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Article abstract

Recruitment of study participants from marginalized populations present unique challenges for researchers and associated institutions. Researchers must be aware of the specific adaptations required in the research process in conducting research within and Indigenous populations. Cultural consciousness is key with any research conducted within these populations to understand the past issues that can influence present and future willingness to participate in research. This article aims to provide context and examples where increasing cultural awareness of specific ethical principles during the recruitment phase can affect the study process as well as the researcher themselves. Integrating Indigenous cultural concepts within the recruitment and study design process can help to lay the groundwork for a positive research process as a whole and facilitate an appropriate study environment for all involved.

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Recruitment of Indigenous Study Participants in Canada: Obligations or Constraints? An Ethical Reflection

Patricia Farrugia[a]

Résumé
Le recrutement de participants à des études au sein de populations marginalisées présente des défis uniques pour les chercheurs et les institutions associées. Les chercheurs doivent être conscients des adaptations spécifiques requises dans le processus de recherche pour mener des recherches au sein des populations autochtones. La conscience culturelle est essentielle pour toute recherche menée au sein de ces populations, afin de comprendre les problèmes passés qui peuvent influencer la volonté actuelle et future de participer à la recherche. Cet article vise à fournir un contexte et des exemples où une sensibilisation culturelle accrue à des principes éthiques spécifiques pendant la phase de recrutement peut avoir un impact sur le processus d'étude ainsi que sur le chercheur lui-même. L'intégration de concepts culturels indigènes dans le processus de recrutement et de conception de l'étude peut contribuer à jeter les bases d'un processus de recherche positif dans son ensemble et faciliter un environnement d'étude approprié pour toutes les personnes impliquées.

Mots-clés
recrutement, autochtones, éthique, défis, recherche

Abstract
Recruitment of study participants from marginalized populations present unique challenges for researchers and associated institutions. Researchers must be aware of the specific adaptations required in the research process in conducting research within and Indigenous populations. Cultural consciousness is key with any research conducted within these populations to understand the past issues that can influence present and future willingness to participate in research. This article aims to provide context and examples where increasing cultural awareness of specific ethical principles during the recruitment phase can affect the study process as well as the researcher themselves. Integrating Indigenous cultural concepts within the recruitment and study design process can help to lay the groundwork for a positive research process as a whole and facilitate an appropriate study environment for all involved.

Keywords
recruitment, Indigenous, ethical, challenges, research

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I am an Anishinaabe scholar from Chippewas of Nawash, Ojibway-Saugeen Nation. The impact of non-Indigenous research practices and historical events cannot be forgotten by the Indigenous communities of Canada. Non-Indigenous researchers, including settlers and newcomers to Canada, must be aware of the history of colonialization involved in research with Indigenous peoples, reflect on its consequences, and support Indigenous populations through healing and reconciliation.

INTRODUCTION

Recruitment of study participants is an essential part of research and can be considered one of the most challenging aspects of any project. Recruitment involves selecting individuals or groups to participate in a research study by building relationships with participants and their communities. Although there are many aspects involved in a research study, proper recruitment techniques are vital as they contribute to the methodological strengths of a study and affect the validity and power of statistical analyses (1). Enrolling individuals in a research study may raise particular challenges depending on the population of interest. Conducting research with individuals from marginalized populations requires insight and allyship for the cultural values and beliefs of each group. Identification and awareness of the research perspectives of a marginalized population is a crucial first step in the recruitment process. The Indigenous (or Aboriginal) populations of Canada – i.e., First Nations, Inuit and Metis – remain marginalized and live with ongoing and important socio-economic challenges (amongst others), which for many is combined with an enduring resentment and mistrust in research based on numerous historical events of unethical research. Non-Indigenous researchers should thus be aware of this context in their recruitment of Indigenous populations. For example, researchers wishing to undertake research projects with these populations or in their communities are encouraged to modify a traditional approach to recruitment, as a matter of ethical principle, and in partnership with the guidance of the Indigenous population themselves. But in transforming recruitment practices, researchers may encounter novel situations (or challenges), including collaborative identification of research questions (and analysis) and indigenous ways of knowing that lead to community benefits without stigmatization for participation in research. Awareness of these issues and acknowledgement of Indigenous perspectives on research are a key step for non-Indigenous researchers in the recruitment process, and the ethical conduct of research more generally.

