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

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Abstract

The principles of ownership, control, access and possession (OCAP) crystallize themes long advocated by First Nations in Canada. Coined by the Steering Committee of the First Nations Regional Longitudinal Health Survey, the principles are discussed as an expression of self-determination in research. The key notions outlined in this paper relate to the collective ownership of group information; First Nations control over research and information; First Nations' management of access to their data and physical possession of the data.

Following a critical review of colonial research practices and recent institutional efforts to improve ethics in Aboriginal research, this paper highlights policies and strategies adopted by First Nations organizations – approaches which offer a way out of the muddle of contemporary Aboriginal research and the ethical dilemmas that characterize it. The benefits of OCAP are described including the rebuilding of trust, improved research quality and relevance, decreased bias, meaningful capacity development, and community empowerment to make change.

Key Words

Aboriginal, First Nations, Indigenous communities, research ethics, self-determination, collective rights, participatory research, research methods, ethics review

INTRODUCTION

Ownership, control, access, and possession, or OCAP, is self-determination applied to research. It is a political response to tenacious colonial approaches to research and information management. OCAP has become a rallying cry to many First Nations and should be a wake up call for researchers. It offers a way out of the muddle of contemporary Aboriginal research and the ethical dilemmas that characterize it.

The principles of OCAP apply to research, monitoring and surveillance, surveys, statistics, cultural knowledge and so on. OCAP is broadly concerned with all aspects of information, including its creation and management.

Originally coined as OCA – a more resonant acronym with its nod to the 1990 Oka Crisis – OCAP is changing the way research is done. OCA originated during a 1998 brainstorming session of the National Steering Committee of the First Nations Regional

Longitudinal Health Survey (RHS). The original acronym has been attributed to Cathryn George, a member of the committee representing the Association of Iroquois and Allied Indians.

Although OCAP originates from a First Nations context, many of the insights and propositions outlined are relevant and applicable to Inuit, Métis and other Indigenous Peoples internationally. Likewise, although many of the examples provided here are related to health information, the OCAP principles have broader application.

The notions inherent in OCAP are not new. The term's salience lies in the fact that it crystallizes themes advocated by First Nations for years. Although there may be a good degree of consensus, the meanings and implications of OCAP continue to take shape and to be debated. OCAP is not a doctrine or a prescription. It is a set of principles in evolution. This paper seeks to contribute to the discussion by offering some context and critical analysis and by outlining strategies for putting the principles into practice. The following definitions are offered to help bring some focus to the subject:

Ownership

Ownership refers to the relationship of a First Nations community to its cultural knowledge/data/information. The principle states that a community or group owns information collectively in the same way that an individual owns their personal information. It is distinct from stewardship. The stewardship or care taking of data or information by an institution that is accountable to the group is a mechanism through which ownership may be asserted.[1]

Control

The aspirations and rights of First Nations Peoples to maintain and regain control of all aspects of their lives and institutions extend to research, information and data. The principle of control asserts that First Nations Peoples, their communities and representative bodies are within their rights in seeking to control all aspects of research and information management processes which impact them. First Nations control of research can include all stages of a particular research project – from conception to completion. The principle extends to the control of resources and review processes, the formulation of conceptual frameworks, data management and so on.

Access

First Nations Peoples must have access to information and data about themselves and their communities, regardless of where it is currently held. The principle also refers to the right of First Nations communities and organizations to manage and make decisions regarding access to their collective information. This may be achieved, in practice, through standardized, formal protocols.

Possession[2]

While ownership identifies the relationship between a people and their data in principle, possession or stewardship is more literal. Although not a condition of ownership per se, possession (of data) is a mechanism by which ownership can be asserted and protected. When data owned by one party is in the possession of another, there is a risk of breech or misuse. This is particularly important when trust is lacking between the owner and possessor.

Most importantly, OCAP is forward-looking and pro-active. It opens up new avenues for the expression of self-determination and self-governance in the areas of research and information and provides a measure of hope for positive change. Before looking at the way forward, a review of the challenges posed by past practices in First Nations as well as Inuit and Métis research is in order.

WHERE RESEARCH HAS GONE WRONG

OCAP has been described as "a political response to colonialism and the role of knowledge production in reproducing colonial relations."[3] Much of the impetus for OCAP can be linked to the sorry history of research relations with Aboriginal Peoples in Canada. According to the report of the Royal Commission on Aboriginal Peoples:

The gathering of information and its subsequent use are inherently political. In the past, Aboriginal people have not been consulted about what information should be collected,

who should gather that information, who should maintain it, and who should have access to it. The information gathered may or may not have been relevant to the questions, priorities and concerns of Aboriginal peoples. Because data gathering has frequently been imposed by outside authorities, it has met with resistance in many quarters.[4]

"We've been researched to death." It has been said many times. To understand what it means, consider some of the recurring grievances about research and researchers over the years. These complaints provide the backdrop out of which OCAP emerges.[5]

- First Nations have been subject to too much research.[6]
- The majority of research projects are initiated, paid for and carried out by non-Aboriginal people from universities, government and industry.
- Researchers have selected subjects of personal or academic interest or of interest to the larger society, but have not been interested in First Nations priorities.
- Researchers have essentially pre-empted meaningful community involvement by presenting completed research designs, often already funded, for community approval rather than collaborating from the start.
- Governments gather administrative and other data on First Nations without their knowledge or consent.
- Governments and researchers analyze, interpret and report First Nations data without consent, approval, review or input by First Nations representatives.
- Research funding is largely controlled by a few external agents and is generally not accessible to community groups and First Nations organizations.
- Researchers have profited professionally and economically from First Nations research without employing local people or compensating research subjects.
- Researchers have treated First Nations as merely a source of data.
- Researchers have pressured community authorities and individuals to support or consent to a project, because it is "good for the community" rather than asking community members what kinds of projects might serve their needs.
- Individuals have felt pressured to participate in a study or other data gathering process because community authorities have consented or are involved.
- Individuals have been persuaded to participate in research without fully understanding risks to health

