

Guidelines for research involving Aboriginal communities in Newfoundland and Labrador

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on behalf of

Labrador Health Research Advisory Committee (LAHRC)

and

NL Health Research Ethics Board (HREB)

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I. Purpose

“Where do I apply first, to the REB or to the community or to the regional health research review committee?”

“The REB told me I need approval from the Aboriginal community; but the Aboriginal community told me they won’t look at it until I have REB approval – what do I do?!?”

This document is designed to assist researchers with the process of engaging in research with Aboriginal communities of Newfoundland and Labrador (NL). Researchers, communities, and REBs have all been frustrated with the convoluted and at times contradictory review policies, procedures and expectations. Recent work by a NunatuKavut-Memorial team examining research ethics related to the NunatuKavut community¹, supplemented by key stakeholder discussions during a workshop on Aboriginal research ethics sponsored by the Labrador Aboriginal Research Committee² has resulted in a “roadmap” for navigating research review.

This document provides information specific to the province of Newfoundland and Labrador. **Other university REBs may require that Aboriginal RAC approval be in place before they will review the application.**

For research that is not conducted on specifically Aboriginal lands (that is, not on a land claims area and not in a specific Aboriginal community) but may implicate a specific Aboriginal community, relevant Aboriginal community Research Advisory Committees (RACs) should be consulted for advice (see *Step 1: Preliminary Discussion*, below).

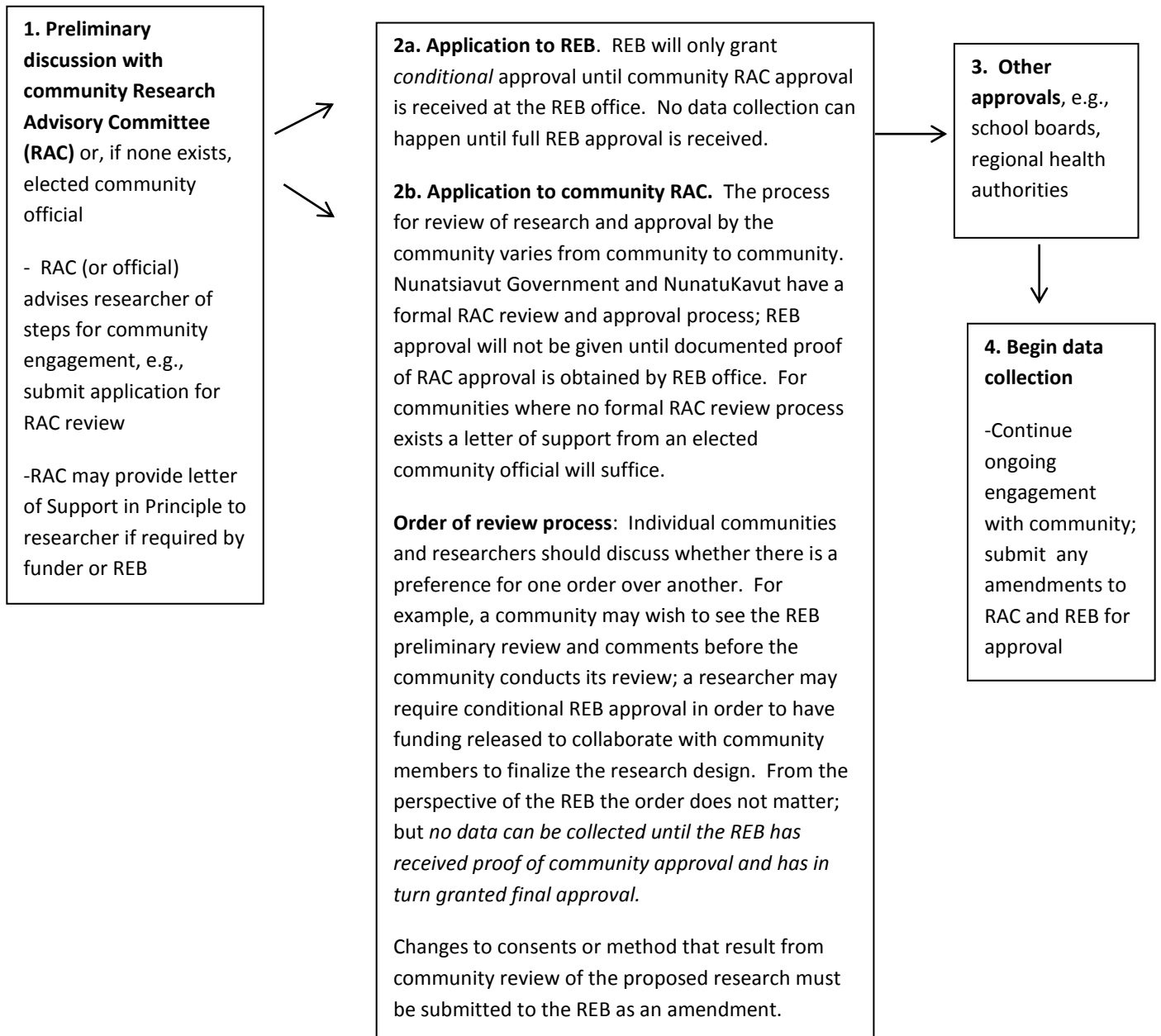
For general information on how to respectfully engage in research with Aboriginal peoples, please refer to:

1. The First Nations Principles of OCAP. First Nations Information Governance Centre. <http://www.rhs-ers.ca/node/2>
2. CIHR Guidelines for Health Research Involving Aboriginal Peoples: <http://www.cihr-irsc.gc.ca/e/29134.html>
3. Tri-Council Policy Statement (2) Chapter 9, Research Involving the First Nations, Inuit and Métis Peoples of Canada <http://www.pre.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-eptc2/chapter9-chapitre9/>

¹ F. Brunger (PI), J. Bull, J. Graham, D. Pullman, D. Wall, C. Weijer (Co-Investigators), with D. Wall, NunatuKavut Community Council, *The NunatuKavut Research Ethics Project: An experiment in Aboriginal governance of health research in complex communities*. CIHR Operating Grant, 2010 – 2013.

² Labrador Aboriginal Health Research Committee (LAHRC), *Aboriginal health Research Ethics Workshop*, Happy Valley-Goose Bay, Labrador, September 25 & 26, 2012. <<http://www.mun.ca/labradorinstitute/news/>>

PROCESS FOR REVIEW OF HEALTH RESEARCH INVOLVING ABORIGINAL COMMUNITIES



II. Definitions of terms referred to in this document

Aboriginal research advisory committee (RAC):

- The committee that reviews applications by researchers to conduct research with a particular community or on Aboriginal lands. The review by an Aboriginal RAC is for the purposes of ensuring that the research is:
 - a) Conducted in a manner that is appropriate to the spiritual, cultural, social and environmental context of the community
 - b) In keeping with the needs, expectations and values of the community
 - c) Conducted in keeping with the principles of OCAP (ownership, control, access and possession [see below])

OCAP Principles:

- The principles of Ownership, Control, Access, and Possession (OCAP) enable self-determination over research³. These principles offer a way for Aboriginal communities to make decisions about what research will be done, for what purposes information or data will be used, where the information will be physically stored, and who will have access. Community review of research ensures that these principles are being adhered to by researchers. This means active engagement with the community Research Advisory Committee must be in place, **including at the design phase and during dissemination of research findings.**

Health Research Ethics Authority (HREA):

- The NL Health Research Ethics Authority (HREA) Act came into force on July 1, 2011. It requires that all health research conducted in NL be reviewed and approved by a local (Newfoundland and Labrador) research ethics review board. The Health Research Ethics Authority (HREA) oversees ethics review of health research by the Health Research Ethics Board (HREB) or an approved health research ethics review body. All health research conducted in NL must be approved by the NL Health Research Ethics Authority regardless of whether it has already been reviewed and approved by a university or other institutional REB.⁴

³ The First Nations Principles of OCAP. First Nations Information Governance Centre. <http://www.rhs-ers.ca/node/2>. See also, 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 First Nations Centre, October 2005 http://www.naho.ca/documents/fnc/english/FNC_OCAPCriticalAnalysis.pdf

⁴ The Health Research Ethics Authority (HREA) of Newfoundland & Labrador, a non-profit agency, was established by the *Health Research Ethics Authority Act* and came into force on July 1, 2011. It is charged with the general supervision of all health research involving human subjects conducted in this province. <http://www.hrea.ca>

III. NL Aboriginal Research Advisory Committees

Nunatsiavut Research Advisory Committee

Inuit Research Advisor for Nunatsiavut
Nunatsiavut Government
17 Sandbanks Road, P.O. Box 70
Nain, NL A0P 1L0
Main line: (709) 922-2380 Fax: (709) 922-2931
E-mail: carla_pamak@nunatsiavut.com
Website: <http://www.nunatsiavut.com>

