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Animating the Concept of Ethical Space: The Labrador Aboriginal Health Research Committee Ethics Workshop

Abstract

This paper reports on an innovative process by which the Inuit and First Nations communities of Newfoundland and Labrador confronted and challenged the policies and procedures of the provincial research ethics system. We describe the ways in which these communities engaged with health and university research review administrators to exchange information, identify challenges with existing processes, and outline a strategy for movement forward. We highlight the innovative structure of the process, and show how that resulted in immediate and ongoing community-led reforms to the provincial research ethics boards. Key to the success of the workshop was the fact that diverse stakeholders—community members, community research review administrators, research ethics board administrators, and health board research administrators—came together in an *ethical space* and worked together to critically interrogate the bureaucratic structure of the government, health, and university-based ethics review processes in the province. Recommendations arising from this process led to changes in the governance of health research involving the province's Indigenous communities.

Keywords

Research ethics, governance, health, Indigenous, Labrador

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(<http://www.nunatukavut.ca>). Ms. Bull contributed some background to the context of Indigenous community research review processes in Labrador.

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Introduction

In recent years, Indigenous Peoples in Canada and elsewhere have increasingly come to oppose colonialist models of research; at the same time, First Nations, Métis and Inuit communities in Canada have called with growing urgency for community control over the governance of research that involves them (Alfred & Corntassel, 2005; Battiste, 2000). In Canada, the resulting innovations in community control over the governance of research have frequently taken the form of community-based research review processes to ensure “ownership, control, access, and possession” (First Nations Centre, 2007) with regard to the design, conduct, and dissemination of research being conducted in Indigenous communities (1-4) Macaulay et al., 2007; Noojmowin, 2003). These processes, distinct from the ethics reviews conducted by research ethics boards in universities and hospitals, explicitly attend to the appropriateness of the research for each involved community in the context of ongoing colonialism, assimilation, and exoticism.

In Labrador, Inuit and First Nations communities—Nunatsiavut, NunatuKavut, and the Labrador Innu Nation—have taken this one step further. The Labrador Aboriginal Health Research Committee (LAHRC) recognized the opportunity offered by a restructured provincial research ethics review system, and mobilized the communities to participate in shaping the conduct of research in the province. In September 2012, LAHRC held a province-wide research ethics workshop, inviting health and university ethics administrators to join with them and the Newfoundland-based Miawpukek and Qalipu First Nations for a frank discussion about the ethics of research involving Indigenous communities in the province, with the goal of shaping the policies and procedures of the province's research ethics boards (REBs). Two non-Indigenous members of LAHRC, a scholar of Indigenous health research (F. Brunger) and a scholar of research ethics (R. Schiff), were invited to take a lead role in planning the workshop.

This paper reports on the proceedings of the LAHRC provincial workshop on research ethics. We describe the process by which the Inuit and First Nations communities of the province engaged with health and university ethics administrators, exchanging information, identifying challenges with existing processes, and outlining a strategy for movement forward. We highlight the innovative structure of the process itself, which led to immediate and ongoing community-initiated reforms to the provincial ethics boards. Key to the success of the workshop was the coming together of the diverse stakeholders—community members, community research review