and safety or the potential application or misapplication of research outcomes.
- First Nations have been led to believe that participation in a research project is necessary in order to maintain their right to health services.
- Researchers have not explained their studies in a language or manner adequate to ensure fully informed consent.
- Researchers have treated First Nations researchers as informants rather than colleagues and have appropriated or failed to acknowledge some of their work.
- Although community Elders consider certain researchers unworthy to speak the community's truths, researchers rely primarily on peers and funding agencies to confer their speaking rights.
- After building good rapport, members of a research team have been replaced with people who are not known or trusted by the community members.
- Researchers have not respected individual or community confidentiality to the same degree that they would for non-First Nations people.
- Research has disrespected basic human dignity of participants or their religious, spiritual or cultural beliefs.
- Researchers have collected First Nations genetic material for purposes that are demeaning to the dignity of First Nations communities and individuals.
- Researchers have gathered information on dissident Indigenous groups, which has later been used against them by repressive regimes (e.g. in South America).
- Researchers have disregarded cultural taboos and secrecy by publicizing (and sometimes profiting from) sensitive cultural information. They have also presented cultural information out of context and drawn inaccurate conclusions.
- Human remains and cultural property have been taken for storage, display in museums, or sale.
- Information made available by researchers has been distorted, appropriated and treated as a commodity. For example, First Nations legends and stories have been used for movies, books, toys etc. Spiritual practices and ceremonies have been adapted and often marketed to practitioners of New Age spirituality.
- Researchers, particularly from governments and industry, have collected information about traditional remedies, sometimes under false pretences, in a search for medicines to be patented and commercial gain.
- Researchers have used leftover portions of blood samples for secondary research without consent.

- Researchers have recklessly sensationalized problems among First Nations, without regard for impact on communities or their social and political interests.
- Research focuses on problems without looking at the positive and has often portrayed First Nations as poor, sick, dependent, violent, and child-like.
- Research results are not returned to the community or they are returned in a form or language that is inaccessible.
- Benefits to First Nations individuals and communities are often unclear.

Many, if not most, First Nations Peoples and communities can relate to at least some of these grievances. Although research in other contexts can fall prey to similar pitfalls, there are a number of reasons why they occur more frequently and are most acutely felt in First Nations communities. Key among these are the small size of First Nations communities and their relative lack of power.

Mainstream society is large enough to more effectively dilute the impacts of research. In First Nations research, the researcher-to-subject ratio is generally higher and communities are usually more tightly knit. Thus, a larger proportion of the population is researched and any negative influences or impacts may well reverberate through the whole community. More significant, though, is the difference in power between First Nations Peoples and communities and the mainstream researchers, government and industry representatives who come to study them.

Researchers, government officials and corporations (including those that are Aboriginal) may or may not understand, support or even be aware of the aspirations of First Nations. They may not prioritize and may even be at odds with community interests. Nonetheless, researchers are generally seen by both Aboriginal and non-Aboriginal people as unbiased experts, endorsed by others with power, and able to speak with authority about First Nations realities. When the results of a study about First Nations, Inuit or Métis health are presented in a scientific journal, at a conference, or at a government policy planning session, academics and government people typically do the talking. In key venues where truth and facts are established about them, First Nations Peoples, themselves, have to shout to be heard, assuming they are present at all. In the research game, the playing field is anything but level.

To put it more succinctly, the problems with research stem from who is in control – and thus what gets done and how it is done – and who knows about it. The question of whose interests are served is central. And of course, there is an unambiguous relationship between control and benefit. Ceal Tournier, former co-chairperson of the First Nations Information Governance Committee (FNIGC),[7] put it this way:[8] "He who controls the data, controls the gold."

HOW RESEARCH HAS TRIED TO RIGHT ITSELF

Ethical guidelines and their enforcers – research ethics boards – are designed to rein in the researchers and encourage/ensure appropriate research practices. They aim to lessen the power differential between researchers and subjects and between researchers and Aboriginal communities or groups. According to a paper prepared for the Inuit Tapirisat of Canada: "Where power, knowledge and authority are clearly unequal, ethical guidelines seek to place limits on the exercise of power by the powerful – chiefly by moral suasion."[9]

In Canada, the Tri-Council Policy Statement (TCPS): Ethical Conduct for Research Involving Humans,[10] adopted by the three major funding agencies,[11] is the established norm for the ethical review of research. Following a series of revisions,[12] the TCPS included a section on research involving Aboriginal Peoples. Unlike the rest of the document, this section restricted itself to discussion and a listing of best practices. The section is prefaced as follows:

> During the drafting of this Policy Statement, suggestions were made to create a Section dealing with research involving aboriginal peoples. The Councils, however, have not held sufficient discussions with representatives of the affected peoples or groups, or with the various organizations or researchers involved. The Councils have therefore decided that it is not yet appropriate to establish policies in this area. The text of Section 6, which builds on the extensive literature on research involving aboriginal peoples, is intended to serve as a starting point for such discussions.[13]

Several years later, the consultations have yet to occur. Nonetheless, the ideas outlined in the TCPS, however tentative, are based on an international literature review – primarily Australian, Canadian and American – and reflect the current shift in thinking about Indigenous research.

The concepts of participatory research and community involvement, the incorporation of traditional knowledge, culturally-appropriate, and community-based research methods have gained momentum in recent years within First Nations and Inuit settings. Important exchanges have been held on the issues and there is a growing body of literature about research ethics in Aboriginal communities. In many cases, researchers have adopted fresh approaches and strategies.

These changes are in no small part a direct response to increasing opposition from First Nations Peoples fed up with the research status quo. Researchers, to some extent, have had to adapt and innovate in order to stay in the game.

Doing respectful research in Aboriginal communities takes more time, more money and, arguably, moral fibre. Imagine having to get permission from Chief and Council, attend joint advisory committee meetings and solicit input from the Elders, in addition to your regular supervisor in order to do your job. The tendency to fall back on the simpler tried-and-true approaches will be strong. There are significant pressures on researchers to complete their projects in a timely manner, publish extensively and for students to complete their theses and get their degrees before debt overwhelms them. These considerations are at cross-purposes with the requirements of ethical research.

A more respectful and ethical approach to research in Aboriginal communities has gained momentum in recent years, but it is not a given. The implications of this new approach were crystallized during a 1995 conference on ethics in Aboriginal and Northern research.[14] Referring to this emerging understanding, some participants commented that certain researchers and government officials simply didn't "get it." On the other hand, a lot of people did "get it" – some for the first time.

The importance of "getting it" underlined the need for the education or re-education of researchers. It also raised important questions about individual suitability. Some individuals may simply not have the necessary sensitivity or interpersonal or research skills to work in a First Nations, Inuit or Métis setting.