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RESPECT FOR INDIGENOUS PERSONS IN RECRUITMENT

Conducting research in an ethical manner begins with respect for both individual participants and the broader population of interest. Respect for human dignity requires that research involving humans be conducted in a manner that is sensitive to the inherent worth of all human beings and the respect and consideration that they are due (2). Historically, there is a legacy of unethical research practices involving the Indigenous populations of Canada, where researchers did not respect the autonomy of Indigenous individuals as independent research participants meriting dignity and able to give free and informed consent. Notable examples include health research within Aboriginal communities that were conducted without appropriate insight and understanding of the cultural differences, i.e., a colonial mentality that treated individuals as subjects – and not participants – in exploitative and even unethical research (3). Non-Indigenous researchers must be cognizant of and recognize the previous unethical circumstances of harm and dishonesty in recruitment strategies of research trials conducted with Indigenous participants. Explicit respect for Indigenous individuals who may potentially participate in research is crucial for non-Indigenous researchers to have in mind, and should be seen as a key starting point in planning for recruitment. Further, the way an Indigenous person views the benefits of research and their reasons for participation in a trial may be different (although not necessarily) from that of a non-Indigenous person.

It is also important to understanding differences in terminology and how different individuals within Indigenous populations in Canada (i.e., First Nation, Inuit or Metis) may name themselves. Terminology can be critical for Indigenous populations, as the term for a group may not have been selected by the population themselves but instead imposed on them by colonizers (4-6). Indigenous individuals may also define themselves according to their historical clan or family nation. The use of these terms is not universal and requires dialogue between non-Indigenous researchers and the study participants to ensure respect during the recruitment process. Building the necessary relationship with an Indigenous community or Nation requires a great deal of time and awareness of unique cultural views of the research process. Non-Indigenous researchers must work together with Indigenous communities throughout the recruitment and research process to, where possible, align with the OCAP principles of Ownership, Control, Access, and Possession (7); researchers should also be particularly attentive to the guidance provided in Chapter 9 of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans – TCPS2 (2), which is specifically focused on “Research Involving the First Nations, Inuit and Métis Peoples of Canada”. These resources can help clarify the important differences that may exist amongst Indigenous communities with regards to, amongst others, values of traditional knowledge and world views, and their relationship with research protocol development processes. They also point to the existence of both individual and community safeguards regarding research participation.

Obligatory collaboration with Indigenous local councils, requests to relinquish primary control of the research process, or mistrust from Indigenous communities may be experiences for which many non-Indigenous researchers are not prepared. Further, the views of and values related to the proposed research may raise issues about community obligations and cultural benefits. These may also extend to the interconnection between humans and the natural world, and include obligations to maintain, and pass on to future generations, knowledge received from ancestors as well as innovations devised in the present generation (2). Although not universal – i.e., not all Indigenous communities will have the same requirements or concerns – non-Indigenous researchers must be very aware that their world views can be distinct from and at times may even be in opposition to those of the individuals and communities with whom they wish to conduct research (3).

INFORMED CONSENT

The unique identities and distinctive culture affirmations of Indigenous peoples need to be acknowledged throughout the consent process, which begins at the recruitment stage and continues through to analysis and dissemination of the findings of a study. Informed consent must be voluntary without coercion and supported by a discussion of the data collection and other research activities used in a study. As already mentioned above, historically, Indigenous populations were denied the right to voluntary participation in research: they were enrolled in studies without even basic informed consent or that involved intentional deception regarding the study objectives. It should thus not be at all surprising that these experiences have severely tainted the views of many Indigenous individuals regarding research in general, and led to lasting apprehensions regarding participation in research, even if ethical norms and oversight have changed radically in the last 40 years.

