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Indigenous Engagement in Health Research in Circumpolar Countries: An Analysis of Existing Ethical Guidelines

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Résumé de l'article

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Abstract
In this paper, we review existing ethical guidelines that support Circumpolar Indigenous Peoples' engagement in health research. For this study, we collated national and regional ethical guidelines addressing health research engaging with Indigenous communities. Our study found that ethical guidelines addressing Indigenous engagement in health research have emerged in Canada and the U.S.A. Currently, there are no Indigenous-specific provisions in national guidelines, or legislation concerning health research engaging Indigenous peoples, in Denmark, Finland, Greenland, Norway, Sweden, or Russia. Where guidelines exist, they show considerable variations. We conclude that guidelines are essential to ensure that research undertaken in Indigenous communities is relevant and beneficial to those communities, is conducted respectfully, and that results are appropriately contextualized and accurate. We believe that our analysis might serve as a checklist to support the development of comprehensive guidelines developed by, or at least in partnership with, Arctic Indigenous communities.

Keywords
American Indians, Alaska Natives, Sāmi, First Nations, Aboriginal peoples, Arctic, partnership, Canada, United States, Greenland, Denmark, Finland, Norway, Sweden, Russia

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Indigenous Engagement in Health Research in Circumpolar Countries: An Analysis of Existing Ethical Guidelines

Internationally, the last two decades have seen a change in the way health research has been conducted. Changes have been motivated primarily by the ethical misconduct of some researchers (Moodie, 2010; Resnik & Master, 2013; Resnik et al., 2015) and governments (Mosby, 2013). After World War II and the Nuremburg trials, the World Medical Association's Declaration of Helsinki was the first example of the international community coming together to identify ethical guidelines for research involving humans (World Medical Association, 1964). Since, international and national guidelines have been developed to regulate biomedical research involving human subjects, patient safety, clinical practice, medical devices, and biological material (for an international and national compilation of guidelines, see U.S. Department of Health and Human Services Office for Human Research Protections, 2017). In addition, there are a diversity of national and regionally specific guidelines for the protection of information, knowledge, and personhood (Bracken-Roche et al., 2017; Canadian Institutes of Health Research et al., 2014; Flicker et al., 2007; Inuit Tapiriit Kanatami et al., 2010; McGrath, 2004; Olsen, 2003; United Nations Educational Scientific and Cultural Organization (UNESCO), 2005; Urrego-Mendoza et al., 2017; Weijer et al., 1999).

In the last decade, some Indigenous nations have drawn attention to how Indigenous peoples have been and are engaged in Indigenous health research. Motivations include the need to safeguard against research-related misconduct, including exploitation, damaging representation of Indigenous peoples in the communication of results, and erroneous conclusions (Couzin-Frankel, 2010; Dyke & Anderson, 2014; Garrison, 2013; Garrison & Cho, 2013; Pacheco et al., 2013). Some Indigenous nations have also sought to protect intellectual property rights over Indigenous knowledge documented during the research process (Dutfield, 2017; Feldman et al., 2013). Most often, research with Indigenous peoples has benefited "the pursuit of knowledge," but failed to benefit those who were being studied. Indigenous nations have expressed an interest in leading research that addresses their own information needs, and directly benefits their communities (Dedats'eetsaa: Tłı̨chǫ Research & Training Institute, 2017; Eriksen et al., 2021; Kovach, 2009; Kukutai & Taylor, 2016; Kyoon-Achan et al., 2018). Several Indigenous communities and organizations (Anderson et al., 2003; Cunningham, 2003; Fitzpatrick et al., 2016; Gwynn et al., 2015; Humphery, 2003; Oneha & Beckham, 2004; Prior, 2007) have drawn from article 20 of the Helsinki declaration to advocate for greater involvement in research:

> 20. Medical research with a vulnerable group is only justified if the research is responsive to the health needs or priorities of this group and the research cannot be carried out in a non-vulnerable group. In addition, this group should stand to benefit from the knowledge, practices or interventions that result from the research. (World Medical Association, 1964)

Ethical guidelines generally provide guidance for research conducted among vulnerable populations, defined as "those whose ability to provide voluntary consent may be compromised by social pressures" (Bracken-Roche et al., 2017, p. 3). Some Indigenous nations have vehemently rejected being labeled as a "vulnerable group," pointing to centuries of resistance to assimilative policies and practices. They have argued that this definition is paternalistic and blames Indigenous nations for their reality, instead of holding nation-states to account for their marginalizing and oppressive practices (Brant Castellano & Reading, 2010; Kukutai & Taylor, 2016; Rainie et al., 2017).