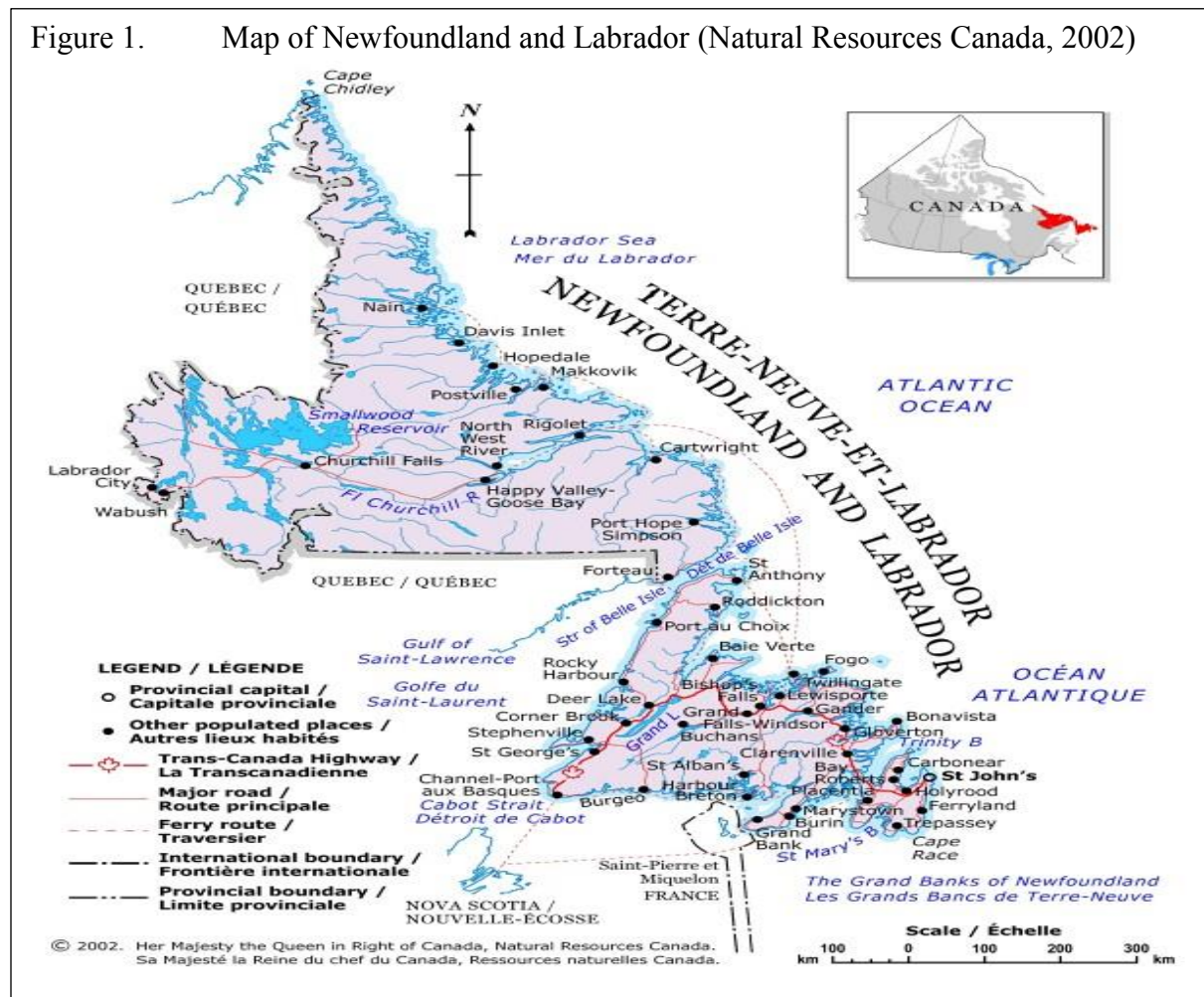
administrators, REB administrators, and health board research administrators—in an *ethical space* (Cook, 2012; Ermine, Sinclair & Jefferey, 2004) to critically interrogate the bureaucratic structure of the government, health, and university-based ethics review processes in the province, and to recommend changes to the governance of health research involving Indigenous communities. Ethical space refers to understanding the strengths and challenges of bringing together different ways of knowing and applying that understanding to practice. The term was coined by Roger Poole (1972) and adopted by Ermine, Sinclair, and Jeffery (2004), who developed the notion into a framework for examining research ethics. It denotes an abstract space in which there is a meeting of entities with different intentions.

The Context: Newfoundland and Labrador, the Health Research Ethics Authority (HREA), and Tri-Council Policy Statement (TCPS 2)