New Ethical Guidelines

For those who do or want to "get it," there are a number of important ideas described in recent documents.[15] Generally, the documents deal with practices, standards, principles, and guidelines. They discourage the long list of bad practices described in the previous section and promote the following:

- All of the usual ethical requirements for research, such as individual informed consent and confidentiality, apply in addition to others specific to the Aboriginal context.
- Researchers should provide ongoing explanations of all aspects of the research project, including its purpose, sponsorship, anticipated benefits and risks, methods, community and individual involvement, and reporting plans.
- Community involvement, participation and consultation are required. Some documents go further by identifying community consent as a requirement (the TCPS does not), also noting that research should be suspended if deemed unacceptable by the community.
- The research relationship must be negotiated, ideally resulting in a written agreement or contract.
- Local and traditional knowledge should be incorporated.
- Research must respect the privacy, protocols, dignity, and individual and collective rights of Aboriginal Peoples. It must also derive from Aboriginal culture and validation methods.
- Meaningful capacity development for Aboriginal Peoples should be incorporated into the project.
- Reports and summaries should be returned to communities in an appropriate language and format.
- Aboriginal Peoples should have access to the research data, not just the reports.
- Community protocols should be respected.
- Community interests should be supported, benefits maximized and harm reduced or avoided.

Before turning to the merits and limitations of these principles, it is important to note that, from the perspective of an Aboriginal community, the guidelines are a form of government/academic self-regulation. Government and the academic research communities have their own set of rules and expectations for how members should behave. The rules may or may not be in the best interests of Aboriginal communities.

The existing research ethics guidelines and the research ethics boards (REBs) that apply them can provide a (sometimes false) sense of security. Unfortunately, the guidelines and REBs are not necessarily able to adequately address First Nations, Inuit or Métis research issues and generally do not have Aboriginal participation or mandates. While self-regulation is entirely understandable and well intentioned, it can have the ironic impact of precluding direct First Nations' regulation of research.

Returning to the principles clearly stated by the new ethical guidelines, perhaps the most important

and progressive element is the move beyond main-stream concern with individuals to a focus on issues related to communities or groups of people. Although many of the principles apply to other groups with common interests or conditions (e.g. Montrealers of Haitian origin, men with prostate cancer), the case of Aboriginal communities is afforded additional consideration, in part because of the unique Constitutional rights and distinct legal status of Aboriginal Peoples in Canada. According to the TCPS ethics policy statement,[16] Aboriginal Peoples "have distinctive perspectives and understandings embodied in their cultures […and…] have a unique interest in ensuring accurate and informed research concerning their heritage, customs and community."

ABORIGINAL RIGHTS AND JURISDICTION

The recognition of alternative, culture-based perspectives and understandings, although an important step forward, is a pale reflection of the broader legal assertions of First Nations. Recognition of the unique status of First Nations as nations and of their inherent, Constitutional and treaty rights has important implications for research and data. Jurisdiction over research, not simply unique interests, are recognized in the following statements from the Kahnawake Research Ethics Code, Martha Flaherty of Pauktuutit and United States Indian Health Service:

> The sovereignty of the Kanien'ke ha ka (the people) of Kahnawake to make decisions about research in Kahnawake is recognized and respected.[17]

> We, Inuit, have more than a "valid concern" over the conduct of … research, we have RIGHTS... It is time for Inuit to set our own terms [which researchers] who want to come to our land... must abide by.[18]

> All research involving American Indian/Alaska Native tribes [must] be approved by the tribal governments with jurisdiction.[19]

First Nations governance and self-government imply jurisdiction and control over a full range of institutions and processes, including research and information. Developing a research project or agenda, setting up a research or statistical office, or implementing an information system are all parts of good governance.

In a thoughtful analysis prepared for the Royal Commission on Aboriginal Peoples, Russel L. Barsh outlines the interaction between the three minimum requirements for effective government: power, resources and legitimacy.[20] OCAP touches on all three.

Power, according to Barsh, is the authority to act, whether derived from a constitution, laws or custom. Most importantly, the actions of a government need to be recognized and respected by other governments and institutions. OCAP asserts First Nations' authority to control their own research and information.

Resources include natural, financial and human resources as well as information, knowledge and technology. In recent years, information and information technology have emerged as critical to both the economy and to governments. Information can produce prosperity and can serve as the bedrock for policy and planning. OCAP is about enhancing First Nations' resources. It is about nation building.

Legitimacy refers to support and public confidence in a government. Information serves to help governments make better decisions and stay in step with their constituents. Governments use information to inform, educate and remain accountable. When outsiders control information, two things can happen: legitimacy of First Nations governments is undermined and the information is suspect in First Nations' eyes. OCAP is about legitimacy and accountability for First Nations' authorities and institutions.

DEFINING THE RESEARCHER

OCAP draws the questions of who into focus. While emerging ethical guidelines encourage better representation in the research process, the principles of OCAP suggest that First Nations communities and groups can also lead or control it. More fundamentally, OCAP raises questions about the rules of the game – what constitutes proper research – and the ability and biases of existing gatekeepers (e.g. academic peer review committees, funding agencies) who evaluate Aboriginal research.

Conventional understandings of who the players are and how the game is supposed to be played are deep rooted. Assumptions can be implied or clearly defined in a variety of ways. Funding program criteria and ethical research guidelines present windows onto how the rules are determined.

First, consider this declaration from the introduction to a set of Australian Indigenous research guidelines:[21] "At every stage, research with and about In-

digenous peoples must be founded on a process of meaningful engagement and reciprocity between the researcher and the Indigenous people."

This generally constructive statement betrays something important. Notice that there are two parties: researchers and Indigenous Peoples. Notice also that the relationship is between a single researcher from the outside and the Indigenous Peoples – an image reminiscent of classic anthropological methods as well as a large number of movies in which a single white hero helps or saves a tribe of nameless Native Peoples.

It is, by definition, the researcher – whether doctor, scientist, expert, academic, student or government agent – who does the research. Communities are consulted, involved or are supportive. They consent. They may be partners. Generally speaking, they are not researchers.

Restrictive definitions of research and researchers are spelled out in project and program funding criteria. Generally speaking, Aboriginal communities and organizations have limited access to research funds, unless they partner with a proper researcher. The researcher must have the appropriate track record and credentials – conferred by peers – and must be affiliated with a recognized institution, usually a major Canadian university. The researcher, not the Aboriginal partner, receives the funding and is responsible for completion of the project.

Model from the United States

More OCAP-friendly alternatives are emerging. Perhaps the most significant example is an initiative from the United States. The American Indian Health Service announced funding for Native American Research Centers for Health (NARCH). The multi-million-dollar strategy debuted in 2001 and has been affirmed and expanded for four additional years since then.[22] Some key elements of the program that depart from the normal way of doing business are shown in Table 1.