NunatuKavut Research Advisory Committee

370 Hamilton River Road
P.O. Box 460, Stn. C
Happy Valley-Goose Bay
NL, Canada A0P 1C0
Tel: 1-877-896-0592
Fax: 1-709-896-0594
Attention: Darlene Wall E-mail: dwall@nunatukavut.ca

Innu – Natuashish community or Innu leadership approval

Mushuau Innu Band Council
PO Box 107
Natuashish, Labrador
Canada, A0P 1A0
Telephone: 1-709-478-8827
Fax: 1-709-478-8936

Innu –Sheshatshiu community or Innu leadership approval

Sheshatshiu Band Council
PO Box 160
North West River, Labrador
NL, Canada, A0P 1M0
Telephone: 1-709-497-8720
Fax: 1-709-497-8757

Conne River Health and Social Services, Miawpukek First Nation

Miawpukek Mi'kamawey Mawi'omi
P.O. Box 10

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Conne River, NL
A0H 1J0
Telephone: 1-709-882-2470
Toll Free: 1-866-882-2470
Fax: 1-709-882-2292
<http://www.mfngov.ca/>

Department of Health and Social Services
Theresa O'keefe
email: theresaokeefe@crhss.com
Ph: (709) 882-5102
Fax: (709) 882-2836

Qalipu Mi'kmaq First Nation

Qalipu Mi'kmaq First Nation Band
3 Church Street
Corner Brook, NL
A2H 2Z4
Phone: (709) 634-0996
Fax: (709) 639-3997
<http://qalipu.ca/>

Health and Social Department
Howard Thistle
709-679-5743
855-675-5743
hthistle@qalipu.ca

IV. Steps in the Process of Community Engagement

1. Preliminary discussion with community leaders (can be done by telephone or email)
-receive conditional letter of support from community, if required for funding or REB application

2a. Submit application to Aboriginal RAC for review
2b. Submit application to REB for review

3. Once community approval and REB approval are obtained, apply for permissions to access institutions (e.g., health authorities, school boards) or lands (e.g., archaeology permits)

4. Do data collection
-ongoing communications; approvals for amendments must be sought from REB and RAC

5. Dissemination, including to the community, in keeping with the terms of application

1. Preliminary Discussion:

The Preliminary Discussion is an informal email or telephone call by the researcher to the RAC Chair or other community member, to introduce the possibility of a research application. The purpose of the preliminary discussion is for the researcher to:

- Introduce the researcher and the project to the community
- Ensure that a proposed topic is appropriate for submission to the review process
- Have an opportunity to ask questions and clarify any steps in the process of review
- Receive help with identifying communities or research support persons, as part of the early design phase of the research

Letter of support:

Guidelines for research involving Aboriginal communities in Newfoundland and Labrador

An RAC may provide, upon request by the researcher, a *letter of support for the research*. The letter of support does not constitute formal review and approval. It signifies that the community has been engaged in the research process and supports the research in principle. This letter can be submitted to REBs and funders as proof of community support and engagement. *Data collection cannot begin, however, until the full application has been submitted and reviewed and formal approval has been granted by both the RAC and the REB.*

Note: Research that will not involve the community, but may implicate the community:

Example 1: A social worker is conducting research on family violence in Happy Valley-Goose Bay generally. She is not specifically focusing on a particular Aboriginal group, but is collecting demographic information which might lead to results that implicate the community.

For research such as this, no review is required, according to national ethics guidelines and policy. However, researchers should: (1) Notify the RAC about the research and confirm that the particular RAC does not require full review; and (2) as a courtesy, submit to the RAC a copy of research findings or final report.

If any emerging or final results do have implications for a particular community, the community Research Advisory Committee should be consulted as soon as possible about how to manage dissemination of findings.