Arguments from Indigenous communities and organizations to foster meaningful engagement in the research process have hinged on three prerogatives: 1) to prioritize research that benefits their people; 2) to end research processes that perpetuate collective marginalization and exclusion from decision-making; and 3) to end the exploitation of Indigenous knowledges, sacred medicines, lands, and other related priorities (Anderson, 2019; Beans et al., 2019; Hiratsuka et al., 2017).

In this paper, we review existing national ethical guidelines that support Circumpolar Indigenous Peoples' engagement in health research. We define national ethical guidelines as guidelines developed by national authorities for the ethical review of research projects. National guidelines are also increasingly used, at least in Canada, by funders to inform the peer review process.

We distinguish national guidelines from regional and local guidelines and guides. A large number of discussion papers and publications have been produced by a variety of agencies, Indigenous communities, and researchers, offering perspectives on ethical conduct when engaging with Indigenous communities (for examples, see Angal et al., 2016; Chadwick et al., 2014; Hull & Wilson Dine, 2017; Inuit Tapiriit Kanatami & Nunavut Research Institute, 2007; Ongomiizwin Indigenous Institute of Health and Healing, 2015; Sámiid Riikasearvi, 2019; The Interagency Arctic Research Policy Committee (IARPC), 2018). Some regional and localized guidelines have become authoritative, in that Indigenous communities refuse to partner in projects that do not comply with their own requirements and protocols (Dedats'eetsaa: Tłı̨chǫ Research & Training Institute, 2017; NunatuKavut Community Council Research Advisory Committee (NCC-RAC), 2013; Qaujigiartiit Health Research Centre, 2019). These initiatives are very important. However, because they are less likely to inform the research funding process at the time of peer review, these initiatives are not presented in our analysis.

We anchor our discussion in four articles prominent in the United Nations' Declaration on the Rights of Indigenous Peoples (UNDRIP), which focus on Indigenous Peoples' rights to: (1) self-determination (article 3); (2) maintain and strengthen their distinct political, legal, economic, social and cultural institutions (article 5); (3) maintain, control, protect and develop their cultural heritage, traditional knowledge, and traditional cultural expressions (article 31); and (4) determine and develop priorities and strategies for the development or use of their lands or territories and other resources (article 32, United Nations, 2007, p. 9). We see these four specific provisions as highly relevant to discussions of Indigenous engagement in all research including health research.

To date, UNDRIP has been endorsed by seven of the eight Circumpolar nations,[1] Russia being the exception. We acknowledge that signatory countries are not obligated to implement UNDRIP. Only Canada has made an explicit commitment, and included this commitment in adopted legislation, and in legislation under review (Last, 2019; Government of British Columbia, 2019; Government of Canada, 2019). Further, all countries including non-signatory nations can use UNDRIP to inform the creation of policies. For instance, the Russian Federation acknowledges Indigenous people's rights "in accordance with usually accepted global law principles and standards" (19, Article 69).

Framework

In this paper, we use a framework developed by Weijer and colleagues (1999) to assess the comprehensiveness of existing and proposed health research ethics guidelines in the Circumpolar regions that are specific to Indigenous peoples of the Arctic. This framework was developed through a review of Indigenous-centric guidelines in Canada and Australia. We selected this framework because Canada and Australia developed some of the most comprehensive Indigenous-centric guidelines in use.

Weijer and colleagues' review identified key requirements for guideline development and research process requirements, which in our view, dovetail neatly with the UNDRIP articles framing our analysis, and validates the use of the framework. We made small adaptations to the framework to more explicitly differentiate Indigenous communities, to acknowledge the right to collective consent, and to add explanations for each criterion. The final framework is shown in Table 1 and was used as a checklist against guidelines to assess comprehensiveness.

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[1] Circumpolar countries include Canada, the Kingdom of Denmark (including Greenland), Finland, Iceland, Norway, Russia, Sweden and the United States. Our article focuses on seven of these countries, since Iceland does not have an Indigenous population.