Labrador is on the Canadian mainland, northwest of the island of Newfoundland and adjacent to the province of Quebec, with a population of approximately 27,000 (Statistics Canada, 2006) including Innu, Inuit, NunatuKavummiut, and non-Indigenous people. Within Labrador, there are multiple political, social, and geographic centres of identity and belonging. These centres include Indigenous political organizations (Labrador Innu Nation, Nunatsiavut, and NunatuKavut) as well as various non-Indigenous politically defined communities. The Nunatsiavut Government represents approximately 7,000 Inuit of Labrador. The Inuit primarily live in the northern coastal communities of Nain, Hopedale, Postville, Makkovik, and Rigolet (see Figure 1). Nunatsiavut beneficiaries also live in Happy Valley–Goose Bay and North West River. The NunatuKavut Community Council (formerly Labrador Métis Nation) represents the 6,000 southern Inuit people of Labrador. NunatuKavut members live primarily in communities along the southeast coast of Labrador from Cartwright to Forteau. A number also live in the Central Labrador (Happy Valley–Goose Bay) area (see Figure 1). The Innu Nation in Labrador has two communities: Sheshatshiu Innu First Nation (SIFN) and Mushuau Innu First Nation (MIFN). The population in SIFN is close to 2,000 while the MIFN population, located in the community of Natuashish, is approximately 900. Sheshatshiu is located close to Happy Valley–Goose Bay; Natuashish is close to Davis Inlet (see Figure 1). These political organizations (which are also cultural and social entities) represent people who are dispersed over multiple, often geographically remote, municipal communities.

Newfoundland, the island portion of the province, is home to two First Nations communities. Qalipu Mi'kmaq First Nation, formerly known as the Federation of Newfoundland Indians, received status recognition under the *Indian Act* on September 22, 2011, and is a landless band representing over 23,877 members who live primarily in central and western areas of Newfoundland (reference). Miawpukek First Nation is also Mi'kmaq First Nation located in the community of Conne River in south-central Newfoundland close to Harbour Breton (see Figure 1). Miawpukek First Nation represents approximately 900 members on-reserve and 1,900 off-reserve. Figure 1 provides a visual representation of these communities and the immense geographic extent of the region.

Figure 1. Map of Newfoundland and Labrador (Natural Resources Canada, 2002)



The Health Research Ethics Authority.

The provincial shift that prompted communities to take action on the governance of research within their jurisdictions was the creation of the Newfoundland and Labrador Health Research Ethics Authority (HREA). In July 2011, the province of Newfoundland and Labrador moved to a legislated province-wide health research ethics review system. Under the HREA Act, all health research in the province requires review by an HREA-approved Health Research Ethics Board (HREB). The Health Research Ethics Authority, managed by a Board of Directors, is responsible for approving research ethics boards to conduct health research under the HREA Act. At the time of this writing, aside from the central HREB only one other HREA-approved board is in existence: the Behavioral and Social Science Ethics Board of Memorial University (Memorial University of Newfoundland 2014).

The timing of the provincial legislation coincided with revisions to national research ethics guidelines, as set out in the second edition of the TCPS, that included a new requirement for community consultation and agreement to proposed research involving Indigenous communities (CIHR, NSERC, SSHRC, 2010). Since proclamation of the HREA in July 2011, all health research—whether publicly or privately funded and whether university, government, or community-initiated—must pass two levels of review, one by the HREB or an HREA-approved

REB, and one by the Indigenous communities involved in or affected by the research. HREB policy also requires that research involving Indigenous Peoples must follow the CIHR's 2008 *Guidelines for Health Research Involving Aboriginal Peoples*; therefore, HREB will not grant ethics approval until community acceptance is obtained. Moreover, any research using the resources, whether physical or human, of a health care system, must undergo a third review by the regional health authority (Newfoundland and Labrador Health Research Ethics Board 2012).

Under the new centralized system, the three regional health authorities that had been primarily responsible for ethics oversight in rural and remote areas of the province would no longer serve as research ethics boards. Instead, they would function only as advisors and gate-keepers, ensuring that research conducted within their institutions or with their patients was appropriate to the health care organizational context in terms of physical and human resource availability, patient and caregiver demographics, privacy concerns with accessing patient records, and so on. This change in the research review mandate of the three rural regional health authorities had far-reaching implications. Specifically, with centralization of the research ethics process, all ethics review of research involving rural and remote communities was performed by REB members in the capital city of St. John's, which is situated in the southern, island portion of the province. Consequently, people lacking first-hand knowledge of the cultural, economic, and social contexts in which research was to occur would make decisions about projects directly affecting Indigenous communities in remote areas.

