



# Recruitment and Engagement of Indigenous Peoples in Brain-Related Health Research

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## Abstract

**Objectives** To characterize recruitment approaches to research on the brain and mind that involves Indigenous peoples.

**Methods** We conducted a secondary analysis of a Harding et al. (2021) scoping review. Reviewers screened studies ( $n=66$ ) for sampling methods, recruitment and engagement, positionality statements, and details on ethics approvals.

**Synthesis** We identified twenty-nine (29) English-language articles relevant to the analysis. Of these, 52% ( $n=15/29$ ) reported a mix of sampling methods; 45% ( $n=13/29$ ) contained statements or information about author positionalities. While, overall, 24% ( $n=7/29$ ) of the studies were missing information about ethics protocols, we observe an improvement over time in the reporting of approvals and use of community-engaged participant recruitment methods. Current brain research studies demonstrate ways of collaborating with Indigenous communities that meet existing ethics guidelines. To be wholly responsive to the needs of Indigenous peoples,

however, researchers may need to exceed existing ethical benchmarks.. Positionality statements successfully detailed the relationships of the research teams with the communities with which they work, and contextualized recruitment methods.

**Conclusion** Improved quality and meaningfulness of brain research with Indigenous peoples and trust in the research process and public health will be enhanced when remaining gaps in protecting and reporting of participant recruitment methods are closed.

**Keywords** Research recruitment · Indigenous peoples · Brain and mind · Mental health · Health · Ethics

## Introduction

There is a destructive past in Indigenous health research that is marked by extraction, delegitimization, and a breakdown of ethical conventions [1–3]. Historically, Indigenous peoples were studied from a Eurocentric lens as subjects of research [4], and leadership or communities were rarely engaged as collaborators and experts about their own lives [5]. These philosophical and practical patterns have led to an overall underrepresentation of Indigenous peoples in research and mistrust of both the process and public health results [6]. It is important to note that “[r]esearch on Indigenous peoples differs from *with* Indigenous peoples” [7] and that Indigenous

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peoples' participation in research is often with the aim of benefitting their communities [8].

Significant progress has been made in recent years, however, to reverse the trend of underrepresentation and mistrust. Today, Indigenous researchers are leading the movement to decolonize the way research is conducted [9–11]. In Canada, relationships with institutional review boards are evolving as the First Nations Information Governance Centre's principles of Ownership, Control, Access, and Possession (OCAP®)<sup>1</sup> and Chapter 9 of the Tri-Council Policy Statement (TCPS-2) [13] form a critical basis for equitable research and data governance. Self-determination is enacted through community-led research ethics protocols, frameworks, review boards [14], and research guidelines [2]. Research questions are expected to be community-defined, as are the epistemologies, ontologies, and methodologies that are applied. Researchers are bringing reflexivity to their work, situating themselves in relation to Indigeneity, the communities with which they are engaged, to the land, and to their research projects. Even collaborative projects with Indigenous peoples that do not require institutional ethics board review are following these standards to promote meaningful relationship building and create ethical spaces for cross-cultural discussions about brain wellness [15, 16]. Work is still needed, however, to better understand adherence to Indigenous ethical guidelines [2].

Given the ways by which Indigenous traditional knowledges have been undermined on the one hand, and the work done by international initiatives such as the International Brain Initiative [17], the Canadian Brain Research Strategy [18], and the USA NIH BRAIN 2.0 [19] to better understand brain in its multiplicity of perspectives on the other, this work aims to explore the unique ethical issues vis-à-vis brain research with Indigenous people. In the context of brain and mind, a distinct focus for neuroethical inquiry [20], and especially research involving Indigenous peoples [21], it is of paramount importance that authors report on the ethically intertwined features of their research. Here, then, we sought to understand how Indigenous peoples are recruited to brain research, and to identify methods that have

proven to be effective in promoting ethical engagement of Indigenous people. To this end, we explored both snapshots in time through individual publications, and temporal shifts across the years over which they were published.