Table 1. Framework Developed by Weijer and Colleagues (adapted from Weijer et al., 1999)

Requirements	Explanation
Guideline development	
1. Target community	Guidelines are explicit about the Indigenous populations for which the guidelines were created.
2. Community representation on committee drafting guidelines	Indigenous populations for whom the guidelines were developed were involved in their development.
Guideline requirements	
1. Consultation in the research protocol development	
a) Respect for culture	Explicit statement that researchers respect the culture of the Indigenous community.
b) Input on protocol	The Indigenous community was involved in the development of the research protocol.
c) Research useful	Explicit provisions emphasizing that the research needs to be considered helpful to the Indigenous community, and/or align with local priorities.
d) Respect for knowledge and experience	The research protocol makes space for Indigenous knowledge and experience in the research process. This may include recognition and compensation for Elders and knowledge keepers, the hiring of local Indigenous researchers, etc.
2. Collective and individual consent: process and informed consent	
a) Non-technical and appropriate disclosure	Guidelines specify the need to communicate with community leadership and participants in a non-technical manner.
b) Face-to-face meetings	Guidelines specify the importance of face-to-face meetings to discuss the study.
c) Adequate time for review	Guidelines require researchers to ensure that the community and individual participants have adequate time to review the protocol before providing consent.
d) Consent required for protocol changes	Researchers are required to submit any change to the research protocol to the community for consent.
e) May withdraw consent	The guidelines specify that individual participants and participant communities can withdraw consent at any time.
3. Involvement in research conduct	
a) Transfer of skills and research expertise	Ideally, the transfer of skills and expertise is described as bi-directional. At the least, the need to support skill development within the community is mentioned.
b) Employment	Indigenous employment is mentioned.
c) Reimbursement for research costs	The guidelines make explicit recommendations on how to compensate Indigenous communities' costs related to their engagement in research.

Table 1. Framework Developed by Weijer and Colleagues (continued)

Requirements	Explanation
d) Informed about research progress	The guidelines recommend regular community updates on the progress of the research.
4. Access to data and samples	
a) Consent for further use of samples and/or data	Secondary analysis of data and samples requires community consent.
b) Storage of data negotiated	Community has a say in how long data is kept, how it is destroyed (especially for tissue samples), and whether data of cultural significance can be kept by the community.
5. Dissemination and publication	
a) Involvement in manuscript preparation	Community and/or local staff included as co-authors, and/or have a right to review and comment.
b) Draft report for comment	All publications are submitted to the community for validation, feedback, and comments. Adequate time is given.
c) Acknowledgement	The role of the community and any Elders and knowledge keepers is explicitly acknowledged in all reports and publications.
d) Consent to identify	Community and participants (especially Elders and knowledge keepers) are explicitly asked whether and how they want to be identified in all publications and reports.
e) Report compliance with guidelines	All reports and publications explicitly report on the role of the community in research.
f) Final report	A final report is provided to the community.
g) Consent for researcher media interview	The community can designate representatives who may be the researchers and/or members of the community to participate in media interviews.

Methods

This work was undertaken in the context of the 2018-19 Fulbright Arctic Initiative program, which brought together Indigenous and non-Indigenous Arctic scholars from Canada, the Kingdom of Denmark (including Greenland), Finland, Iceland, Sweden, Russia, and the USA. Our collective purpose in developing this article was to highlight areas where Circumpolar ethical guidelines hold promises for ensuring ethical Indigenous engagement in health research, thus improving opportunities for relevant research and ensuring enhanced health and wellbeing.

Our team includes researchers fluent in Danish, English, Norwegian, Russian, and Swedish. All researchers have extensive experience in conducting research with Indigenous organizations and communities, including in Alaska, Nunavut, Greenland, Norway, Sweden, Finland, and Russia. All have extensive experience with the national and regional ethical guidelines in place in their own country and in countries where they conduct research. All have experienced the ethical review processes required. Some have also worked on the creation of existing guidelines. In addition, we conducted a search for additional national ethical guidelines through a review of national sites hosting ethical guidelines in the countries under study, and through internet searches using key words such as Indigenous, Aboriginal, American Indian, Alaska Native, Sámi, Inuit, and their equivalent in Danish, Norwegian, Russian, and Swedish. We specifically looked for guidelines and additional directives addressing health research engaging with Indigenous communities.

Findings

As summarized in Table 2, Indigenous-centric ethical guidelines for health research have emerged in some Circumpolar countries (primarily Canada, the United States, and more recently, Norway). The Sámi Parliaments of Norway and Finland have created guidelines to inform and regulate Sámi health research (Finland Sámediggi, 2016; Sámediggi, 2018). In 2020, Sámi-specific ethical guidelines for health research in Norway were adopted as policy and a Sámi specific ethical review system is now in place (Sámediggi, 2020). In contrast, the Finnish guidelines focus exclusively on traditional knowledge and cultural heritage research, in relation to the convention on biodiversity: They do not include health research. At present, scholars at the Finnish University of Lapland are working with Sámi researchers and organizations to develop comprehensive guidelines for research with the Sámi (Eriksen et al., 2021). Greenland is also in the process of developing its own general guidelines for research.