The Indian Health Service program unambiguously defines American Indian organizations as research organizations and their staff as researchers. At the same time, the 70 per cent rule helps ensure AI/AN organizations will benefit by making it impossible for university-based researchers to use AI/AN organizations as fronts to flow funding.

Model from Northern Quebec

Another example of innovation in funding criteria, from the author's own experience in Northern Quebec, provides some insight. In the early 1990s, the Health Board for the Inuit region of Nunavik restricted its research-funding program to local and regional organizations. This was a departure from years of funding projects designed and implemented by outsiders from the south. The new policy resulted in two distinct shifts: a gradual increase in the number of true

Table 1: American Indian Health Service's Native American Research Centers for Health

Purpose of Program	"Develop a cadre of American Indian/Alaska Native (AI/AN) scientists and health professionals… competitive in securing National Institutes of Health (NIH) funding; to increase the capacity of both research-intensive institutions and AI/AN organizations to work in partnership to reduce distrust by AI/AN communities and people toward research; and to encourage competitive research linked to the health priorities of the AI/AN organizations and to reducing health disparities."
Recipient of Funds	AI/AN organization, which may not sub-contract more than 70 per cent of funds (i.e. must use at least 30 per cent internally).
Principal Investigator	Must have primary appointment with the AI/AN applicant organization.
Partnership	Must be a working partnership of the AI/AN organization and a research-intensive institution. The AI/AN organizations define criteria and eligibility for participation in all aspects of the partnership.
Advisory Board or Committee	Must have a community and scientific advisory council with more than 50 per cent of its membership appointed by the AI/AN applicant.

community-led projects and a renegotiation of relationships between several university-based researchers and regional/community groups.

Most of the projects under the new criteria involved a Northern promoter partnering with or contracting a university-based researcher(s). In some cases, southern-based researchers essentially used regional organizations to administer and flow funds with little or no input into the project. (There was no equivalent to the IHS' 70 per cent rule.) This generally involved a friend of the project or of the researcher based at the Northern organization. In other cases, there was a close partnership based around a southern-designed project. In a few cases, projects were initiated by Northern organizations and carried out by external researcher(s) or students on contract. In those cases, the researchers were generally also able to use the work to advance their academic careers.

Most interesting were the true community-based projects. At first, many of the applications did not fit program criteria. Differences in perspective were revealed. Community leaders and workers generally want to take action on problems, not study them. They wanted intervention, not research, dollars. Also, generally speaking, community members saw research as something done by experts from the south.

Promotion of a broader definition of research, which spoke to community experience, helped to refocus the issue. For example, making the connection between data gathering and analysis and the skilled and organized methods required to make decisions about a hunt or camp move helped demystify the research process. From that perspective, Inuit have always conducted their own research. This refocusing of research and a relatively broad definition of eligible projects encouraged applications from organizations that had never previously led research projects. Other factors that increased accessibility include active promotion of the program; a short, plain-language, tri-lingual application form and guide; and the availability of ongoing assistance for proposal writing, methodology and all aspects of project implementation.

Among those projects that were led and carried out by communities themselves, the level of scientific rigour was uneven. But in terms of project relevance, developing and drawing out community capacity and ultimately in terms of community impact, these home-grown projects were clearly superior.

CAPACITY AND QUALITY

Capacity development and OCAP are interwoven. They are the warp and the weave that support successful First Nations-controlled research initiatives. On the one hand, the capacity to access resources, manage and carry out research, and promote and disseminate results makes it possible and desirable to have control. On the other hand, having control implies a sense of ownership and responsibility that motivates – even requires – accelerated capacity development.

But what kind of capacity development is most useful? The first and most obvious answer is that all kinds of capacity development – in all aspects of research – are needed. The next answer is that, while capacity development should benefit individuals, it must also support and build Aboriginal communities and organizations. Capacity building is fundamental to nation building, not just career building. The implications are important.

Increasing the number of First Nations, Inuit and Métis Peoples with PhDs related to research, while laudable, does not by itself necessarily result in any benefit to the community. In fact, the individuals are often lost to their communities as they pursue careers in the mainstream. Government and university departments and industry are the actual beneficiaries.

The potential for Aboriginal communities to benefit from their people working within the system is unclear at best. Meanwhile, opportunities to work directly for the community in a research capacity are rare. There is also concern about the effect of assimilative education processes on First Nations students in mainstream universities. Holding on to First Nations perspectives, values and interests while learning and working in academia, industry or government is a monumental challenge. First Nations students in academia may have to work twice as hard to meet and bridge academic and community expectations. They are sometimes forced to make difficult choices between their values and advancing their careers as they walk a two-culture tightrope.

The way out of this apparent catch-22 is to implement strategies that provide individual opportunities that also produce benefits for the collective. Putting research dollars into First Nations communities and organizations[23] and other strategies that increase First Nations control tend to serve both purposes.

The issue of research capacity quickly leads to questions about quality (i.e. scientific excellence, rigour). Critics of OCAP are quick to raise concerns

about the potential consequences if appropriate expertise is not present. Some may say:

- We believe 100 per cent in community control, but we need to ensure that the community-based capacity is there.
- These things require a high level of expertise.
- But a partnership will ensure strong, reliable results and I'm sure the community would want that.

These kinds of suggestions may appear supportive and helpful at first glance. On closer inspection however, paternalistic assumptions are revealed. They imply communities cannot go it alone and cannot grasp the mysteries of serious research. The upshot is that it would be best for everyone if the researchers, in the conventional sense, stay in control. The paternalism, distrust and generally low expectations of First Nations research capacity mirror attitudes towards self-government, described below in the American context:

> Studies of intergovernmental relations on Indian reservations in the past 20 years, for example, show that in the unhealthy and unproductive stages of these relationships, state and local government tend to object to the very idea of tribal government itself, the notion often being that Indian people should not have the right to and lack the capacity for self-government in any circumstances.[24]

Undeniably, building capacity is important. It is a central principle of countless Aboriginal initiatives undertaken in the last decade in just about every field. There is, therefore, something perverse about using lack of capacity as an argument to quash or take control of Aboriginal initiatives. Discouraging messages about Aboriginal non-capacity are deeply ingrained and can be heard from both Aboriginal and non-Aboriginal people. Fortunately, the growing number of Aboriginal success stories – in research and in other areas – is helping to overcome the false stereotype that Aboriginal Peoples can't do it.