Moreover, termination of region-based ethics review processes would result in greater responsibility being placed on Indigenous community-review. In the absence of regional oversight to ensure that the Indigenous community context was considered and respected, Indigenous communities themselves must diligently engage in the process of reviewing, accepting/declining, or requesting revisions to research being proposed with their community. Moreover, under the HREA Act, communities would have to ensure that their own reviews were conducted in a timely manner so that the research could proceed to the stage of ethics review by the HREB, which had legislated requirements for an 'efficient' (30-day) turnaround (reference). While some Newfoundland and Labrador Indigenous communities had well-established processes in place, others did not. There was uncertainty over the adequacy of the support for communities to develop and maintain these processes, and over how to effectively coordinate with the provincial HREB to ensure a seamless process for communities and researchers.

The Labrador Aboriginal Health Research Committee.

The Labrador Aboriginal Health Research Committee (LAHRC) emerged in 2004 as an advisory committee to the Atlantic Aboriginal Health Research Program (AAHRP), which was formed as a result of the Network Environments for Aboriginal Health Research program (NEAHR) funded by the Canadian Institutes of Health Research (CIHR). From 2004 onward, with funding from AAHRP, LAHRC expanded beyond the role of an advisory body to take a lead in building research capacity for Labrador Indigenous communities and organizations. The committee comprises representatives from the Innu Nation, Nunatsiavut and NunatuKavut, along with Health Canada, the regional health authority, and the Labrador Institute (a Memorial University research centre). Its mandate is to support research activities designed to assist Labrador Indigenous communities and organizations in their efforts to promote healing and wellness and to improve health services in their communities.

Between 2004 and 2008, LAHRC focused on community capacity-building. LAHRC members identified what knowledge, skills, and competencies would enable community

members to participate as full partners in community-based health research. Workshops initiated and hosted by LARHC included: How to Use Data for Effective Community Health Planning; Evaluation Workshop, A Tool for Empowerment; Review of CIHR Ethics Guidelines for Health Research; and Health Determinants Workshops. In 2006, LAHRC invited researchers to meet with community members to identify research priorities at a workshop on “Community Health Research in Labrador: Listening, Learning, and Working Together”, an event that stimulated significant new directions in health research in Labrador. This was followed in 2008 by a Proposal Development Workshop and a workshop targeting oral health research in Labrador (Labrador Oral Health Intervention Research Workshop).

In 2011, Indigenous members of LAHRC identified a need for increasing Indigenous oversight of research and research ethics in the province. The committee agreed that a collaborative, interagency effort was needed to establish viable procedures for governance of health research involving Indigenous communities in rural and remote areas of the province. LAHRC wanted to ensure an active and meaningful role for Indigenous groups from across the province in the approval of health research involving Indigenous people. More than that, LAHRC members wanted to take an explicitly community-led approach to research ethics policy reform. As a first stage of that initiative, the group proposed hosting a province-wide workshop in which Indigenous groups could engage with administrators of research review processes.

The Workshop

Workshop participants were invited from each of the Indigenous governments and councils in the province: from Newfoundland, the Miawpukek First Nation and Qalipu Mi’kmaq First Nation; and from Labrador, the Mushuau Innu First Nation, Sheshatshiu Innu First Nation, Nunatsiavut Government, and NunatuKavut Community Council. In addition, representation was sought from the HREA, the HREB, Memorial University’s Social Science and Behavioral Research Ethics Board, the four provincial regional health authority research approval committees, Health Canada’s First Nations and Inuit Health Branch, and the Atlantic Aboriginal Health Research Program. A total of 35 participants, out of 40 invited, attended the workshop (Appendix: Workshop Participants). All but one of the province’s Indigenous communities was represented, however, the lone Innu participant was formally representing Health Canada. Other Innu involved in research and research ethics were unable to attend, despite flexibility with scheduling the timing of the workshop. Their absence is a reflection of how thinly stretched the human resources for oversight of research are in many northern and remote communities. Because of government restrictions on travel budgets and leave time, only one of the province’s four regional health authority research review committees had representation. The goals of the workshop were to build an understanding of ethical conduct for health research in Indigenous communities, and to develop communication channels for streamlining the research review process.