2a). Application to Aboriginal research advisory committee/s (RAC)

Individual community RACs should be consulted about the process for applying for review. Along with the Application, community review requires that consent forms and recruitment materials (posters, letters of invitation etc.) be approved. The purpose of the review is to ensure that the proposed research will be:

- 1) Conducted in a manner that is appropriate to the spiritual, cultural, social and environmental context of the community
- 2) In keeping with the needs, expectations and values of the community
- 3) Conducted in keeping with the principles of OCAP (ownership, control, access and possession)

Possible decisions are:

- a) The proposal is acceptable as submitted

- b) The proposal requires additional information or revision; the researcher is requested to revise and resubmit in a timely manner
- c) The proposal is unacceptable to the community context and is rejected

***NOTE:** The greater the level of engagement with community members at the design stage, the less the opportunity for a decision of rejection to occur. A thorough process of engagement with researchers means that a researcher who submits a full proposal for review has already had their project idea and general design screened by and discussed with community members.

Notice of Approval of Application

The RAC provides Approval of the research proposal once it has been reviewed and all conditions have been met to the satisfaction of the Committee.

*** NOTE:** Some Aboriginal RACs may require that REB approval be in place before they will review the application. In Newfoundland and Labrador, Nunatsiavut does require proof of REB approval before they will grant RAC approval.

*** NOTE:** *In some cases, community review may result in an amendment to the protocol or consent form that has to go back to the REB for approval.*

2b). Application to Research Ethics Board (REB)

Researchers should consult the website of the REB/s for specific application guidelines. In the province of Newfoundland and Labrador, under the *Health Research Ethics Authority Act*, all health research conducted in the province must be reviewed and approved by an HREA-approved, Newfoundland and Labrador based, REB, regardless of whether it has also been reviewed and approved by another REB.

*** NOTE:** Newfoundland and Labrador has two REBs: The NL Health Research Ethics Board (HREB) and Memorial University's Interdisciplinary Committee on Ethics in Human Research (ICEHR). They do not require formal Aboriginal community review and approval to be in place before the REB conducts the ethics review and approves the research. An informal letter of support from community collaborators will suffice. However, **data collection cannot begin until both REB and Aboriginal RAC approvals are in place.** (Note that some other university REBs may require that Aboriginal approval be in place before they will review the application.)

3. Other approvals

Researcher-Community Agreement: For those research projects that involve a collaboration or partnership with the community, a signed researcher-community agreement may be required. Individual community RACs should be consulted about this possible requirement.

Other approvals: For certain research projects, other approvals may be necessary, such as approval by Regional Health Authorities (RHAs) for access to patient records, or resources at facilities, or staff time; approval by School Boards where the project involves educational resources or staff or students; and approval by the Nunatsiavut or Newfoundland & Labrador governments for particular land, plant or animal usages. Examples of the types of approvals that may be necessary can be found in Section V of this document.

4. Data collection

Once REB and RAC approvals are in place, data collection can be initiated. During the period of data collection, any purposeful **changes** to the method (amendments) or inadvertent deviations from the method or serious and unexpected adverse events **must be reported to the RAC** as well as to the REB.

5. Dissemination

Dissemination of findings must be in keeping with the terms of the Application made with the individual RAC. In cases where terms of a researcher-community agreement stipulated that the community has the right to review materials prior to publication, researchers should not publish information about Aboriginal communities or implicate Aboriginal communities without the knowledge of the community (that is, they should not disseminate information without receiving prior approval of the community)⁵. Failure to comply with terms of a researcher-community agreement bears the risk of breaching important relationships of trust between researchers and communities.

⁵ For further guidance on community-researcher agreements related to academic publishing responsibilities (including co-authorship with community members) see Murielle Nagy, "Access to data and reports after completion of a research project," *Inuit Studies* 2011 Vol 35 (1-2):201-222.

V. Examples of Additional Research Approvals and Permissions

This list is not all-inclusive. It is meant to provide some guidance and should not be the only source you consult.

Animal Care Committee:

Memorial University Institutional Animal Care Committee

The Animal Care Committee reviews and approves the use of animals in university programmes including teaching and research. This applies to all other users of animals who are not affiliated with the University, but who are using University facilities.

<http://www.mun.ca/acs/guidelines.shtml>

Health Regions:

Labrador-Grenfell Regional Health Authority Research Review Committee

Information on the application process is available by contacting:

<http://www.lghealth.ca/index.php?pageid=224>

Eastern Regional Health Authority Proposals Approval Committee (RPAC)

Website: <http://www.easternhealth.ca/Professionals.aspx?d=1&id=1007&p=81>

For further information you may contact the Patient Research Center at 777-7283

Western Regional Health Authority Research Resource Review Committee

website: <http://westernhealth.nl.ca/index.php/About-Us/best-practices-innovation-and-research/research-ethics-board>

For further information you may contact Ms. Darlene Welsh, Regional Manager Research and Evaluation, at 634-4306 or darlenewelsh@westernhealth.nl.ca.