As former First Nations Centre Director at the National Aboriginal Health Organization Gail McDonald has often noted, "research is not rocket science." At least not all research has to be. While specialized, education-intensive research is undeniably important in many disciplines. It is not the only, nor necessarily the most worthwhile type of research. This is particularly true when looking at population health or social phenomena. Complex methodology, sophisticated academic frameworks and scientific jargon are not – or should not be – the only game in town.

Decisions about whether to fund a research project or allow publication of the results are normally made on the basis of culturally circumscribed notions of quality. Typically, scientific excellence, rigour or some variant is the primary yardstick. From inside academia, the measures may seem obvious and uncontroversial. For many Aboriginal communities and organizations, scientific excellence is a self-serving barrier that keeps control and resources where they are.

In addition to excluding those lacking the formal credentials, conventional thinking about what constitutes good research effectively puts blinders on the research endeavour, restricting it to a western, scientific model – an approach that is particularly ineffective in Aboriginal and other non-western societies.

According to Dr. W. Freeman, research that relies on Aboriginal knowledge and ways of knowing is, in all likelihood, methodologically stronger as it diminishes outsider biases.[25] Although OCAP does not guarantee the development of Indigenous research frameworks, it does provide fertile ground for their development.

What other means of assessing the value of a research project or report could be adopted? Consider the following anecdote:

> An Aboriginal community of about 1,000 people wanted to assess the extent of the solvent abuse in their community and find solutions that could be applied by their locally-controlled treatment facility. They wanted to know which kids were sniffing and how to help them.

> An outside researcher conceived a careful, ethically-sensitive and scientifically-rigorous approach involving one-on-one confidential interviews with school children. If implemented, the results were expected to help identify risk groups and risk behaviours. The proposed study would provide only a rough idea of numbers and, certainly, no names. The results would be available in about two years, if all went well.

> The community did not want to wait so long for so little return. An alternate research strategy was quickly put into place. A small delegation of respected adults went from classroom to classroom and asked the students "Who sniffs?" Generally after a pause, the

children turned and pointed fingers to the sniffers. The data collection, which confirmed suspicions, was complete in an afternoon. Discussion with sniffers and their families ensued and the students and families received offers of support, counselling and treatment.

It is rather unlikely that this project would have passed a conventional academic review process. It would likely have been declared unethical and the scientific merit would have probably received a score close to zero. In fact, it is doubtful that the project description would have ended up on a 40-page application in the first place.

Was the community's initiative a bad idea? Should it have gone ahead? Could it even be qualified as research? These questions aside, the story suggests that a simple, home-grown research strategy can be quicker, cheaper, more relevant, and more useful than a painstaking and complex methodology. Further, because the approach was conceived and implemented by the community to meet community goals, the commitment to follow-up and deal with potential fallout was strong.

The most elegant study design in the world is only as valuable as the impact that it makes in people's lives. By the same token, a methodologically inferior study can have tremendous impact and benefit.

The answer to the question of how to evaluate research now suggests itself. Rather than focus on scientific excellence, an assessment of potential and anticipated community benefits, however these are measured, could be emphasized.

This is, by no means, an argument against high quality research. All else being equal, a higher quality project is more likely to produce positive results. The point here is that, particularly in an Aboriginal context, community relevance and community usefulness may be the most telling measures of the worth of a study. The question of quality is subordinate. The next point is that a community-driven, community-controlled project is more likely, although not guaranteed, to score highly on those measures.

Aboriginal communities have gone along with externally-driven research – both excellent and not-so-excellent projects – for generations with relatively few examples of clear benefit. Is it now time to support communities' own research initiatives – whether they are excellent or not? The potential benefit is tremendous.

OCAP IN PRACTICE

OCAP hinders bad research practices and fosters good ones. The real challenge now is how to do research in ways that respect OCAP. The challenge is taken up and worked through in a variety of ways.

In trying to put the principles into action, it is important to recall that at the heart of OCAP is self-determination, including recognition of First Nations jurisdiction over research in their communities. It is also important to remember that OCAP represents a threat to existing authority. It is a threat that is guaranteed to be taken up on many fronts.

Resistance

One of the first responses to this perceived attack is that it has been taken too far. Those who have something to lose from a redistribution of power might complain. Some may say:
- You need to compromise.
- If you are too inflexible in applying your principles, you'll end up with nothing.
- Your principles are getting in the way of essential research that is needed to develop policy or interventions to improve Aboriginal health.

They may also cite concerns about capacity (described in the previous section) or the threat to their academic freedom and the pursuit of the objective truth.

While not outright rejections of OCAP, these positions are important challenges. On the part of the researcher, they imply unwillingness to compromise and a resistance to adopting new approaches. The attribution of blame for perpetuating poor health conditions is particularly insidious. A community might reply that it is the researchers who need to rethink their principles and that it is their inability to adapt that is continuing to put health at risk.

Ultimately, some researchers might look elsewhere, where there are fewer hurdles. Before mourning such a loss, a community might do well to ask itself what it is really losing here. Undoubtedly, the answer will sometimes be not much. At other times, when the community perceives great value in a given project, they may seek to carry it out themselves, with or without the involvement of another, more amenable researcher.

However communities choose to interpret and apply OCAP principles, the road ahead is bound to be rocky at times. Until OCAP is better understood, more firmly entrenched, and researchers and Aboriginal groups find new ways of relating, some research will undoubtedly be held hostage.

Strategies

The parties involved will have to judge: how to respect OCAP and get research done; what compromise is acceptable; whether to proceed with a project; and under what terms.

Consider the following strategies. They have been employed by First Nations organizations.

- Be clear about what you want and don't want to get from research. Determine priorities.
- Become more informed and share information about research initiatives that impact your community or constituency. Influence them. Talk to their proponents. Seek to improve First Nations representation in key decision-making venues (e.g. university and government committees).
- Transfer or take over First Nations initiatives run by non-First Nations entities (when appropriate and properly resourced).
- Refuse to participate in processes that do not respect OCAP or First Nations protocols.
- Seek advice and support from Elders and leadership. Educate leadership. Raise the profile of health research/data issues.
- Self-fund autonomous research projects run by and for your community or constituency with little or no outside involvement.
- Develop culture-based frameworks, methods, tools, training, review, and reporting strategies. Don't let anyone tell you: "That's not the way you do research."
- Model good research practices by following stringent ethical guidelines and community and cultural protocols.
- Build research skills among people in your community or organization. Focus on those who have a strong commitment to the community.
- Access research funding sources with criteria and processes that are community/Aboriginal friendly.
- Identify respectful researchers and cultivate long-term relationships with them. An excellent discussion and template to help communities negotiate research relationships was prepared in 1993 for Dene and Métis in the Northwest Territories.[26]
- Collaborate with other like-minded Aboriginal groups/communities.
- Build on successful First Nations initiatives and processes.
- Negotiate written agreements or memoranda of understanding that spell out the research relationship between your community or organization and your research partner(s).