The workshop spanned one and a half days, and was structured into three primary components: (a) keynote presentations, which provided foundational information about research ethics and the governance of health research involving First Nations, Inuit, and Métis communities in Canada, to establish the framework for a common dialogue; (b) case-based discussion to identify issues, concerns, resolutions, and realities in the provincial context; and (c) an *open spaces* dialogue to brainstorm ways to move forward.

Keynote presentations.

Doris Cook is a researcher who has done extensive work in developing research ethics protocols for health research involving the First Nations of Canada. She is the former Manager of Aboriginal Ethics Policy Development in the Ethics Office of the CIHR, and an Elder in the Akwesasne Mohawk Nation. She spoke about the need to create ethical space, and gave an overview of some of the models for community-based research review that exist across Canada. Julie Bull is a member of NunatuKavut and a PhD student whose thesis work focuses on the ethics of health research involving Indigenous communities. She spoke about the ownership, control, access, and possession (OCAP) principles developed by the Assembly of First Nations (First Nations Centre, 2007). She also reviewed the principles of respect, relevance, reciprocity, responsibility, and relationships in community-based health research (Estey et al., 2009). Dr. F. Brunger chairs the HREB and had been a member of the working group that drafted the CIHR *Guidelines for Health Research Involving Aboriginal Peoples* (CIHR, 2007). She is an anthropologist and ethicist and has conducted research on Indigenous governance of research ethics in collaboration with NunatuKavut. She described the provincial context of ethics review and pointed to some of the challenges that the new HREA legislation raised for the review of health research involving Indigenous communities in the province's remote areas.

Case-based discussion.

The second component involved the review of case studies, bringing diverse stakeholders together to work in groups to identify a range of issues, concerns, resolutions, and realities. Participants were divided into working groups with five members each. Group membership was pre-arranged by the organizers to reflect the diversity of stakeholder representation. Each group had a facilitator, a graduate student chosen because of the proximity of his or her thesis research to the workshop topic, who was trained by the organizers to lead discussion. This strategy enabled the opportunity to build research ethics capacity amongst graduate students who work in the area of Indigenous health. Graduate student travel expenses were included in the conference budget. The use of a facilitator external to the stakeholder groups enabled discussion to be shared equitably, allowing full attention to the views of community members as well as those of the university-based academics. The workshop design permitted controversies arising from the review of research by different stakeholders to be explicitly held up for scrutiny.

The groups were provided with one common case study exemplifying a “good practice” scenario of ethics review for research involving Indigenous communities, and one case study containing problematic issues related to ethics review, with each group having a different problem scenario to discuss. Case studies were used to promote discussion and highlight the range and types of problems that the various stakeholders—community participants, community review administrators, REBs, health authority administrators—may face in the context of the review by REBs, communities, and health authorities. The facilitators made notes that were compiled by the organizers following the discussion, and synthesized into themes.

Examples of themes that emerged were: the order and process for reviews by the three systems (REB, health authority, and Indigenous community); the order and process for multi-site and multi-jurisdictional reviews; content of and process for community-researcher agreements; distinctions between the roles and priorities of the various types of review processes; navigating dissenting opinions from different types of review boards on a particular protocol; funding challenges for community review processes; funding and administrative challenges for meaningful researcher-community design and dissemination of research; consent form templates;

dealing with controversial findings; avoiding “research fatigue”; monitoring and addressing misconduct of researchers; and the means by which communities’ right of refusal of research can be implemented and respected. The themes were further refined into four questions for moving forward. The questions were used as catalysts for stimulating the *open spaces* discussion the following day.

Open spaces.