## Methods

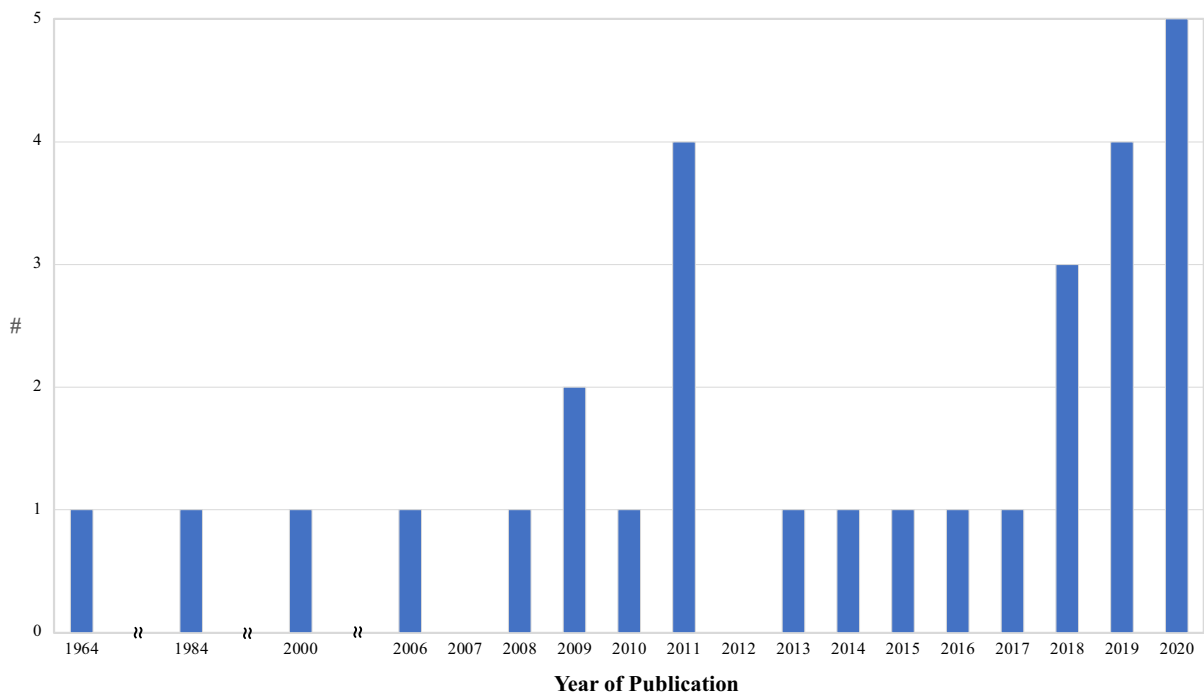
### Definitions

**Research recruitment:** Research recruitment is any activity pertaining to the identification of eligible participants for research, explanation of a study, recruitment of adequate samples based on study goals and design, process of informed consent, ethical standards, and participant retention until study completion [22].

**Positionality:** Positionality statements declare the epistemological and ontological beliefs that researchers believe may influence their work [23]. Positionality statements are widely used in the social sciences and have a special meaning in research with Indigenous peoples [24]. As Opaskwayak Cree scholar Shawn Wilson suggests, positionality links to principles of relationality and relational accountability within an Indigenous research paradigm [10]. In the context of this paper, authors 1, 3, and 4 declare their positionality as settlers of European descent who are actively engaged in research at the intersection of neuroscience and biomedical ethics—neuroethics—with Indigenous communities. Author 2 is a citizen of the Métis Nation of Ontario and with interests in methodological approaches for the proper incorporation of Indigenous ideologies into preclinical and clinical neuroscience research.

**Indigenous people:** There are many existing definitions of Indigenous peoples. The primary study [25] on which the present analysis is based, referred to “Indigenous communities, peoples and nations ... [that have] a historical continuity with pre-invasion and pre-colonial societies that developed on their territories, consider themselves distinct from other sectors of the societies now prevailing on those territories, or parts of them” [26].

<sup>1</sup> OCAP® is a registered trademark of the First Nations Information Governance Centre [12].



**Fig. 1** Number of studies published by year

#### Source for analysis

The primary study [25] and data source contained 66 papers, of which 46 were empirical. Articles were in English ( $n=59$ ), Spanish ( $n=6$ ), and French ( $n=1$ ). Years of publication ranged from 1963–2020. Overall, 66 Indigenous groups were identified, primarily in the USA, Australia, and Canada. Using a search strategy developed through a literature search and consultation with a health reference librarian, the original study included articles on “the opinions, beliefs, views, and attitudes of any Indigenous individual or community about the brain, mind, or any brain or mind condition, disorder, or disease”.

#### Analytic Approach

We applied a secondary analysis approach [e.g., 27] and content analysis methodology [28] to extract information on sampling, participant recruitment and engagement, author positionality statements, and information on approvals from research ethics boards and communities from the full texts of the set of studies. All empirical studies were included for analysis.

Studies that were not empirical, then, such as reviews, were excluded. Occurrences of each variable of interest were noted and tabulated and temporal trends visualized.