Table 2. Existing Circumpolar Countries' Indigenous-centric Health-specific Ethical Guidelines

Region/Indigenous populations	Indigenous population, total population (% of total population)	Indigenous-centric national ethical guidelines and processes	Regional ethical guidelines and processes
Yukon (Canada)/ Indigenous people	8,195; 35,111 (23.3%)[a]	Ch 9 of the Tri-Council guidelines (Canadian Institutes of Health Research et al., 2014)	Protocols and Principles for Conducting Research with Yukon First Nations (Government of Yukon Cultural Services Branch Department of Tourism and Culture, 2013)
NWT (Canada)/ Indigenous people	20,860, 41,135 (50.7%)[a]		• NWT Licensing required • No specific guidelines were located.
Nunavut (Canada)/Inuit	30,550, 35,580 (85.9%)[a]		Check list created by the Qaujigiartiit Health Research Centre (Qaujigiartiit Health Research Centre, 2019).
Nunavik (QC, Canada)/ Inuit	10,880, 7,965,450 (0.1%)[a]		
Labrador (NFLD&LAB, Canada)/Innu and Inuit	1,285 (Innu) and 6,450 (Inuit)/512,250 (1.5%)[a]		
Denmark/ Greenlanders	Estimate, 16,470; 5,581,190 (0.30%)[b]	None located	
Greenland	50,187; 56.421 (89.8%)[c]	None located.	Scientific Ethics Committee for biomedical research. Code of Conduct has been produced by the Greenland Medical Society. Guidelines for research involving the health care system has been produced by the Government of Greenland (Grønlandsmedicinsk Selskab [Greenland Medical Society], 2015)..
Finland/Sámi	Estimate, 9,000; 5,517,830 (0.2%)[d]	None located	
Sweden/Sámi	Estimate, 20,000-40,000; 10,230,185 (0.2-0.4%)[d]	None located	

Table 2. Existing Circumpolar Countries' Indigenous-centric Health-specific Ethical Guidelines (continued)

Region/Indigenous populations	**Indigenous population, total population (% of total population)**	**Indigenous-centric national ethical guidelines and processes**	**Regional ethical guidelines and processes**
Norway/Sámi	Estimate, 55,544; 5,295,619 (1.0%)[d]	Proposal for Ethical Guidelines for Sámi Health Research and Research on Sámi Human Biological Material (Sámediggi, 2018)	
Russia/north, multiple tribes	Estimate, 270,000, based on small population rule; 146,000,000 (0.2%)[e]	None located	
Alaska (U.S.A.)/ Alaska Native peoples	147,954 of 796,697 in 2018 (18.6%)[f]	• Belmont report, • Common rule	• Alaska Area Institutional Review Board (Smith, 2013). • Regional tribal health organizations, such as Southcentral Foundation (Hiratsuka et al., 2017)

[a](Statistics Canada, 2017);
[b](Statistics Denmark, 2018);
[c](Det Gronlandske Hus, n.d.);
[d](Samiskt informationscentrum, 2020);
[e](International Work Group for Indigenous Affairs, 2019);
[f](Alaska Department of Labour and Workforce Development, 2010)

Ethical review processes vary by countries. In **Canada,** all university-affiliated researchers must follow the Tri-Council[2] guidelines (Canadian Institutes of Health Research et al., 2014). Ethics review boards (ERBs) exist in all universities and non-university institutions that are eligible for Tri-Council funding, such as teaching hospitals. As a result of recent changes in policy, a small but growing number of Indigenous organizations have also begun to develop ERBs and have adopted their own guidelines (Dedats'eetsaa: Tłı̨chǫ Research & Training Institute, 2017; NunatuKavut Community Council Research Advisory Committee [NCC-RAC], 2013). Indigenous organizations and communities who pursue research or who partner with universities or hospitals in research might have ERBs themselves, with their own binding guidelines. Generally, and in accordance with Tri-Council guidelines, university ERBs require formal indication by the Indigenous partner that the study has been reviewed by the

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[2] Canada has three primary research funders, the Social Sciences and Humanities Research Council (SSHRC), the National Science and Engineering Research Council (NSERC), and the Canadian Institutes of Health Research (CIHR). These form the Tri-Council and have harmonized policies regarding ethics.

