and more important picture of achieving true cultural safety.[25] Although each of the facets of cultural safety are important to acknowledge and achieve, building authentic relationships with the intent of ethically serving the community and focusing on the successes of the interaction will help to ensure culturally safe practices are followed.

The reciprocal trust and relationships built between researcher and co-researcher (or doctor/nurse and patient) is critical to the success of cultural safety. Co-researchers' ways of Knowing and contributions made to a research project are a valued aspect of research as it creates a safe space for empowerment and self-determination.[25] Students in the field of health identified participatory learning as the most effective form of cultural learning, by adding cultural practice and ceremony the student can connect with cultures at its key points. Participation in culture translates to a greater understanding of the role it plays in achieving health and wellness. The connection made through culturally safe exchanges ensures that patients feel more comfortable seeking access to medical aids and interventions.[27]

The objective of culturally safe activities is clearly linked to achieving health equity cross-culturally while understanding power differentials in health service delivery and academia. Redressing inequities through educational processes that focus on systemic issues, including colonial-based-racism, is an integral step that must be taken in order to deconstruct bias, and ensure more frequent positive health outcomes for all co-researchers. Personal and systemic racism are major factors as to why the practice of cultural safety is necessary for not only healthcare professionals, but the greater general Canadian population. Systemic racism is rooted in colonial history, along with processes that continue to disconnect Indigenous Peoples from their lands, language, and cultures. Those who have experienced the negative impacts of colonization hold much knowledge, along with culturally safe solutions.[27]

Principles of ownership, control, access, and possession (OCAP®)

Self-determination is a key component of Indigenous community-based research. It can be defined as the community's sovereignty over the research being conducted in their communities, and that the direction and discretion of research be guided by community members.[10] This concept is also an important component in the advancement of Indigenous self-governance as self-determination expressed through research is integral to the overall autonomy of Indigenous communities and First Nations governments. Indigenous Peoples are taking their voices in many areas around resource extraction and protection. Their data is seen as a vital resource that has garnered the same recognitions. The First Nations Information Governance Centre[18] has created four principles for

establishing how First Nations' data should be collected, used, shared, and protected. OCAP® was developed in response to the lack of standards in recognizing the rights and interests in First Nations Peoples' information. The four principles include aspects of OCAP® and assert that First Nation individuals and communities have authority to own, control, and to have access to their information and have possession of the data.[17] It is a direct political response to colonial approaches to information and is ultimately self-determination applied to data. In practice, OCAP® implies that ownership of data is with communities, who have control over, access to and possession of data and information.

The First Nations Information Governance Centre[18] outlines the following definitions on the four principles of OCAP®:

> Ownership refers to the relationship of First Nations to their cultural knowledge, data, and information. This principle states that a community or group owns information collectively in the same way that an individual owns his or her personal information. Control affirms that First Nations, their communities, and representative bodies are within their rights in seeking to control over all aspects of research and information management processes that impact them. First Nations control of research can include all stages of a particular research project-from start to finish. The principle extends to the control of resources and review processes, the planning process, management of the information and so on. Access refers to the fact that First Nations must have access to information and data about themselves and their communities regardless of where it is held. The principle of access also refers to the right of First Nations communities and organizations to manage and make decisions regarding access to their collective information. This may be achieved, in practice, through standardized, formal protocols. Possession while ownership identifies the relationship between a people and their information in principle, possession or stewardship is more concrete: it refers to the physical control of data. Possession is the mechanism by which ownership can be asserted and protected.[18]

OCAP® is a registered trademark of the First Nations Information Governance Centre (www.FNIGC.ca/OCAP. MSL) research uses the principles of OCAP® and the researchers are well versed in the value of adhering to these principles.

Another valuable resource for researchers is available by the Canadian Institutes of Health Research (CIHR), the Natural Sciences and Engineering Research Council of Canada (NSERC), and the Social Sciences and Humanities Research Council of Canada (SSHRC). Together they created the *Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans (TCPS2)*, which contains essential components for ethical research involving First Nations, Inuit, and Métis Peoples in Canada. This includes concepts of reciprocity, relevance, respect, and responsibility.[28] These values are priority in the work done with any Indigenous community. A number of relevant recommendations can be part of the training for researchers.

Case study on ethically engaged research

One of MSL's recent Indigenous community-based health research projects, "Indigenous older adults requiring dementia care: Making space for technology" is an ideal case study when examining ethically engaged research with Indigenous communities. This research project was driven by the community and MSL partnered with Indigenous older adults, caregivers, and health practitioners through a CRAC in the File Hills Qu'Appelle Tribal Council (FHQTC) in southern Saskatchewan. The CRAC guided the research project and identified research priorities to examine the needs for technology to enhance the wellbeing and support the independence of Indigenous older adults requiring dementia care.