A notable and shocking example involved studies in 1942 on malnourished Indigenous children of residential schools, who were divided into intervention and control groups, with half of the 300 children receiving vitamin supplements with the remainder, i.e., the control group, being denied a beneficial supplement (8). Consent to participate was not obtained from any parent or guardian, nor were the risks of the study explained; and researchers simply observed the physical effects of malnutrition on these children without correcting the harmful effects when the study concluded. Similar studies were also conducted at the Hospital for Sick Children in 1942-1952, to document the effects of malnutrition on dental health, by denying Indigenous children proper health and dental care when they developed complications of severe malnourishment. Even as children died, the experiments continued (9). And in the North, Inuit were recruited as research participants in studies from 1967-1973 involving skin graft experiments, without informed consent or explanation regarding the risks or objectives of the studies. The skin of one Inuit’s arm was removed and the skin from another individual was put in its place in order to observe the viability of the skin graft in different temperatures and environments (10). Decades later, Inuit participants involved in these studies continued to suffer physical and mental health issues as a result of these unethical experiments. Another classic

Unethical research involving Indigenous populations in Canada continued well into the late 1980s, with the high profile case of biological sample misuse in the Nuu-Chah Nulth First Nation in British Columbia. The study in question aimed to learn more about rheumatoid arthritis, and the samples collected were subsequently shared with other investigators around the world for a variety of research purposes beyond the scope of the original research. Although these practices were common among researchers at the time, the Nuu-Chah-Nulth did not consent to this secondary use of their samples and so viewed this as a breach of faith and demanded that the samples be returned (11). Despite the absence of consent for secondary research, additional research was funded by major funding agencies, including the US National Institutes of Health, and was approved through multiple university ethics review boards (12).

The TCPS2 (2) has specific guidelines to enable non-Indigenous researchers in conducting mutually beneficial and culturally competent research with Indigenous populations in Canada. Yet, a 2016 systematic review identified a limited number of articles that evaluate preferences or understanding of the optimal communication methods to be used in seeking informed consent for research with Indigenous populations (13). Awareness and acknowledgement by non-Indigenous researchers of the events of the past that have affected how Indigenous populations view research is necessary to foster a sense of trust in a community of interest prior to the recruitment process. Without first developing such trusting relationships, e.g., through open communication with Indigenous band councils and communities, researchers risk being confronted by revelations of previous unethical research, and thus experience a generalised distrust and rejection of their project, regardless of its ethicality.

CONCERN FOR WELFARE

Indigenous populations have many health challenges and societal disadvantages as a result of historical colonial activities. First Nations, Inuit and Metis peoples continue to experience considerably lower health outcomes than non-Indigenous Canadians (14). As such, disparities in the burden of chronic diseases, mental health issues and social determinants of health for Indigenous peoples need to be a focus for health research. Researchers have a responsibility to care for the welfare of all research participants, but even well-intentioned research has been a source of distress for Indigenous people because of its implications, methods, and lack of responsiveness to community needs and concerns (15).

Indigenous communities may view research through a different cultural lens compared to non-Indigenous Communities. For example, they may be particularly concerned that research should enhance their capacity to maintain their cultures, languages, and identities as First Nations, Inuit, or Métis peoples, and to support their full participation in and contributions to Canadian society (2). Attending to the welfare of both the individual and the community, Indigenous research requires alterations to the standard recruitment process, notably through diversifying recruitment practices by engaging with the community to acknowledge Indigenous perspectives. The Western approach to much health research is still grounded in a positivist worldview that maximizes an objective and value-free approach to studying human and natural realities. As Smith notes, “[f]rom an Indigenous perspective, Western research is more than just research that is in a positivist tradition. It is research which brings to bear, on any study of Indigenous peoples, a cultural orientation, a set of values, a different conceptualization of such things as time space and subjectivity, different and competing theories of knowledge, highly specialized forms of language and highly specialized forms of power” (16). And this worldview may be disconnected from how Indigenous populations value and understand the research.