Indigenous partner and is acceptable. This may take the form of a letter or of a formal partnership agreement detailing the governance of the study, budget, community involvement, intellectual property rights over the data collected, and mutual obligations related to the publication and dissemination of results. In the Northwest Territories and Nunavut, the Scientists Act 1988 (Government of the Northwest Territories, 1988) describes territory-specific research licensing processes and other regulations designed to ensure that all research conducted in the territories is locally reviewed for relevance and benefit, and catalogued. In Nunavut, a licensing process exists which requires any study undertaken in Nunavut to undergo ethical review in Nunavut, informed by a guide created for that purpose (Qaujigiartiit Health Research Centre, 2019).

In the **United States**, the predominant framework for analysing ethical issues comes from *The Belmont Report* (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979), which identifies respect for persons, beneficence, and justice as the three ethical principles to govern research on human beings. *The Belmont Report* is silent on the importance of collective consent and on the specific needs of Indigenous Peoples. The Common Rule, first adopted in 1991 and amended in 2018, added provisions for certain vulnerable subjects. Both versions recognize the laws of “federally recognized American Indian and Alaska Native Tribal Governments” thereby entrenching recognition of Indigenous Peoples’ sovereignty over research conducted on their territories within the United States (Angal et al., 2016; Chadwick et al., 2014).

Across the United States, a system of Institutional Review Boards (IRBs) is federally mandated. This process of review was developed within institutions such as universities or health research organizations (Catania et al., 2008). Some Indigenous Nations in the United States have developed their own research review processes, which vary by tribal entity, and may change over time. For example, some Indigenous communities and organizations have declared a moratorium on research, others may require a letter of support from an Indigenous official or research review board, and others have chosen to develop Indigenous IRBs to review and approve potential research (Harding et al., 2012).

In **Alaska**, researchers hoping to conduct research with Alaska Native people are required to submit their research for review by the tribal health organization in the region where they intend to work, which may also require review by the Alaska Area IRB of the Alaska Native Tribal Health Consortium. In addition, academic researchers are often bound to ethical review of research at their home academic institution. For example, at the time of writing this paper, the process to conduct research with Alaska Native people in Southcentral Alaska for a researcher who works at the University of Alaska Anchorage (UAA) would entail first submitting a concept proposal to Southcentral Foundation (an Alaska Native healthcare organization in Southcentral Alaska), comprised of a brief document in lay language outlining the idea, method, and potential benefits of their proposed research. Once reviewed, and if approved, Southcentral Foundation would provide a letter of support to the researcher, who then would apply to Alaska Area IRB through an online portal. The research may be submitted for exempt, expedited, limited, or full review, depending on the topic and subjects of research. If the proposal is approved, an application would then be submitted to Southcentral Foundation for their review and approval. In addition, the researcher would submit an IRB application to the UAA IRB, including information on their tribal and Alaska Area IRB review and approvals, as well as an explanation for how their proposal is responsive a series of principles produced by the Interagency Arctic Research Policy Committee for the conduct of research in the Arctic (The Interagency Arctic Research Policy Committee [IARPC], 2018). This process is intended to ensure that research is both methodologically sound (AAIRB and academic home institution IRB), as well as benefits tribal communities (tribal health organization review). However, the length of the process can be a barrier for researchers to engage in community-based participatory research, especially when communities' research needs are immediate and where community engagement requires flexibility in design and approach.

In the **Nordic states**, ethics in health research is primarily influenced by the Helsinki declaration (World Medical Association, 2013). Therefore, in these countries, the main provision for Indigenous rights in the health research context has been the categorization of Indigenous peoples as a "vulnerable population" as per the Helsinki declaration article 20. The General Data Protection Regulation legislation, introduced in the European Union in May 2018, is now the underlying regulation of all data collection and research in EU countries, which include Denmark as well as Sweden and Finland (European Union, 2018).

Sámi in Nordic countries have pushed for a change towards systematically ensuring that Sámi interests are prioritized within research (Sámediggi, 2011). For example, the Sámi parliament of Norway has been calling for establishment of a Sámi ethical review board since 1997, which would review projects, including those related to health (Sámediggi, 2018). Following this, the Northern Norway ethical review committee hired a Sámi medical consultant, to be called upon if needed in matters concerning Sámi health research. However, it is unknown to what extent this practice was successful in fulfilling its purpose, and the procedure has been discontinued for several years (Stordahl et al., 2015). Regardless, the lack of structures and guidelines securing inclusion of Sámi interests in health research ethics review processes has resulted in considerable variations, within and between countries, in terms of how Sámi interests are operationalized in the ethical review processes (Sámediggi, 2018). To remedy this within Norway, the Sámi parliament of Norway has supported the adoption of a set of Sámi specific ethical guidelines in health research (Sámediggi, 2018). Those guidelines were created by a committee organized by the Sámi parliament of Norway, inspired by discussions with other Indigenous groups (most notably, Aboriginal people in Australia and Māori in New Zealand) and are now in effect (Sámediggi, 2020). The two main principles of those guidelines are the right to collective consent (likely to be given through creation of a new Sámi ethical review board, supplementing the existing structure), as well as acknowledgement and recognition. This last principle addresses the right of Sámi people to be recognized as such, including being allowed to register their ethnicity in health registers (currently, registering ethnicity and similar categories including race is illegal in Nordic countries). Although the Sámi parliament in Sweden have made it a political priority to establish similar ethical guidelines

(Sámediggi, 2019), no similar developments have taken place there, nor in the other parts of the Sámi homeland (Finland and northwestern Russia).