Using a combination of IRM and community-based involvement, co-researchers were recruited through existing community partnerships and based on their first-hand knowledge and experiences of dementia programs and services. Qualitative data ($n = 62$) were collected by conducting research circles and individual interviews with Elders, Knowledge Keepers, healthcare providers, healthcare professionals, as well as Indigenous older adults living with dementia and their caregivers. The research project, its objectives, and progress were part of community dialogue whenever possible, for example during health fairs the research team set up tables and distributed information and fact sheets to community members.

There was widespread community engagement and uptake throughout the research project. The team was involved with more than forty information and awareness sessions in the FHQTC communities. Through these sessions, they shared the knowledge gained about dementia as it related to Indigenous populations. As follow up work, the researchers explored the ways in which technology can assist people living with dementia and their caregivers. The team also examined the level of technology use and the barriers in the communities. The CRAC also worked closely with the research team to create dementia factsheets and start language groups in their respective communities.[3] This meaningful engagement has created a platform for

other research related to dementia and culturally safe care.

Through qualitative data analysis, the research findings revealed that Indigenous older adults living with dementia in rural communities require specific technology in order to improve quality of life and to foster Ageing in Place. This includes utilizing locally developed Indigenous language applications that were previously created by the File Hills Qu'Appelle Tribal Council. The use of these language Apps on iPads led to the electronic use of medication reminders, cognitive health games, education, social networking, and other activities. Caregivers were able to see the value of technology use as it relates to their loved ones ageing in place, being able to stay in the home.

In partnership with the CRAC, the MSL has collaborated on three publications outlining technology use and Indigenous older adults living with dementia, and we have modified dementia factsheets that are unique to the FHQTC.[3,29–31] The communities ensured the data included in the factsheets were relevant to their territories.

Through this research partnership, we have increased capacity within the FHQTC as well as contributed to innovation in the Indigenous health and dementia fields of study. It is important to point out that the work we have done with the CRAC has changed the way the eleven First Nations communities in the File Hills Qu'Appelle Tribal Council view research and more importantly, it has changed their thoughts around dementia and how they view their health. It is important to understand the CRAC members all come from the member communities, so their access to the research information is first-hand. The work they do with the research partnerships have become normalized within their homes. For example, many individuals in the eleven FHQTC communities are now looking at the relationships between diet and exercise and dementia onset. The CRAC encourages the MSL to move ahead in other research projects. We look forward to continuing our work together with our community partners and co-researchers. Funding for this project was provided by AGE-WELL.

Conclusion

Removing Eurocentric dichotomies when approaching research, such as engaging in a pre-dialogue with Indigenous Peoples about how research should be approached, conducted and disseminated is fundamental to engaging Indigenous communities in ethical ways. Partnering alongside Indigenous communities as co-researchers and leaders of the research through the co-creation of knowledge ensures the ownership of the research belongs to the community and that the research remains community driven. While there is no single myopic way in which IRM can be deployed, undertaking research to be done in "a good way" is the platform from which to build.

Previously, research was done "to" and "on" Indigenous Peoples. However, Indigenous Peoples are resilient and have become much more involved with community engagement and consequently are more eager to provide direction than ever before. Indigenous communities are asserting their authority over their research and research outcomes. The ways in which research is conducted is changing. Indigenous communities have greater capacity and are creating the acceptable parameters on their own terms, rather than having an external arbitrary reference point. Indigenous Peoples are not allowing anyone to do it for them because they are demanding recognition for what they know. Seeing value in Indigenous Knowledges and Indigenous Knowledge systems while incorporating it into the research and dissemination ensures the research is relevant and able to affect change within Indigenous communities.