In a recent literature review examining research methodology and community participation, studies that included Indigenous participations were more likely to include Indigenous epistemologies and participatory evidence sources and evaluation methods (17). Non-Indigenous researchers must acknowledge the potential colonialist principles present in both the recruitment of research participants and the subsequent analytic processes, as being potentially harmful to Indigenous participation. They must consider the impact of their research on Indigenous communities and avoid stigmatization or discrimination in research outcomes. Engagement, during the design process, with groups whose welfare may be affected by the research can help to clarify the potential impact of the research and indicate where measures can be taken to minimize such effects (2). Community-based participatory research (CBPR) is increasingly being adopted by Canadian researchers to facilitate research “with” Indigenous peoples compared to “on” Indigenous peoples (18). CBPR can help researchers acknowledge and address the imbalance of power, focus research on important community issues and include multiple world views. Through fostering empowerment and working with partners, community capacity is developed by approaching research as education, and respecting the established protocols of working with Indigenous people (19).

JUSTICE

Justice in research involves the fair selection of research participants, and ensuring that the risks, benefits and harms of research are distributed equitably (i.e., between participants, their communities and the broader population). But how justice is understood can vary depending on the population of interest. For example, Indigenous research participants may view participation in a research study as the community coming together to contribute to overall well-being. Four axiological assumptions – often called “the four R’s” – can be embedded within Indigenous research: responsibility, respect, reciprocity, and rights (20). Non-Indigenous researchers should thus make explicit their paradigm of justice and explore how this relates to Indigenous perspectives. Yet, in practice, this has often not been the case.

Historically, Indigenous communities were involved in research that benefited only non-Indigenous populations. According to Honorable Murray Sinclair: “We do know that there were research initiatives that were conducted with regard to medicines that

were used ultimately to treat the Canadian population. Some of those medicines were tested in Aboriginal communities and residential schools before they were utilized publicly." (21) Research has been inequitable due to power imbalances between non-Indigenous researchers and Indigenous study participants. And alongside an absence of consent, there has been limited access to data, lack of involvement in research question development and study design, and lack of acknowledgement as research contributors (22). In the past, Indigenous communities were perceived as groups of subjects available for experimentation and subject to acts of injustice at the hands of non-Indigenous researchers and elected officials. The principles of colonialism violated the ethics of justice in research by eradicating the adoption of Indigenous community perspectives in recruitment for research. "During the war and early postwar period bureaucrats, doctors, and scientists recognized the problems of hunger and malnutrition, yet increasingly came to view Aboriginal bodies as "experimental materials" and residential schools and Aboriginal communities as kinds of "laboratories" that they could use to pursue a number of different political and professional interests" (23).

The Canadian government, in the early 1930s, attempted to improve living conditions on a reserve in remote Saskatchewan by implementing colonial principles of health. Although rates of infant mortality and death rates decreased in the Qu'Appelle region, there was concern about spread of tuberculosis from Indigenous to non-Indigenous populations. Tuberculosis was an ongoing public health crisis and research was underway to determine the efficacy of the tuberculosis vaccine. Tuberculosis associations had increased public awareness of tuberculosis prevention and treatment and exerted steady pressure on the federal government to control the tuberculosis "menace" on reserves (24). The government determined that vaccines were cheaper than paying to improve the conditions of Indian residential schools and reserves or treating people in sanatoriums which could turn into lengthy stays (25). The Bacille Calmette-Guérin (BCG) trials with the Qu'Appelle reserve remains an important example of injustice in Indigenous research. The medical superintendent of a sanatorium chose to experiment with the BCG vaccine in the Qu-Appelle reserve simply out of convenience and without disclosing the risks and benefits of the vaccine (24). While vaccine development and research could benefit a large portion of the Canadian population, the researchers chose to ignore many factors present on the reserve that contributed the spread of the disease. Recruitment of members of the Qu'Appelle reserve to participate in these trials was done by capitalizing on the poor tuberculosis health protection measures available in the community. And study participants, including Indigenous infants, died as a result of poor living conditions, something not addressed in this trial. The benefits of research were thus for other privileged populations in Canada, while the people of the Qu'Appelle reservation bore the risks and obtained no direct or indirect benefits from the research. The vaccine trial was noted to be the first randomized control trial in Canada and demonstrated the efficacy of the BCG vaccine against tuberculosis. But its success was predicated on the exploitation of the suffering in the Qu'Appelle Indigenous community.