- Require review prior to publication of research involving your community or constituency.
- Alternatively, agree to a right to dissent - an elegant solution to the conflict between academic freedom and OCAP, whereby each party can include their own interpretation in any publication. The need to actually resort to this sort of he-said, she-said scenario is extremely rare as partners are motivated to work out their differences.
- Contract, rather than partner with, researchers (if you can afford it). The contract involves the purchase of services and makes clear the lines of accountability.
- Spread it around. By involving numerous parties in various capacities at various stages, you can avoid having one of them overwhelm and control. Be wary, though, of situations where the community or First Nations organization is outnumbered or outgunned by experts.
- Develop a code of research ethics, guidelines, policies, by-laws or legislation where applicable. Once in place, ensure they are disseminated, understood and respected.
- Set up a research review board.
- Develop data sharing strategies and agreements that maximize the distribution of information while protecting sensitive information.

Other strategies have undoubtedly been identified elsewhere as well. Because available capacity and resources vary, and because First Nations perspectives on OCAP do too, there can be no blanket prescriptions. Although larger communities and organizations may have more latitude in applying the principles, the potential for smaller groups to make change remains significant.

A more in-depth discussion of two of the key strategies is provided below:
- First Nations research policy
- Data ownership and data sharing

First Nations Research Policy

Research guidelines and codes of ethics developed by First Nations quickly distinguish themselves from the self-regulating codes developed by funding agencies and universities. The policy statement excerpts from two recent codes – First Nations Regional Longitudinal Health Survey (RHS) and Kwanlin Dün Health Centre – are examples:

It is acknowledged and respected that the right of self determination of the First Nation and Inuit peoples includes the jurisdiction to

make decisions about research in their communities. The benefits to the communities, to each region and to the national effort should be strengthened by research. Research should facilitate the First Nation and Inuit communities in learning more about the health and well-being of their peoples, taking control and management of their health information and to assist in the promotion of healthy lifestyles, practices and effective program planning.[27]

And

It is acknowledged and respected that the right of self-determination of the Kwanlin Dün First Nation includes the jurisdiction to make decisions about research in the community. The Kwanlin Dün First Nation has designed this Code as a tool to assist in the protection and safety and well-being of the community in research activities and to facilitate cultural self-determination and preservation.

The Kwanlin Dün recognizes the importance of research to its community, Aboriginal people and society in general.

Research should benefit the community by providing information on the health and well-being of its people which will assist community leaders, health professionals and individuals to make decisions on health and health services which are based on evidence.

Research should empower the community to support community goals of health and wellness, capacity development, increased knowledge of health practices and benefits and provision of effective health services to its population.

When determining whether or not approval should be given to a proposed research project, greater consideration should be placed on the risks to the physical, psychological, human, proprietary and cultural values than to the potential contribution of the research to knowledge.[28]

Principles of the Mi'kmaw Ethics Watch address similar themes, emphasizing the role of the collective and of traditional protocols:

Mi'kmaq knowledge is collectively owned, discovered, used, and taught and so also must be collectively guarded by appropriate delegated or appointed collective(s) who will oversee these guidelines and process research proposals.

Each community shall have knowledge and control over their own community knowledge and shall negotiate locally respecting levels of authority.

Mi'kmaw knowledge may have traditional owners involving individuals, families, clans, association and society which must be determined in accordance with these peoples own customs, laws and procedures.[29]

Research policy documents prepared by First Nations include the following common themes and objectives:
- Research should provide clear benefits to First Nations Peoples and communities
- Research should help develop capacity in meaningful ways
- Research should increase First Nations control of information and research processes
- Research should respect sovereignty/jurisdiction/rights of First Nations
- Research should support self-determination
- Research should support cultural preservation and development

A growing number of communities and organizations have developed research and ethical guidelines,[30] ethical review processes,[31] privacy codes,[32] and other key framework documents that can serve as models.

Data Ownership and Data Sharing

OCAP has gained the attention of some departments of the Canadian government in connection with negotiations around the sharing (or not) of survey databases.[33] Because it is a fundamental resource in the research industry, the exchange and sharing of data has significant implications. In the information age, data is a form of currency.

Many researchers and others have argued that data cannot and should not be owned, that it should be freely available to all who wish to derive meaning from it. This seemingly progressive notion – essentially an adjunct of the search for truth – is a fallacy based on unexamined assumptions of power.

There is a mistaken assumption here that data is value neutral, ready to be gathered or collected and interpreted by anyone on an equal basis. In fact, data is not gathered, but created by those with the resources and opportunity to do so. Data is constructed through the choice of research framework, methods and instruments. Delsys Research Group describes the issue in connection with Statistics Canada's activities:[34]

> Data are not out there existing absolutely. Instead, we (every single one of us) are situated in a social experience. What emerges as problematic from one experience may not be problematic to another experience. What emerges as an important area of study for Statistics Canada or government policymakers may not be an important area of study for First Nations. Who emerges as a legitimate knower in the problematic is a pre-research choice. What categories emerge as related to the problematic will differ based on social location and/or culture. Although analysis of the data is undertaken by Statistics Canada and also by outside institutions, the ability to control the epistemology and the creation of the data is central to defining the universe available for analysis or interpretation.

First Nations' claim to ownership of their own data is not some strange new aberration. On the authority of their own institutions and laws, governments and academics have long possessed and owned data without really thinking twice about it. OCAP brings the illegitimate owners into the spotlight. Those who most strongly reject the notion of data ownership tend to have control or possession of considerable volumes of it.

A considerable amount of First Nations data is in the hands of entities that are not accountable to them. Returning that information to First Nations Peoples is similar to the protection of cultural medicinal knowledge, regaining sacred material from museums, or getting back land.

As First Nations become increasingly involved in research and in possession of research data, the question of whether to share that data and how becomes more important.

Sharing data provides opportunities to do more with it. By making their information available to others, First Nations groups can help maximize its dissemination and its potential impact. But this is a two-

edged sword. Once data is out there, the way it gets used may or may not coincide with the community's aspirations.