ORCID iD

Jennifer Billan https://orcid.org/0000-0002-8676-6407

References

1. Hulko W, Camille E, Antifeau E, et al. Views of First Nations Elders on memory loss and memory care in later life. *J Cross Cult Gerontol* 2010; 25: 317–342.
2. Westfall JM, VanVorst RF, Main DS, et al. Community-based participatory research in practice-based research networks. *Ann Fam Med* 2006; 4: 8–14.
3. Morning Star Lodge. *Knowledge Distribution [Internet]*, www.indigenoushealthlab.com (accessed 11 March 2020).
4. Carter S. *Aboriginal people and colonizers of Western Canada to 1900*. Ontario: University of Toronto Press, 1999.
5. Smith LT. *Decolonizing methodologies: research and Indigenous peoples*. 2nd ed. London: Zed Books, 2012.
6. Israel BA, Schulz AJ, Parker EA, et al. Critical issues in developing and following community-based participatory research principles. In: Minkler M and Wallerstein N (eds) *Community-based participatory research for health*. San Francisco, CA: Jossey-Bass, 2008, pp.47–62.
7. Canadian Institutes of Health Research. *Indigenous health research at CIHR [Internet]*. Canada: Canadian Institutes of Health Research, 2019.
8. Auger M. Cultural continuity as a determinant of Indigenous Peoples' health: a metasynthesis of qualitative research in Canada and the United States. *Int Indig Policy J* 2016; 7: 3.
9. Government of Canada. TCPS 2 (2018) – Chapter 9: Research Involving the First Nations, Inuit and Métis Peoples of Canada [Internet], https://ethics.gc.ca/eng/tcps2-eptc2_2018_chapter9-chapitre9.html?wbdisable = true (2019, accessed 11 March 2020).
10. Dieter J, McKim L, Tickell J, et al. The path of creating co-researchers in the File Hills Qu'Appelle Tribal Council. *Int Indig Policy J* 2018; 9.
11. Smith SA and Blumenthal DS. Community health workers support community-based participatory research ethics: lessons learned along the research-to-practice-to-community continuum. *J Health Care Poor Underserved* 2012; 23: 77–87.
12. Kovach M. *Indigenous methodologies: characteristics, conversations and contexts*. Toronto: University of Toronto Press, 2010.
13. Auger M, Psych TH and Gomes T. Moving toward holistic wellness, empowerment and self-determination for Indigenous peoples in Canada: can traditional Indigenous health care practices increase ownership over health and health care decisions? *Can J Public Health* 2016; 107: 1.
14. Ritchie S, Wabano M, Beardy J, et al. Community-based participatory research with Indigenous communities: the proximity paradox. *Health Place* 2013; 24; 183–189.
15. Ball J and Janyst P. Enacting research ethics in partnerships with Indigenous communities in Canada: "Do It In A Good Way". *J Empir Res Hum Res Ethics* 2008; 1556-2654: 33–55.
16. Wilson DD and Restoule J. Tobacco ties: the relationship of the sacred to research. *Can J Native Edu* 2010; 33: 29–45, 156.
17. Canadian Institutes of Health Research. *Knowledge translation [Internet]*. Canada: Canadian Institutes of Health Research, 2016.
18. First Nations Information Governance Centre. *OCAP*® [Internet]. Canada: First Nations Information Governance Centre, 2019.
19. Starblanket D, Lefebvre S, Legare M, et al. Nanâtawihowin Âcimowina Kika-Môsahkinikêhk Papiskîci-Itascikêwin Astâcikowina [medicine/healing stories picked, sorted, stored]: adapting the collective consensual data analytic procedure (CCDAP) as an Indigenous research method. *Int J Qual Methods* 2019; 18.
20. Estey E, Kmetic A and Reading J. Knowledge translation in the context of aboriginal health. *Can J Nursing Res* 2008; 40: 24–39.
21. Absolon K and Willett C. Putting ourselves forward: location in aboriginal research. In: Brown L and Strega S (eds) *Research as* resistance: critical, *Indigenous* and anti-oppressive approaches. Ontario (Canada): Canadian Scholars' Press, 2005, pp.97–126.
22. Health Council of Canada Council. *Empathy, dignity, & respect: creating cultural safety for Aboriginal people in urban health care [Internet]*.Canada: Health Council of Canada Council, 2012.
23. Curtis E, Jones R, Tipene-Leach D, et al. Why cultural safety rather than cultural competency is required to achieve health equity: a literature review and recommended definition. *Int J Equity Health* 2019; 18: 174.
24. Brown C. Self-determination and data control vital to Indigenous health research. *Can Med Assoc J* 2018; 190: E893.
25. Papps E and Ramsden I. Cultural safety in nursing: the New Zealand experience. *Int J Qual Health Care* 1996; 8: 491–497.
26. Brascoupe S and Waters C. Cultural safety: exploring the application of the concept of cultural safety to aboriginal health and community wellness. *J Aborig Health* 2009; 6–41.
27. First Nations Health Authority. *Cultural Humility [Internet]*, www.fnha.ca/wellness/cultural-humility (2020 accessed 6 Jan 2020).
28. Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada. *Tri-council policy statement: ethical conduct for research involving humans TCPS2 [Internet]*. Canada: Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, 2019.
29. Starblanket D, Jardine M, Hickey D, et al. Dementia and aging in rural and remote communities: an Indigenous technology needs exploration. *Int J Indigenous Wellbeing*. Epub ahead of print 2020.
30. Starblanket D, O'Connell M, Gould B, et al. Defining technology user needs of Indigenous older adults requiring dementia care. *Gerontechnology* 2019; 18: 142–145.
31. Dieter J, McKim LT, Tickell J, et al. The path of creating co-researchers in the File Hills Qu'Appelle Tribal Council. *Int Indig Policy J* 2018; 9: 1–17.