#### Results

Twenty-nine (29) studies (Appendix 1) met inclusion criteria. Publication dates spanned nearly a half century from 1964 to 2020 (Fig. 1). The studies primarily involved Indigenous peoples with communities in Canada ( $n=8$ ), the USA ( $n=8$ ), and Australia ( $n=5$ ) (Table 1). Mental health and illness, as well as aging and dementia were prevalent topics explored in these studies.

#### Sampling

Fifty-two percent (52%;  $n=15$ ) of papers reported a mix of sampling methods. The majority were convenience and purposive samples that drew directly from within the populations in focus (Table 2). Sampling

**Table 1** Indigenous communities represented in included studies on recruitment and engagement of Indigenous peoples in brain-related health research

Country/Region	Citation	Indigenous Communities
Amazon (Peru, Bolivia, Brazil, Ecuador, Columbia, Venezuela)	Dobkin de Rios, <i>Medical Anthropology</i> , 1984	Amazon tribal Indians; Mestizo
Australia	Arkles et al., <i>Dementia</i> , 2020 Armstrong et al., <i>Disability and Rehabilitation</i> , 2019 Carr et al., <i>PLoS One</i> , 2019 Cawte, <i>Medical Journal of Australia</i> , 1964 Hamilton et al., <i>Sociology of Health &amp; Illness</i> , 2020 Hatala et al., <i>Culture, Medicine, and Psychiatry</i> , 2015 Cornect-Benoit et al., <i>Canadian Journal on Ageing</i> , 2020 Hunt et al., <i>Public Health Nursing</i> , 2018	Aboriginal peoples of Australia; Torres Strait Islanders Aboriginal peoples of Western Australia Aboriginal peoples of Groote Eylandt and its vicinity Aboriginal Australians in Kalumburu Aboriginal peoples of Australia Q'eqchi' Maya in southern Belize Anishnaabek people of Wiikwemkoong Unceded Territory; Cree First Nations across Ontario
Belize	Keightley et al., <i>Canadian Journal of Occupational Therapy</i> , 2011	First Nations communities near Kenora, Ontario
Canada	Lanting et al., <i>Journal of Cross-Cultural Gerontology</i> , 2011 Pace, <i>Canadian Journal on Ageing</i> , 2020 Webkamigad et al., <i>Canadian Journal on Ageing</i> , 2020 Wilson et al., <i>American Indian and Alaska Native Mental Health Research</i> , 2019	Métis; Salteaux Southern Inuit in NunatuKavut, Labrador Indigenous people living in a northern Ontario urban community; Inuit; Métis Diné (Navajo) Nation
Canada/USA	Mehl-Madrone, <i>Explore</i> , 2009	Arikara-Hidatsa; Caribe; Carrier; Cree; Eastern Cherokee; Haida; Lakota; Ojibway; Penobscot; Seneca; Taino; Tohono O'odham; White Mountain Apache; Yaqui; Maya
Fiji	McNamara et al., <i>Cognition</i> , 2019	iTaukei Fijians from Yasawa Island (Yasawans)
Mexico	Hammerschlag, <i>Journal of Religion and Health</i> , 2009	Huichol (Wixarika)
New Zealand	Corbett et al., <i>Contemporary Nurse</i> , 2006 Mark & Lyons, <i>Social Science &amp; Medicine</i> , 2010 Taitimu et al., <i>Transcultural Psychiatry</i> , 2018	Māori Māori Māori
Pakistan	Choudhry et al., <i>Frontiers in Public Health</i> , 2018	Kalasha
Peru	Loizaga-Velder & Verres, <i>Journal of Psychoactive Drugs</i> , 2014	Cocama; Quecha-Lamista; Mestizo/Chazutino
USA	Friedman et al., <i>The International Journal of Ageing and Human Development</i> , 2011 Haozous et al., <i>Journal of Transcultural Nursing</i> , 2016 Haozous et al., <i>Psycho-Oncology</i> , 2011 Laditka et al., <i>Ageing and Society</i> , 2013 Torsch & Ma, <i>Qualitative Health Research</i> , 2000 Whealin et al., <i>Psychological Services</i> , 2017	American Indian Alaska Native tribes; American Indian; Pacific Northwest tribes in the United States; Southwest tribes in the United States Tribes throughout the Northern Plains region in Southeastern Montana American Indian Chamorro Native Hawai'ian; Pacific Islander

**Table 1** (continued)

Country/Region	Citation	Indigenous Communities
	Yurkovich & Lattergrass, <i>Mental Health, Religion &amp; Culture</i> , 2008	Eight tribes from two Northern Plains States

**Table 2** Sampling methods

Type of Sampling	Number of Studies
Not specified	14
Convenience	6
Purposive	4
Snowball	3
Criterion	1
Judgment	1

methods were not explicitly specified in 48% of the papers ( $n = 14$ ).