The final component of the workshop made use of an *open spaces* approach. Open Spaces for Dialogue and Enquiry is a methodology developed at the Centre for the Study of Social and Global Justice (CSSGJ) at the University of Nottingham for the creation of safe, inclusive spaces for dialogue on global issues (Murphy, 2010). *Open spaces* is a technique that can be used with groups having as few as five members or as many as two thousand and allows people address complex issues in a relatively short time. This method was chosen as a way of facilitating an ethical space (Ermine, Sinclair & Jeffery, 2004) within which to move forward on pressing issues that emerged from discussions on day one. The *open spaces* method is based on the assumption that all participants equally have something of value to contribute to discussions and decision making. The method facilitates dialogue among people identifying their own priorities among the spaces, contributing where they feel most energized. The intent is to enable participants to shape the direction of discussion according to where their own priorities and interests lie. At this workshop, questions were presented on large sheets of paper taped to walls around the meeting room. Once questions were introduced, people were free to address whichever question they found interesting or relevant, for however long they wanted, and were asked to record their thoughts on the paper. People congregated around questions and discussed their ideas with others who were interested in the same question. Participants were encouraged to define action items and recommendations.

Five spaces were designated, with a key question posted in four of the spaces. The four key questions chosen for discussion were:

1. *How will we continue this dialogue?* Participants were encouraged to consider the exact mechanisms—such as feedback loops or the use of designated spaces to meet and exchange information—that should be put in place to ensure ongoing communication among REBs, communities, and health authorities.
2. *How will we implement a system of monitoring and compliance? What exactly are our recommendations and action steps?*
3. *What does our streamlined process of review look like?* Participants were encouraged to provide a “road map” or schematic of a process to streamline the three types of review.
4. *What terms or concepts need to be defined to create common understandings?* Participants were encouraged to begin the process of creating common understandings of three concepts: ethics, ethical research, and an ethical review system.

The fifth space was reserved as a ‘catch-all’ for ideas and concepts that participants wished to discuss but that did not fit into one of the other four spaces.

Recommendations

Immediately following the workshop, organizers met to synthesize the information gathered from the presentations and the discussions that occurred during the *case studies* and *open spaces* activities, and to create a set of recommendations. Recommendations included:

1. Create a flow chart and checklist detailing the research approval process.

2. Advocate for cost-recovery for community ethics reviews and capacity building.
3. Construct a lay-language consent form template.
4. Use consistent terminology across various types of research review committees.
5. Compile a list of organizational contacts for researchers.
6. Devise a work plan for a pan-provincial Indigenous health research interface.
7. Provide information to researchers about the ethics review process for research involving Indigenous communities.
8. Develop community-defined concepts of ethical research.
9. Facilitate capacity building within Indigenous community research advisory committees that review and approve research.
10. Develop workshops for Indigenous community research advisory committees that review and approve research.
11. Liaise with and disseminate these recommendations to appropriate branches of the provincial government, researchers, and communities, including sharing a workshop report.

The recommendations were shared with participants in the form of a workshop report, compiled by the lead graduate research assistant for the workshop (M. Morton-Ninomiya). Some recommended actions were initiated immediately; others are in the process of implementation; and some are longer-term initiatives.

Workshop Evaluation.

Participants were invited to submit an evaluation immediately following the event. The evaluation was available online and in paper format. Its 17 questions focused on understanding participants' levels of satisfaction with the workshop format and outcomes. For example, participants were asked whether the workshop had met the identified objectives

The evaluation was completed by 77% of participants (n=27) and provided valuable feedback on the effectiveness and appropriateness of the event. Overall feedback was positive, with 85% percent of respondents indicating that they were satisfied or very satisfied with the event; no responses indicated overall dissatisfaction. Over 96% of respondents felt that the workshop met its objectives.

Participants also provided a substantial amount of qualitative feedback, which indicated the specific contributions of the event. Most significantly, participants discussed the effectiveness of this approach for enhancing communications with Indigenous communities in the province about challenges related to research ethics and community review. In fact, the value of ongoing communications was a central theme of participant feedback. Pointing to the significance of bringing together diverse groups, one participant noted that:

The Aboriginal groups and REBs have different perspectives on research ethics, and both need to be taken account of by all those involved in the process. For me this was my first workshop and it was all very informative and a great learning experience.

On this theme, another participant noted "the importance of listening to all groups involved, such as community, researchers, university," and that "everyone needs to listen to everyone else before decisions are made."

There were additional indications of overall interest and commitment to these processes in such comments as "people want this process to work," and "[there is an] overall willingness to

make the system work.” Similarly, one participant said, “All players are keen to collaborate to find ongoing ways to communicate and move forward.”