THE NON-INDIGENOUS RESEARCHER: RECRUITMENT, RESEARCH ETHICS AND COMMUNITY PROSPERITY

Recruitment of Indigenous research participants for a study may appear challenging for non-Indigenous researchers, for many of the reasons presented previously. Several influential research studies (26-29) have been completed by non-Indigenous researchers by applying Indigenous research perspectives during the recruitment process. There are several methods for each ethical research principle that can be applied by non-Indigenous researchers in their recruitment practices with Indigenous populations (Table 1).

Table 1. Research Ethics and Indigenous Paradigm for Recruitment

Research Principle	Adaptation for Recruitment in Indigenous Research
Respect for persons	• Ensure the use of appropriate terminology for the Indigenous research participant • Value of self-determination in research • Value of traditional knowledge and world views with research (OCAP)
Autonomy and Informed Consent	• Voluntary, full disclosure of study intentions and knowledge dissemination • Acknowledgement and awareness of past events, and importance of informed consent as part of recruitment • Open communication with Indigenous bands, councils and communities
Concern for Welfare	• Recruitment as a participant in research should benefit the Indigenous community • Avoid stigmatization with recruitment practices and research participation • Awareness of Indigenous epistemologies and effects of colonialism on beliefs of community welfare during research recruitment • Community based research practices in recruitment
Justice	• Indigenous perspective for recruitment - community comes together for all • Recruitment for participating in a research study will benefit Indigenous individuals and communities • Ensure power balance between researcher and community

Respect for the Indigenous ways of knowing and research interests is the foundation of any successful recruitment process involving this population. A recent research protocol, developed with Indigenous culturally appropriate research views to gain knowledge of urban Indigenous populations living with obesity and type 2 diabetes mellitus with reference to bariatric surgery (26), can be a helpful model. Recruitment methods were designed in consultation with Indigenous elders and a

community advisory group, and included sequential sharing circles and semi-structured conversational interviews to highlight Indigenous ways of communication. In a study by Ball and colleagues, the “Indigenous Fathers Project” (27), consultations with community groups in British Columbia explored how Indigenous fathers conceptualize their roles with their young children and navigate the transition to fatherhood. In this qualitative study, the researchers outlined the benefits of early partnership and inclusion of local communities and how this directly benefited study participant recruitment and enrolment. In addition to ensuring relevance and potential benefit of the research with reference to community priorities, ethical preconditions for communities to partner in the research included developing trust with members of the university-based team and negotiating an agreement about how the community would be involved in every stage of the research (2).

Although the implementation traditional principles or collaborative approaches are not always easy in practice, they can result in much greater interest, buy-in, response, and retention rates with consequent increased effectiveness and efficacy of the research (7). By contrast, when research decisions are taken without meaningful participation of Indigenous researchers, organizations, traditional knowledge holders and communities, there is a risk of harm through misrepresentation or conducting research in a disrespectful way (30). Experiencing resistance from the community may also promote humility and encourage non-Indigenous researchers to think critically about their methodologies, invest more effort into the relationship building process, and seek out help from Indigenous community members (31). Recruitment of participants under these circumstances can be frustrating for new researchers as participant recruitment influences participant retention rate impacting the validity of the study. Providing opportunities for community-based participation in research is an approach to address these issues. One such example is a recent collaborative study partnership combining indigenous ways of knowing and research methods examined end of life care service delivery gaps for Indigenous people in Ontario (29). The research team included a national Indigenous Health organization, Indigenous researchers and Knowledge Holders to form a research partnership. Using community based participatory research to develop this partnership, the project focused on the “two-eyed seeing approach” with research recruitment and objectives relevant to Indigenous people (29). The study was successful in demonstrating collective community benefits with a learning process to help adapt non-Indigenous researchers to Indigenous ways of knowing.