Most of the research undertaken in **Greenland** is organized by or in partnership with Danish universities. Danish universities have ethical guidelines directing researchers on ethical conduct, but these do not recognize the need to engage Indigenous communities in the design and implementation of studies. Greenland has a Scientific Ethics Committee for health research where all biomedical research must be approved (www.nun.gl). Health researchers are encouraged to submit all research protocols to the Ethics Committee, although this is only mandatory for biomedical research following the Helsinki Declaration (and consistent with the practice in Nordic countries). Along with their protocol researchers must submit a lay description of the project and a copy of the information provided for participants in the research projects in *Kalaallisut* (the Inuit language in Greenland). The Greenland Medical Society has published a Code of Conduct for health research (in Danish only) focusing on local (not Indigenous-specific) engagement, but these are not official guidelines nor legally binding (Grønlandsmedicinsk Selskab [Greenland Medical Society], 2015). Further, the Ministry of Health has published guidelines to ensure respect for limited capacity in the health sector (Naalakkersuisut [Government of Greenland], 2015). Natural sciences research is regulated through a mandatory permitting process for expeditions to remote areas (Government of Greenland, 2010). As with Denmark, these guidelines do not include Indigenous-centric provisions.

In **Russia**, neither university ethics review boards nor arctic research centres existing in most Arctic territories of the country use Indigenous-specific guidelines. As a result, researchers' engagement with Indigenous communities depends on the relationships between the researchers and the Indigenous communities in which they work. Some attempts at addressing ethical issues in Indigenous-centric health research can be found in regional policies and target programs. For instance, two programs (Yamalo-Nenets and Nenets) have been designed with the objective to ensure availability of research and to increase efficiency of research aiming at new models of health care in the context of traditional lifestyle and changing conditions of northern Indigenous peoples. Still, the purpose of such programs is to promote health research rather than to involve Indigenous peoples in leading the study or to conduct studies according to specific values or perceptions of Indigenous peoples. Very often, research with Indigenous populations is complicated by geographical, cultural, and historical specificity of the Russian Arctic— Indigenous settlements are sparsely spread in the Arctic territories with insufficient road and air transportation; certain groups of the contemporary Indigenous population preserve nomadic or semi-nomadic lifestyles based on reindeer breeding and migrate long distances which make research relationships difficult to almost impossible to sustain; research is sometimes conducted in the context of limited staff, insufficient financing, and reluctance of Indigenous population to interact with cultural outsiders. Within these circumstances, the lack of clear guidelines in Russia might result in missed opportunities for Indigenous communities to be either actively engaged in the research or to benefit from findings, and might result in irrelevant or erroneous findings.

We reviewed more closely national ethical guidelines that are health-focused and contain Indigenous-specific provisions. Table 3 shows variations in the guidelines we reviewed, which included:

- Canada: Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans – TCPS 2 (Canadian Institutes of Health Research et al., 2014).
- The United States: the Belmont Report: ethical principles and guidelines for the protection of human subjects of research (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979); the Federal Policy for the Protection of Human Subjects ('Common Rule'), and the Revised Common Rule (U.S. Department of Health & Human Services Office for Human Research Protections, 1991, 2018).
- Norway: Proposal for Ethical Guidelines for Sámi Health Research and Research on Sámi Human Biological Material (Kvernmo et al., 2018).