Central Regional Health Authority Research Review Committee

Website: <http://www.centralhealth.nl.ca>

School Boards, for example:

Labrador District School Board

Website: <http://www.lsb.ca>

Nova Central School District

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Website: <http://www.ncsd.ca>

Western School District

Website: <http://www.wnlsd.ca>

Eastern School District

Website: <http://www.esdnl.ca>

Conseil Scholaire Francophone

Website: <http://www.csfp.nl.ca/>

Mamu Tshishkutamashutau: Innu Education

Website: <http://www.innueducation.ca>

Land and Animal use Permissions, for example:

Archaeology Permits

- Archaeological investigation permit for research in Inuit Lands, required for Nunatsiavut. Website: <http://www.nunatsiavut.com/>, Contact: Carla Pamak, Carla_Pamak@nunatsiavut.com
- Archaeological research in the Labrador Inuit Settlement Area (LISA) requires a permit from the Provincial Government. Website: <http://www.tcr.gov.nl.ca/>
- Archaeological Research inside the Torngat Mountains National Park requires a permit from Parks Canada. Website: <http://www.pc.gc.ca/>

Nunatsiavut land use permits

This list is not exhaustive. Please contact Nunatsiavut government office to ensure that your research meets all requirements. Website: <http://www.nunatsiavut.com/>, Contact: Carla Pamak, Carla_Pamak@nunatsiavut.com

- Archaeological investigation permit for research in Inuit Lands
- Land Use Permit, required by the Nunatsiavut Government: (as per Chapter 4 of the Labrador Inuit Lands Act, Part 4.15)
- Harvesting Permit (Permit to Access Labrador Inuit Lands for the Purpose of Harvesting)

Firearms acquisition certificate (FAC) permit from RCMP

Website: <http://www.rcmp-grc.gc.ca/>

Wildlife protection permits from NL Environment and Conservation

Guidelines for research involving Aboriginal communities in Newfoundland and Labrador

Website: <http://www.env.gov.nl.ca/env/>

- [Livestock protection from Coyote permit](#)
- [The collection, sale and export of Big Game/Big Game Animal Parts](#)
- [Permit to possess a Non-game specimen for Taxidermy](#)
- [Permit to transport Big Game in Closed Season](#)
- [Distribution of Big Game meat](#)
- [Bear Protection Permits](#)
- [Big Game Replacement Licence](#)
- [Resident General Caribou Licence and Resident Special Caribou Licence - Labrador](#)
- [CITES Permit](#)
- [Export Permits](#)
- [Firearms Transport Permit](#)
- [Permit to Destroy Problem Animals](#)
- [Permit to Run Dogs](#)
- [Permits under Endangered Species Legislation](#)
- [Salmonier Nature Park Entry/Travel Permits](#)
- [Temporary Outdoor Identification Card](#)

Federal Permits for Research on Birds

A federal permit is required for collections from birds, bird tissues (e.g. feathers, blood etc.), attachment of ancillary markers (e.g. nasal tags, radio transmitters, etc.). Website:

<http://www.ec.gc.ca/>

Federal Permits for Banding (to mark birds with bands).

Canadian Wildlife Scientific Permit

Website: <http://www.ec.gc.ca/>

Department of Fisheries and Oceans Canada Permits

Website: <http://www.dfo-mpo.gc.ca/>

Parks Canada permits

Website: <http://www.pc.gc.ca/>

VI. Links to resource documents

The First Nations Principles of OCAP. First Nations Information Governance Centre.
<http://www.rhs-ers.ca/node/2>

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 First Nations Centre, October 2005
http://www.naho.ca/documents/fnc/english/FNC_OCAPCriticalAnalysis.pdf

Tri-Council Policy Statement (2) Chapter 9, Research Involving the First Nations, Inuit and Métis
Peoples of Canada [http://www.pre.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-
eptc2/chapter9-chapitre9/](http://www.pre.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-eptc2/chapter9-chapitre9/)

CIHR Guidelines for Health Research Involving Aboriginal Peoples: [http://www.cihr-
irsc.gc.ca/e/29134.html](http://www.cihr-irsc.gc.ca/e/29134.html)

Health Research Ethics Authority (HREA) <http://www.hrea.ca>