With an understanding of the impact of historical events of unethical research practices involving Indigenous populations in Canada, researchers have gained insight into reconciliation principles that can open a new door for many Indigenous communities to become involved in research. For non-Indigenous researchers, to some degree, the complexities of conducting research with Indigenous partners can be stabilized and brought to a more ethical position by the increased practice of reflexivity, which has as its primary goal the reduction of “unintentional effects of power” (32). Non-Indigenous researchers can, for example, adapt their sense of ownership of the recruitment process and perceived power and control of the study objectives. Chan and colleagues led a national study involving multiple Indigenous chiefs and band councils in observing nutritional health and environments of First Nations communities (28). From the start of the trial, with recruitment, the research mandate of the study was constructed in collaboration with the people involved. Data analysis and training workshops were conducted to help community members interpret community specific data. Power was provided to the study participants and community members throughout this study, with the results delivered to each community for their own use. Indigenous groups were given the opportunity to be in control of the recruitment process and knowledge dissemination of the study’s findings, a role that has been denied in the past to Indigenous research participants.

Whether an Indigenous or non-Indigenous person is conducting research, it is essential the recruitment practices involving Indigenous populations reflect and uphold Indigenous values and ethical principles. Non-Indigenous researchers must be aware of colonial events and unethical research practices that still affect the current state of research amongst Indigenous communities. Recruitment practices should respect the ideals of self-determination and community benefit of research participation. Mutual partnerships with local Indigenous councils and community groups begins with the recruitment process and continues through all the stages of research. By abiding by these principles in recruitment practices with Indigenous communities, research studies can attain a sense of community and respect for all those involved.