### Recruitment and community engagement

Reporting of processes for recruitment and community engagement varied across the data set. For example, Cawte et al. [29] describe observational methods in an ethnographic study of attendees of Catholic mission in Kalumburu, Australia. They did not provide details, however, about adherence to cultural protocols. In a 1984 paper, Dobkin de Rios et al. [30] describe how a pre-existing relationship with a healer provided access to interviews with the healer's patient population. They too did not provide details or methods about the protection of confidentiality or how the possibility for coercion was mitigated. In a 2000 study by Torsch and Ma [31], the researchers describe holding one-on-one interviews and utilizing participant observation in social and cultural settings.

After 2006, all studies except one described working directly with communities and local experts to aid in the recruitment of research participants. This date could reflect a shift in ethical standards coinciding with the growth of the global Indigenous human rights movement and adoption of the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) in 2007 [32], which brought longstanding issues facing Indigenous peoples to the forefront [25]. For example, Hammerschlag [33] involved the Huichol people with invitations from the school principal, the parents association, and the local community. Using snowballing sampling, Mark and Lyons [34] recruited Māori spiritual healers by first recruiting a healer known to the researchers who then recruited friends and associates. Laditka et al. [35] collaborated with tribal organizations and community

partners to hire a recruiter with strong community networks to recruit participants. McNamara et al. [36] recruited Yasawans and Indo-Fijians by having iTaukei and Indo-Fijian research assistants, respectively, visit their homes and request participation. Armstrong et al. [37] employed a local Indigenous person to facilitate participant recruitment; Arkles et al. [38] recruited study participants by way of local community health workers; and, Cornect-Benoit et al. [39] engaged a community advisory group and a community researcher for recruitment. In these instances, by engaging community members in the recruitment process, researchers were likely more successful in achieving community buy-in and assuring meaningful research outcomes for community members. Community- and patient-driven research, affirmed through programs such as Canada's Strategy for Patient-Oriented Research (SPOR) [40], emphasize the importance of community engagement in research.

### Ethics approvals

The majority of studies (76%;  $n=22$ ), all published after 2006, detailed ethics approvals received from institutions (such as university research ethics boards), local communities, or both. While adherence to institutionally established ethics standards does not necessarily equate to culturally safe research practices or the incorporation of Indigenous ethics [9], this trend does highlight growing transparency in the dissemination of research results. Nonetheless, papers were generally not highly descriptive in discussions of what types of ethical approvals were obtained, or the degree to which the required approvals may impart cultural safety. That said, several ( $n=5$ ) studies explained the establishment of advisory groups. Corbett et al. [41], for example, described the process of engaging in a traditional *korero* (discussion) to each *whānau* (the family in the Māori language) who participated in the study to arrive at an understanding of research practices and parameters before obtaining oral consent for participation. Taitimu et al. [42] created a Māori advisory group (*rangahau whānau* research family) to advise the research process. Mention of ethics approvals was absent from the three studies published prior to 2006, and one after.

### Positionality Statements

Forty-five percent (45%;  $n=13$ ) of articles contained positionality statements or other explicit information that situated authors in relation to the communities they studied. Some of these statements provided nuance to findings, such as by recognizing that “cultural insights and knowledge informed how the data were read and interpreted” [34, p. 1758]. They also contextualized the use of personal and professional networks to recruit participants with community ties. In other cases, positionality statements served to clarify epistemological and ontological limitations. For the creation of focus group questions, for example, Keightley et al. [43] acknowledged the positioning of questions from a “Western worldview” (p. 244) as a limitation in seeking to learn Indigenous perspectives. In Carr et al. [44] and Mehl-Madrona [45], positionality statements were used to describe how Indigenous people from the communities studied were invited to join the research team as partners or authors. One article also mentioned the inclusion of and leadership by Indigenous researchers on the research team [37].

### Limitations

This study is limited to the papers and timeframe of the primary analysis [25]. Accordingly, it carries the limitations of the original search strategy, including the challenges of locating research about global Indigenous populations especially prior to mid-2000. Further, Indigenous peoples around the globe are diverse and the results are not generalizable to all communities. What is considered ethical and effective with one community may not be the case with another.

Several studies were missing information on their recruitment methods, which may have introduced bias into our analyses [46]. While mental health was a major area of foci in the included articles, this topic area may have been underrepresented as no search terms specific to mental health were used in the original scoping review. Finally, the focus here was on studies of brain and mind. While a special category unto itself with a unique imperative, the data are similarly restricted to it.