While certain types of information might seem to be fair game to a researcher, the community might consider them private or confidential. Sensitive cultural information, including knowledge and teachings about traditional medicines, may need to be kept within the community of origin. In many cases, community or group privacy may also be a cultural value. The desire to avoid the identification of specific groups has been heightened by unfortunate experiences involving stigmatizing depictions of specific communities and populations.

The First Nations Regional Longitudinal Health Survey (RHS) has developed a simple protocol to address collective ownership. Community level data or statistics[35] are not released without the explicit permission of community authorities. The same applies to regional-level statistics. Nationally, a Chiefs-appointed steering committee, the First Nations Information Governance Committee, makes decisions about the release of nationally aggregated information.[36]

Another consideration in decisions about data sharing relates to the uneven playing field for Aboriginal participants in research activities. Control of data can help counterbalance the relative lack of capacity and lack of voice at those privileged venues where the interpretation of data is heard and validated.[37] The following protection mechanisms have been used both individually and in combination to help offset the imbalance:

- Releasing or sharing data only after there has been adequate time for the First Nations/Aboriginal group to complete and disseminate its own interpretation.
- Releasing/sharing data for specific and agreed upon purposes only.
- Releasing only tabular or statistical data for quantifiable information, not record-level information.
- Reviewing and approving prior to release of publications developed using the data or, alternatively, invoking a right to dissent.

Sharing statistics diminishes the potential for unforeseen and potentially incorrect or inappropriate analyses and interpretations. On the other hand, a large record-level database opens a wide and unpredictable range of outputs. It may be quite difficult to track the uses.

There are potentially substantial benefits to First Nations that decide not to share record-level data – benefits in the form of increased resources and capac-

ity. If those interested in the data cannot perform the desired analyses for themselves, they may become clients of the First Nations data holder. The organization can offer data products and various reports, on a cost-recovery basis perhaps, while the staff and organization build skills in statistical analysis, report writing, etc. The release of statistics can also be linked to a review process that addresses data release and/or publication approvals.

Some researchers may balk at the idea of a First Nations review/approval process, construing it as political interference contrary to academic freedom. They do, however, readily accept the constraints of peer review for funding proposals, journal articles, and so on. As with academic review, a First Nations review process is generally intended to ensure quality of the work, its relevance, and the appropriateness of interpretation. The review should be viewed as an opportunity rather than a threat. The definition of peer needs to be broadened.

The RHS Code of Research Ethics outlines a procedure for First Nations review of analysis and interpretation "to ensure accuracy and avoid misunderstanding."[38] In the East, the Mi'kmaw Ethics Watch was formed to review research proposals according to Mi'kmaw Principles and Guidelines that "seek to ensure that the right of ownership of Mi'kmaw knowledge and heritage rests with the appropriate Mi'kmaw communities."

Institutional review prior to publication is also a common requirement in both corporate and governmental contexts. Here is an excerpt from Statistics Canada's policy:

> All information products, and especially interpretative, analytical and methodological products, for which Statistics Canada is wholly or partially responsible, are subject to review prior to release outside the Agency. The review should ensure that their content is compatible with the Agency's mandate as a government statistical agency, and that they adhere to the generally accepted norms of good professional practice.

> These reviews consist of institutional review for all information products, and peer (professional) review for interpretative, analytical and methodological products…

> Institutional review is intended to ensure that information products disseminated to the pub-

lic are free of material which would compromise the Agency's reputation for non-partisanship, objectivity and neutrality. Institutional review is a line management responsibility and is carried out as part of normal line management processes.[39]

The key challenge in data sharing is how to maximize benefits while protecting First Nations information. There are no right answers, only options to explore and practical decisions to be made considering the nature of the information and the interests of the parties. Over time, it is anticipated that proponents of OCAP will innovate various data sharing/data access protocols and some best practice options will emerge.

THE BENEFITS OF OCAP

The previous sections outlined how non-First Nations institutions have had a lock on research and information management through legislative authority, the control of funding, peer and ethical review processes, definitions of research and researchers, formulation of theoretical frameworks, methods and instruments, possession of databases, and so forth. OCAP underlines this situation as intolerable and calls for change.

The application of OCAP principles promises to deliver significant benefits to governments, researchers, First Nations Peoples, and their communities. Research and information management practices also stand to benefit. OCAP:

- Helps rebuild, and may be a prerequisite, for community trust. It allows research to happen where it might otherwise be impossible.
- Improves quality and accuracy because First Nations communities will invest more effort in data collection when the information is perceived as valuable.
- Results in more democratic (participatory) research methods.
- Translates into increased participation rates.
- Encourages a more holistic (First Nations) approach to health.
- Promotes coherent First Nations analyses and perspectives and minimizes the biases and misinterpretations stemming from other cultural frameworks.
- Contributes to community empowerment, self-determination, and healing activities.
- Produces more relevant and useful results, which lead to change.
- Encourages meaningful capacity development. [40]

Research is a tool for promoting changes that can transform people's lives. Putting OCAP into practice enhances that potential. OCAP is part of the broader self-determination aspirations of Aboriginal Peoples. By regaining control of institutions and processes that impact them, communities build hope for a healthy future.

ACKNOWLEDGMENTS

ENDNOTES

1. For an excellent discussion of the ownership/stewardship distinction, see: Jennifer Espey, *Stewardship and OCAP: A Discussion Paper for the First Nations Statistical Institute* (First Nations Statistics, May 2002).

2. The 'P' (Possession) was added to 'OCA' following a legal review by Krista Yao (Nahwegahbow, Nadjiwan, Corbiere) highlighting how statistical information in the government's possession is readily accessible through Access to Information requests regardless of ownership or written agreements. Another example of how possession is nine-tenths of the law.

3. Espey, *Stewardship and OCAP*.

4. Canada, Royal Commission on Aboriginal Peoples, *Report of the Royal Commission on Aboriginal Peoples, Volume 3: Gathering Strength*, Chapter 5 p. 4 (1997) http://www.indigenous.c.ca/v3/Vol3Ch5s8.2tos9.3asp.

5. Several items paraphrased from: American Indian Law Center, *Model Tribal Research Code: With Materials for Tribal Regulation for Research and Checklist for Indian Health Boards*, 3rd edition (September 1999).

6. The same cannot be said for the Métis, among whom very little, some say not enough, research has been done.

7. Previously the National Steering Committee for the RHS, the FNIGC's role was broadened to more globally address issues related to First Nations data, research and information issues. The group was mandated by and reports to the Assembly of First Nations' Chiefs Committee on Health. It is composed of representatives from 10 regional First Nations organizations.