Table 3. Analysis of Existing National Ethical Guidelines Specific to Health Research that Contain Indigenous-specific Provisions

Country	Canada	U.S.A.	U.S.A.	Norway
Guideline	TCPS2[a]	Belmont[b]	Common rule 2018 amendmt[c]	EGSHR[e]
National, regional or community specific guidelines	National, overarching	National, overarching	National, overarching	Sápmi
Year	2018	1978	1991, 2018	2018
1. Indigenous-specific component	Ch 9	None	Recognizes Tribal laws	All
2. Indigenous representation on committee drafting guidelines	Extensive	None noticeable	None noticeable	Extensive
Guideline requirements				
1. Consultation in research protocol development				
a) Respect for culture	√			√
b) Input on, co-development of protocol	√			√
c) Research useful	√			√

Table 3. Analysis of Existing National Ethical Guidelines Specific to Health Research that Contain Indigenous-specific Provisions

Country	Canada	U.S.A.	U.S.A.	Norway
d) Respect for local knowledge and experience	√			√
2. Collective and individual consent: process and informed consent				
a) Appropriate disclosure of research protocols	√			
b) Adequate time for review	√			
c) Consent required for protocol changes	√			
d) May withdraw consent	√			√
3. Community involvement in research conduct				
a) Recognition of community expertise, Indigenous knowledge	√			√
b) Employment	√			
c) Reimbursement for research costs	√			

Table 3. Analysis of Existing National Ethical Guidelines Specific to Health Research that Contain Indigenous-specific Provisions (continued)

Country	Canada	U.S.A.	U.S.A.	Norway
d) Researchers' continued accountability to the community	√			√
4. Access to data and samples				
a) Consent for further use of samples, data	√			√
b) Storage of data negotiated	√			
5. Dissemination and publication				
a) Involvement in manuscript preparation	√			
b) Draft report for comment	√			
c) Acknowledgement	√			
d) Consent to identify	√			
e) Report compliance with guidelines				
f) Final report	√			
g) Consent for researcher media interview				

Table 3. Analysis of Existing National Ethical Guidelines Specific to Health Research that Contain Indigenous-specific Provisions (continued)

Country	Canada	U.S.A.	U.S.A.	Norway

[a] Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans – TCPS 2 (Canadian Institutes of Health Research et al., 2014);

[b] The Belmont Report: Ethical principles and guidelines for the protection of human subjects of research (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979);

[c] Federal Policy for the Protection of Human Subjects ('Common Rule'), and the Revised Common Rule (U.S. Department of Health & Human Services Office for Human Research Protections, 1991, 2018);

[d] Procedure for seeking the free, prior, and informed consent of the Sámi from the Sámi Parliament in Finland for research projects dealing with Sámi cultural heritage and traditional knowledge and other activities that have or may have an impact on this heritage and knowledge (Finland Sámediggi, 2016);

[e] Proposal for Ethical Guidelines for Sámi Health Research and Research on Sámi Human Biological Material (Sámediggi, 2018).

[f] Participation in research activities is mentioned, employment is not specifically mentioned.

Overall, guidelines used in Canada appear to be the most comprehensive and include Indigenous-specific provisions. In contrast, the U.S. Belmont report and common rule defer Indigenous-specific provisions to Tribal Law, and presumably, to Indigenous guidelines where they exist. As discussed, Alaska Native people have developed a different process through both regional Tribal organizations and the Alaska Area IRB of the Alaska Native Tribal Health Consortium. Thus, regional variations have been systematized, reflecting principles of Indigenous sovereignty, and the diversity of Indigenous nations in the U.S. Guidelines in Sápmi could not possibly defer to Sámi "tribal laws" since this structure is not relevant in the Sámi context. Provisions for collective consent have nevertheless been included in the Norwegian Sámi-specific guidelines. Areas that remain outstanding in these guidelines include recognition of Sámi contributions in dissemination and publication activities.

Discussion

Our study focused on an analysis of national guidelines as they pertain to Indigenous health research. We recognize clear limitations to our study. To begin, we limited our research to national guidelines, which although authoritative, remain subject to interpretation. Second, countries lacking explicit guidelines might nevertheless have adopted practices that align with the principles described in Table 3. Given our team's engagement in the funding and peer review process of research in our respective countries, we are confident that if this is the case, then these practices are localized and tied to specific individuals whose influence may be considerable in specific settings but unnoticeable elsewhere. We also recognize that individual researchers might have co-developed their own research processes with Indigenous communities which go beyond the expectations embedded in national guidelines. Finally, we acknowledge that high level guidelines represent a minimum for ethical expectations, which may be deemed insufficient by Indigenous communities.

Our study shows that to date, ethical guidelines addressing Indigenous engagement in health research have emerged in Canada, Norway, and the U.S.A., with more integrated and streamlined implementation processes in Alaska. Guidelines with an Indigenous-specific focus are under discussion in Greenland. Progress is not apparent on Indigenous-specific ethical guidelines for health research in Sweden or Russia.