## Discussion

Of the 66 papers detailing Indigenous perspectives on brain and mind, 29 empirical papers contained information on participant recruitment. The analysis revealed diverse sampling methods, approaches to recruitment and engagement, researcher positionalities, and ethics protocols. The presence of each of these variables became increasingly explicit beginning in 2006, and suggests improvements in practices and transparency over time.

In prior studies that focused on the involvement of Indigenous Peoples on research on brain and mind, Schroter et al. [47] found that ethics approval was absent from 31% of *all* manuscripts published in leading medical journals in 2003. In a study of publications in nursing journals about the extent to which ethics approval and informed consent are reported in clinical research Wu et al. [48] found that while 88% of selected studies discussed informed consent, only 53% reported that written informed consent had been obtained. Eijkholt et al. [49] found only scant references to ethics approvals in their study of imaging research involving treatment-naïve individuals with first-episode schizophrenia, and an overall lack of ethical discussion relevant to this vulnerable population.

Anderson et al. [50] called for better ethical transparency and ethical reproducibility in the reporting of empirical research. Indeed, research has routinely emphasized the importance of such scholarly transparency for the reproducible production and dissemination of research with human participants [51, 52], an imperative also supported by the International Committee of Medical Journal Editors and the Committee of Publication Ethics [48]. The inclusion of positionality statements further supports that movement with the expression of limitations on Western ways of knowing to the context of research with Indigenous communities.

While advances are being made in Indigenous research, both in terms of funding allocations and awareness, many institutions have been critiqued for lacking robust ethical policies regarding Indigenous community research [2]. Concerns abound that institutional research ethics review processes are not yet ready to react to research grounded in Indigenous research methodologies [53]. As institutional research review processes play catch up, Indigenous research done ethically will often be forced to exceed existing standards of which transparent reporting of ethical benchmarks is only the start.

## Conclusion

Many of the papers on research on brain and mind in the present study reported on ways of collaborating with Indigenous communities that reflect updated institutional research boards' requirements for community engagement. For example, while older studies rarely acknowledged the positionality of the researchers or the contributions of community members in research, recent studies are apt to acknowledge author positionality and the involvement of community members. Although we observed an improvement over time, there is still room for fuller engagement in critical reflexivity, a necessary part of research with Indigenous peoples. Most studies still do not discuss the integration of Indigenous protocols and standards throughout the research process. Beyond research recruitment standards, then, researchers must pay heed to other ethical benchmarks including confidentiality, anti-coercion, and adherence to Indigenous ethics protocols which advance sovereignty and self-determination. Future research might also look further at such considerations as it relates to Indigenous brain and health research. Through expanded reflexivity and transparency alongside it, researchers will strengthen culturally safe engagement, accountability, trust, meaningfulness of brain and health research.

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**Authors' Contribution** Miles Schaffrick: Conceptualization, Methodology, Investigation, Visualization, Writing—Original draft preparation. Melissa L. Perreault: Writing—Review & Editing. Louise Harding: Investigation, Writing—Review & Editing. Judy Illes: Conceptualization, Methodology, Supervision, Writing—Review & Editing.

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**Code Availability** Not applicable.

**Declarations**

**Ethics approval** Not applicable.

**Consent** Not applicable.

**Original Submission Statement** This submission is original, unpublished, and is not under consideration by another journal.

**Competing Interests** The authors have no competing interests to declare that are relevant to the content of this article.

**Appendix 1****Papers Included in Review**

- Arkles, R., Jankelson, C., Radford, K., & Jackson Pulver, L. 2020. Family caregiving for older Aboriginal people in urban Australia: Disclosing worlds of meaning in the dementia experience. *Dementia*, 19(2), 397–415.
- Armstrong, E., Coffin, J., Hersh, D., Katzenellenbogen, J., Thompson, S., Ciccone, N., & Mcallister, M. 2019. You felt like a prisoner in your own self, trapped”: The experiences of Aboriginal people with acquired communication disorders. *Disability and Rehabilitation*, 1–14.
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## Appendix 2

### Papers in Primary Source (Harding et al., 2021)

Arkles, R., Jankelson, C., Radford, K., & Jackson Pulver, L. 2020. Family caregiving for older Aboriginal people in urban Australia: Disclosing worlds of meaning in the dementia experience. *Dementia*, 19(2), 397–415.

Armstrong, E., Coffin, J., Hersh, D., Katzenellenbogen, J., Thompson, S., Ciccone, N., & Mcallister, M. 2019. You felt like a prisoner in your own self, trapped”: The experiences of Aboriginal people with acquired communication disorders. *Disability and Rehabilitation*, 1–14.

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