8. Ceal Tournier, "Don't be on the other side of the digital divide: An overview of Current Health Information Initiatives Impacting Aboriginal Peoples," live address, Feb. 12, 2002, delivered as part of the Aboriginal Health Information Symposium held in Ottawa, Feb. 11 to 13, 2002.

9. Inuit Tapirisat of Canada, *Negotiating Research Relationships in the North*, 1993.

10. Online at http://www.sshrc.ca/english/programinfo/policies/ethics.htm.

11. The funding agencies include the Canadian Institutes of Health Research (previously the Medical Research Council), the Social Science and Humanities Research Council, and the Natural Sciences and Engineering Research Council.

12. Described in: J. Kaufert, *Looking for Solutions: Recognizing Communities in Research Ethics*. In: K.C. Glass and J. Kaufert, eds, Research Involving Aboriginal Individuals and Communities: Genetics as a Focus, Conference Proceedings, National Council for Ethics in Human Research, Ottawa, 2001, p.40-48.

13. Canada, Medical Research Council, Social Sciences and Humanities Research Council, Natural Sciences and Engineering Research Council, *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (1997), Cited March 2002, http://www.nserc.ca/programs/ethics/english/sec06.htm.

14. International Workshop on Ethical Issues in Health Among Circumpolar Indigenous Populations, Inuvik, NWT, June 2 to 3,1995.

15. For example: Canadian Association of Universities of Northern Studies, *Ethical Principles for the Conduct of Research in the North*, 1997; Canada, Royal Commission on Aboriginal Peoples, Appendix B: Ethical Guidelines for Research, Integrated Research Plan (Ottawa: RCAP, 1993); Canada, Royal Commission on Aboriginal Peoples, *Report of the Royal Commission on Aboriginal Peoples*, Vol. 5, Appendix E: Ethical guidelines for research (1996), p. 325-328; and Canada, Medical Research Council, the Natural Sciences and Engineering Research Council, and the Social Sciences and Humanities Research Council. *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (1997), Section 6.

16. Canada, Medical Research Council, the Natural Sciences and Engineering Research Council, and the Social Sciences and Humanities Research Council. *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (1997).

17. Kahnawake Education System, *Kahnawake Schools Diabetes Prevention Project Code of Research Ethics* (Kahnawake, Que.: 1998).

18. Martha Flaherty, Speech to the Association of Canadian Universities for Northern Studies 4th National Students Conference on Northern Studies, held in Ottawa, live address November 1994.

19. Indian Health Service, "Notice of Availability of Funds for Native American Research Centers for Health," Native American Centers for Health Program Announcement, Press release, 2000, cited January 2002, http://www.ihs.gov/publicinfo/publicaffairs/pressreleases/pressreleases/pressrelease2000/researchprgmannounce2000.asp.

20. Russel Lawrence Barsh, Aboriginal Self-Government in the United States: A Qualitative Political Analysis, RCAP Paper Number 10, revised October 1993.

21. The Australian Institute of Aboriginal and Torres Strait Islander Studies, *Guidelines for Ethical Research in Indigenous Studies*, May 2000.

22. Indian Health Service, "IHS and NIH continue partnership in 2002 by expanding funds available for American Indian and Alaska Native Research Centers," Indian Health Service Media Advisory, August 2001, cited January 2002, http://www.ihs.gov/publicinfo/publicaffairs/pressreleases/press%5Frelease%5F2001/press%5Frelease%5F2001/release%5F16%5Fnarch%5Fannounce%5F2001.asp.

23. Indian Health Service, "IHS and NIH continue partnership in 2002 by expanding funds available for American Indian and Alaska Native Research Centers."

24. American Indian Law Center, *Model Tribal Research Code*.

25. Indian Health Service Research Program Director Dr. W. Freeman, Personal communication, Feb. 13, 2002.

26. B. Masazumi and S. Quirk, *Dene Tracking: A Participatory Research Process for Dene/Métis Communities: Exploring Community-Based Research Concerns for Aboriginal Northerners*, Dene Tracking, Sombak'è, Denendeh, September 1993.

27. *First Nations and Inuit Regional Health Survey Project Code of Research Ethics*, July 25, 1997.

28. Kwanlin Dün Health Centre, *Kwanlin Dün Health Centre Research Code of Ethics*, May 22, 2001.

29. Mi'kmaw Ethics Watch, *Mi'kmaq Research Principles and Protocols*, Mi'kmaq College Institute, University College of Cape Breton, cited October 2002, http://mrc.uccb.ns.ca/mci/default.htm.

30. Kahnawake Education System, *Kahnawake Schools Diabetes Prevention Project Code of Research Ethics*; and American Indian Law Center, *Model Tribal Research Code*.

31. The Mi'kmaw Ethics Watch, which reviews research proposals, is co-ordinated by the Mi'kmaq College Institute, University College of Cape Breton.

32. For example: Carcross Tagish First Nation, *Protection of Personal Data and Information Policy*, Approved by Chief and Council September 1998.

33. Most notably were negotiations related to the First Nations and Inuit Regional Health Survey.

34. Espey, *Stewardship and OCAP*.

35. The 1997 and 2002 FNIRLHS samples permit relatively little in terms of community level statistical aggregation.

36. National Steering Committee of the First Nations and Inuit Regional Health Survey, *First Nations and Inuit Regional Health Survey Project Code of Research Ethics*, July 25, 1997.

37. Example include scientific journals, conferences, government meetings, and key government policy and briefing/background documents.

38. National Steering Committee of the First Nations and Inuit Regional Health Survey, *First Nations and Inuit Regional Health Survey Project Code of Research Ethics*, July 25, 1997.

39. Canada, Statistics Canada, *Statistics Canada's Policy for RDC Researchers*, Approved Jan. 18, 1995, cited March 2002, http://fosthall.library.ubc.ca/rdc/pdf/STCPoliciesforResearchers.pdf. "RDC" refers to Research Data Centres.

40. Several points are paraphrased from: J. O'Neil and J. Blanchard, *First Nations Perspectives on Public Health Surveillance*, 2001, prepared for the Assembly of First Nations Health Secretariat, First Nations Information Governance Committee.

Call for Papers

The *Journal of Aboriginal Health* will share success stories in Aboriginal health, discuss issues and opportunities, and provide the latest information and research of interest to First Nation, Inuit and Métis Peoples. It will publish in-depth analysis of health research and issues with full citation of sources; facilitate informed discussions on new research, recent publications and projects; and explore health determinants from an Aboriginal viewpoint.

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