The theme of communication continued in participants’ written feedback on whether the workshop was successful in meeting its objectives. Participants noted the value of meeting; one participant reported enjoying “the personal interaction among the various groups,” and commented that this was an invaluable component of workshop goals, further stating that “[it is] difficult to meet workshop objectives without understanding the perspectives of all concerned.” Another noted that “considerable progress was made through clarifying roles and building relationships.”

Overall, the workshop was extremely useful for enabling in-depth and frank dialogue on sensitive and complex issues related to governance of health research involving Indigenous communities within the province. It resulted in immediate and significant changes to the processes used for the ethics review of research involving Indigenous communities. In particular, processes and guidelines for researchers and communities were developed that included a “road map” for navigating the ethics and community review processes for research involving Indigenous communities in Newfoundland and Labrador (Brunger, 2013).

Conclusions: Innovation, with a Lament

The success of the workshop was largely due to Indigenous community members inviting various administrators of research review processes to engage in dialogue, with the explicit purpose of giving direction to those administrators concerning where and how policy must be reformed. We identified two other features that contributed to the workshop process working so well in terms of both shifting the perceptions of various stakeholder groups and facilitating communication among them. Firstly, we enabled an exchange that was frank and transparent, with organizers reinforcing the importance of being “authentically” (Bull, 2008) present. Secondly, we emphasized introspective self-examination amongst key players. For example, during the discussions that were part of the case studies and open spaces activities, facilitators encouraged participants to reflect on their own beliefs and values in relation to research and the research ethics process and to articulate, and consider assumptions about, various stakeholders and organizations engaged in the research ethics process. This combination of transparency and introspection in negotiating a provincial strategy for research involving Indigenous communities enabled an ethical space to be created.

LAHRC seized an opportunity offered by a restructured provincial research ethics review system, mobilizing Indigenous communities in the province to actively shape REB policies and procedures. The workshop approach taken by LAHRC did not just actively resist colonial models of research by creating space for community control over the governance of research involving First Nations, Métis and Inuit communities. It added a new dimension to models of resistance and decolonization. By emphasizing transparency and introspection, the workshop process *animated* the concept of ethical space, leading to trust and positive change in the governance of research involving Indigenous communities.

LAHRC’s future, with the termination of funding for the Network Environments for Aboriginal Health Research, is uncertain. Currently, the province’s HREB remains committed to communicating with and accommodating requests by the province’s Indigenous communities. For example, F. Brunger and the HREB Ethics Officer met with members of Indigenous communities across various sites in Labrador in June 2014 to identify and address ongoing or

emerging concerns. In the absence of funding to ensure that active engagement by LAHRC or equivalent champions is maintained, and as key players across the various stakeholder groups change over time, the questions of whether and how the vision that emerged from this ethical space can be maintained, loom large.

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Appendix: Workshop Participants

Indigenous Organizations

NunatuKavut Community Council (four participants including representatives from coastal communities)

Nunatsiavut Government (four participants including representatives from coastal communities)

Innu (one participant who formally represented Health Canada)

Conne River Health and Social Services, Miawpukek First Nation (two participants)

Qalipu Mi'kmaq First Nation (one participant)

Newfoundland and Labrador Regional Health Authorities' Research Review Committees

Eastern Health (no participants due to travel funding constraints)

Central Health (no participants due to travel funding constraints)

Western Health (no participants due to travel funding constraints)

Labrador Grenfell Health (two participants)

Health Research Ethics Authority of Newfoundland & Labrador

Interdisciplinary Committee on Ethics in Human Research, Memorial University (two participants)

Newfoundland & Labrador Health Research Ethics Board (three participants)

Newfoundland & Labrador Health Research Ethics Authority (two participants)

Government Agencies

First Nations and Inuit Health Branch, Health Canada, Atlantic region (three participants)

Newfoundland & Labrador Centre for Health Information (one participant)

Aboriginal Health Liaison Division; Department of Health and Community Services, Government of Newfoundland and Labrador (one participant)

Other Participants

Labrador Aboriginal Health Research Committee members (seven participants)

Atlantic Aboriginal Health Research Program (one participant)

Labrador Institute of Memorial University (one participant)