The guidelines we reviewed harmonize to some extent with articles 3, 5, 31, and 32 of UNDRIP discussed earlier in this paper (United Nations, 2007). The variations appear to reflect the extent of debate on Indigenous self-government within each country. We recognize that these debates are fluid, vary in aspiration and scope, and are evolving (Broderstad, 2014; Shadian, 2017; Strommer & Osborne, 2015).

Where guidelines and processes exist, evidence of partnership-based research is emerging in the published literature (Beans et al., 2019; Chu Yang et al., 2018; Hiratsuka et al., 2017; Kyoon-Achan et al., 2018). We recognize that the inclusion of a description of partnerships may be underrepresented as a result of editors and peer reviewers insisting that such detail is unnecessary, as we have experienced.

Literature is also emerging on lessons learned from projects undertaken in partnership, although thus far, this literature has only emerged in Canadian and Alaskan contexts (Ball & Janyst, 2008; Baydala et al., 2013; Genuis et al., 2015; Morton Ninomiya & Pollock, 2017; Vukic et al., 2009; Wallis et al., 2015).

Where clear guidelines and process do not exist, some iteration of partnerships and collective consent may be present (for example, Stoor et al., 2015), but this is less likely to be reported in detail. This lack of reporting perpetuates the impression that Indigenous peoples are *the object* of research, and that these studies are poorly aligned with UNDRIP.

In all countries under study, we note that Canada generally tends to have more comprehensive guidelines for health research, with explicit provisions for Indigenous health research. We link this to the creation of the Canadian Institutes for Health Research (CIHR), which replaced the Medical Research Council of Canada in 2001. Since its creation CIHR's funding of research has seen a proportional shift, from funding nearly exclusively discovery research (biomedical and clinical research) in 2001 to progressively increasing investments in health systems and services research and population health research. These latter themes focus on system and population health transformation and require decision-makers, patients, and the community to be involved in the research process. As a result, ethical guidelines have expanded their focus to provide guidance on how to best protect human participants in participatory studies. These new guidelines recognize that participants in such studies might face significant risk, but also that that risk is very different from the risk patients engaged in a randomized controlled trial might encounter. Alongside these developments, Indigenous communities in Canada have become more vocal about the need for university-based researchers to stop studying Indigenous peoples and to instead engage them as equal in the research process. Thus, the development of Indigenous-centric guidelines are the results of two processes: increased funding to health system and population health research and associated expectations that the result will produce improvements (rather than simply naming the problem), and a push by Indigenous communities for increased participation in research that benefits them.

As a result of these changes, which echo changes in ethical guidelines in Australia, New Zealand, and elsewhere, the Canadian Journal of Public Health issued what is, to our knowledge, the first guideline requiring a disclosure of researcher–Indigenous partnership as a condition of publication (Canadian Journal of Public Health, 2020). This guideline resonates with a small but emerging literature (Beans et al., 2019; Huria et al., 2019). This initiative, should it spread to other publishers, could add pressure onto researchers to adopt partnership-based practices, and add important energies to national discussions.

Conclusions

International trends towards greater inclusion of Indigenous Peoples in research leadership roles are apparent in research ethics processes in Canada, the United States, and, most recently, in Norway. These trends are emerging in Greenland and Finland but remain largely absent in other Circumpolar contexts.

We reflect that this may be attributed to different factors, including more emphasis (and importance) being placed by funding bodies on biomedical and clinical research, where the development of mechanisms supporting participatory research is less relevant. Alternatively, or alongside, Circumpolar countries have various levels of commitment to Indigenous self-determination. We surmise that a lack of Indigenous-specific guidelines might signal as lesser commitment, more so than an endorsement of UNDRIP.

We acknowledge that Indigenous and non-Indigenous researchers engaging in research across Circumpolar contexts may readily partner with Indigenous communities, endorse principles entrenched in UNDRIP, and adhere to Indigenous-centric ethical guidelines even when they are not in place in their jurisdictions. While this voluntary endorsement of principles is commendable, it is insufficient to expect all researchers to voluntarily adhere to guidelines they may not even be aware of. We contend that Indigenous-centric ethical guidelines are required in all Circumpolar contexts, developed by, or at the least co-developed with, Indigenous stakeholders.

Our work shows considerable variation between existing Indigenous-specific guidelines for ethical heath research, which might reflect divergent priorities between Indigenous nations, or incomplete guidelines. The generation of knowledge that accurately reflects Indigenous realities and priorities is paramount to addressing health inequities existing in Circumpolar contexts. We believe that Indigenous-centric ethics guidelines are a necessary requirement for this to be realized. We believe that our analysis might serve as a foundation to support discussions among Indigenous communities and nations that allows for a broad conversation on topics to include within ethical guidelines.

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