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REFERENCES

1. Vadeboncoeur C, Foster C, Townsend N. Challenges of research recruitment in a university setting in England. Health Promotion International. 2018;33(5):878-86.
2. Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council. Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans. 2018.
3. Nadalin V, Maar M, Ashbury F, McLaughlin J. Issues in the recruitment and retention of Aboriginal health research participants in Canada. Aboriginal Policy Research Consortium International (APRCi). 2010;44.
4. Indigenous Foundations Arts UBC. Indigenous Foundation. 2021.
5. Constitution Act. Part 1: Canadian charter of rights and freedoms. 1982.
6. UN General Assembly. United Nations Declaration on the Rights of Indigenous Peoples: resolution / adopted by the General Assembly. 2007.
7. First Nations Governance Centre. Ownership, Control, Access and Possession. 2021.
8. Hyett S, Marjerrison S, Gabel C. Improving health research among Indigenous Peoples in Canada. CMAJ. 2018:190(20):E616-21.
9. MacDonald NE, Stanwick R, Lynk A. Canada's shameful history of nutrition research on residential school children: the need for strong medical ethics in Aboriginal health research. Paediatrics & Child Health. 2014;19(2):64
10. Martens K. Inuit files lawsuit for being guinea pigs in late 60s biological experiment. Aboriginal Peoples News. 6 June 2019.
11. Absolon K, Willett C. Putting ourselves forward: Location in Aboriginal research. In: Brown L, Strega S, editors. Research as Resistance: Critical, Indigenous, and Anti-oppressive Approaches. Canadian Scholars' Press; 2005. p. 97-126.
12. Garrison NA, Hudson M, Ballantyne LL, et al. Genomic research through an indigenous lens: understanding the expectations. Annual Review of Genomics and Human Genetics. 2019;20:495-517.
13. Fitzpatrick EFM, Martiniuk ALC, D'Antoine H, et al. Seeking consent for research with indigenous communities: a systematic review. BMC Medical Ethics. 2016;17:65.
14. National Collaborating Centre for Indigenous Health. An overview of Aboriginal health in Canada. July 2013.
15. Kolb B, Wallace AM, Hill D, Royce M. Disparities in cancer care among racial and ethnic minorities. Oncology. 2006;20(10):1256-61.
16. Smith LT. Decolonizing Methodologies: Research and Indigenous Peoples. Zed Books Ltd.; 2021.
17. Dion ML, Diaz Rios C, Leonard K, Gabel C. Research methodology and community participation: a decade of Indigenous social science research in Canada. Canadian Review of Sociology/Revue Canadienne de sociologie. 2020(1):122-146
18. Goodman A, Morgan R, Kuehlke R, et al. "We've been researched to death": exploring the research experiences of urban Indigenous peoples in Vancouver, Canada. International Indigenous Policy Journal. 2018;9(2):3.
19. Koster R, Baccar K and Lemelin HR. Moving from research ON, to research WITH and FOR Indigenous communities: A critical reflection on community-based participatory research. The Canadian Geographer/Le Géographe canadien. 2012;56(2):195-210.
20. Snow KC, Hays DG, Caliwagan G, et al. Guiding principles for Indigenous research practices. Action Research. 2016;14(4):357-75.
21. Aboriginal children used in medical tests commissioner says. CBC News. 31 Jul 2013.
22. Schnarch B. 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. International Journal of Indigenous Health. 2004;1(1):80-95.
23. Mosby I. Administering colonial science: nutrition research and human biomedical experimentation in aboriginal communities and residential schools, 1942–1952. Histoire sociale/Social history. 2013;46(1):145-72.
24. Lux M. Perfect subjects: race, tuberculosis, and the Qu'Appelle BCG Vaccine Trial. Canadian Bulletin of Medical History. 1998;15(2):277-95.
25. Blackburn M. First Nation infants subject to "human experimental work" for TB vaccine in 1930s-40s. Aboriginal Peoples News. 24 Jul 2013.
26. Hardy K, Clouston K, Zmudzinski M, et al. Decolonizing qualitative research to explore the experiences of Manitoba's urban Indigenous population living with type 2 diabetes mellitus, obesity and bariatric surgery. BMJ open. 2020;10:e036595.
27. Ball J, Janyst P. Enacting research ethics in partnerships with Indigenous communities in Canada: "Do it in a good way". Journal of Empirical Research on Human Research Ethics. 2008;3(2):33-51.

28. Chan HM, Fediuk K, Batal M, et al. The First Nations Food, Nutrition and Environment Study (2008-2018)-rationale, design, methods and lessons learned. Canadian Journal of Public Health/Revue Canadienne de sante publique. 2021;112(Suppl 1):8-19.
29. Funnell S, Tanuseputro P, Letendre A, Bearskin LB, Walker J. "Nothing about us, without us." how community-based participatory research methods were adapted in an indigenous end-of-life study using previously collected data. Canadian Journal on Aging/La Revue Canadienne du vieillissement. 2020;39(2):145-55.
30. Kilian A, Fellows TK, Giroux R, et al. Exploring the approaches of non-Indigenous researchers to Indigenous research: a qualitative study. CMAJ Open. 2019;7(3):E504-9.
31. Ashery RS, McAuliffe WE. Implementation issues and techniques in randomized trials of outpatient psychosocial treatments for drug abusers: recruitment of subjects. The American Journal of Drug and Alcohol Abuse. 1992;18(3):305-29.
32. Nado A. 'Don't talk about what you don't know': on (not) conducting research with/in Indigenous contexts. Critical Studies in Education. 2013;54(2):203-14.