



OCAP

Ownership, Control, Access and Possession

Sanctioned by the First Nations Information Governance Committee

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Under the *Canadian Constitution Act, 1982*, the term Aboriginal Peoples refers to First Nations, Inuit and Métis people living in Canada. However, common use of the term is not always inclusive of all three distinct people and much of the available research only focuses on particular segments of the Aboriginal population. NAHO makes every effort to ensure the term is used appropriately.

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Introduction

First Nations need to protect all information concerning themselves, their traditional knowledge and culture, including information resulting from research. The principles of Ownership, Control, Access and Possession (OCAP) enable self-determination over all research concerning First Nations. It offers a way for First Nations to make decisions regarding what research will be done, for what purpose information or data will be used, where the information will be physically stored and who will have access. This piece of work was sanctioned by the First Nations Information Governance Committee (FNIGC) and the First Nations Regional Longitudinal Health Survey (RHS).

In First Nations' world view, the Regional Health Survey (RHS) and its processes and principles of OCAP "come from the people". Rooted in self-determination and inherent rights, within the context of data and information management, the cultural framework of this project was the foundation from which many tools, documents, theories and mechanisms emerged and developed. The success of the work, past, present and into the future, is directly attributed to and dependent on the support, investment and vigilance of First Nations people at the grassroots and leadership levels. Without this, no success would ever have been achieved and no foundational principles would have been developed to challenge the status quo in research, data collection, data holdings and stewardship. This body of thought, along with the obligation to ensure its integrity in the appropriate contextual application, was entrusted to a regionally represented steering committee which transitioned over time into the First Nations Information Governance Committee (FNIGC). This work has had a transformational impact on the status quo; the credit for which needs to remain with "the people". The trust obligation requires FNIGC to ensure that the products that came from the work of the people are attributed rightfully back to the people, in a manner that is recognizable and attached to its initial formulation. It is for this reason that appropriate citation in the written world is credited back to the people through reference to the mandated custodians of this knowledge, the FNIGC. It is also why

sanction is sought from and given by the FNIGC to the veracity and application of these principals and processes in third party documents and applications.

It is because of the strength of the First Nations teachings and the support and encouragement given by the people that this work was accomplished. The work must be appropriately recognized and attributed, as that is the only respectful thing to do.

This guide explains the principles of OCAP and all that they encompass – from regulating the collection of data, to analyzing, managing and storing the data. It also provides some useful models in the form of policies, protocols, or strategies that reflect OCAP and have been adopted by First Nations to regulate all research activities that affect their people and communities. It also outlines key issues and concepts of OCAP, as well as existing barriers and challenges towards its implementation.

OCAP offers a First Nations approach to research, data and information management. It is a way to say "yes" to beneficial research and "no" to research that may result in harm. It is a way to improve research relevance.

Those interested in OCAP may also find the following First Nations Centre (FNC) materials useful:

- **Understanding Research;**
- **Health Surveillance;**
- **Privacy;**
- **Ethics in Health Research; and,**
- **Considerations and Templates for Ethical Research Practices.**

The Origin of OCAP

OCAP, as we call it today, was originally expressed as “OCA”¹ in 1998 by the National Steering Committee² of the First Nations and Inuit Regional Longitudinal Health Survey (RHS).³ As a result of heightened interest in the issue of First Nations ownership of information, the OCAP principles were developed during the inception of the RHS. The OCAP principles apply to all research, data or information initiatives that involve First Nations.

The RHS is a survey of health in First Nations communities. It is the only national research initiative in Canada under complete First Nations control.

Recognized as the “First Nations Survey of Choice”, the RHS has gained tremendous credibility in First Nations, among First Nations leaders, in academic and government circles, and internationally. Providing information that is both scientifically and culturally validated, the RHS contributes to effective health promotion, planning and program development. The survey also provides First Nations leaders and decision makers with the knowledge they need to advocate on behalf of First Nations. Finally, the RHS helps communities take control of their health information, while serving as a model of First Nations Information Governance in all areas of research, data and information management.



The RHS is recognized not only as OCAP-compliant but also as the primary innovator and driver of emerging OCAP policies, data sharing protocols, research practices and appropriate questionnaire content for use in First Nations communities.⁴ Capacity development is also an important outcome of the RHS. It promotes building long-term research and data management capacity within First Nations communities and organizations, not only on an individual level.

The RHS has done a great deal to advance the assertion of OCAP principles and has led to

the rebuilding [of] trust and belief of First Nations in research processes. [It] has produced important innovations in data sharing protocols, training, research ethics, methodology, and culturally appropriate questionnaire content. Most significantly, it has highly invested in individual and institutional capacity development at the community, regional and national levels (nation building). This capacity has not only demonstrated its effectiveness in undertaking survey research, but also in generating and disseminating knowledge, and in influencing health and social policy development.⁵

“RHS origins are rooted in the assertion of First Nations self-determination, self-governance and nationhood...[It] is based on the values of trust and respect for First Nations peoples, communities and Nations.”⁶ This has ultimately contributed to a renewed sense of pride in First Nations Research!

Research Legacy

Research involves gathering, organizing and interpreting the information around us. Everyone engages in some form of research on a daily basis. For instance, before purchasing a car, the buyer might research the vehicle by reviewing its features, comparing costs or asking friends and family what they’ve heard about the car. Research guides us in making more informed decisions and generally helps us to understand the world around us.

OCAP is about doing research the First Nations way—for First Nations, by First Nations. Before we look at OCAP itself, it is useful to consider how previous research involving First Nations has been done.

Good research has the potential to create valuable new knowledge or substantiate what we already know. It can also foster positive change or confirm that things are working well.

Research has been used by First Nations to:

- access funds for programs and services;
- assess community health and evaluate the effectiveness of health interventions;
- develop strategies or plans for community services and programs;
- lobby for policy changes or the creation of new policies;
- preserve and revive traditional languages;
- appropriately document and preserve traditional information and ceremonies;
- support land claims and Aboriginal rights court cases; and,
- prevent projects or developments that would negatively impact on traditional land use and the environment.

In the past, research was usually conducted in ways that excluded the people it aimed to understand. In general, an outside researcher would initiate a research project while the community and its members were simply the research subjects. Communities were seldom consulted with and had very little, if any, control over the research process. The Report of the Royal Commission on Aboriginal Peoples, Vol. 3 (RCAP) addressed this point:

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.⁷

Social research was used as “an instrument of oppression, imperialism and colonialism.”⁸ Negative experiences have led First Nations to feel distrustful and reluctant to participate in social research. Past research practices were often disrespectful, damaging

and stigmatizing to First Nations people. Examples of such research include: cultural ceremonies that have been misunderstood; the disturbance of sacred burial grounds to collect human remains and cultural artifacts for display in museums; and the stereotypical portrayal of First Nations.

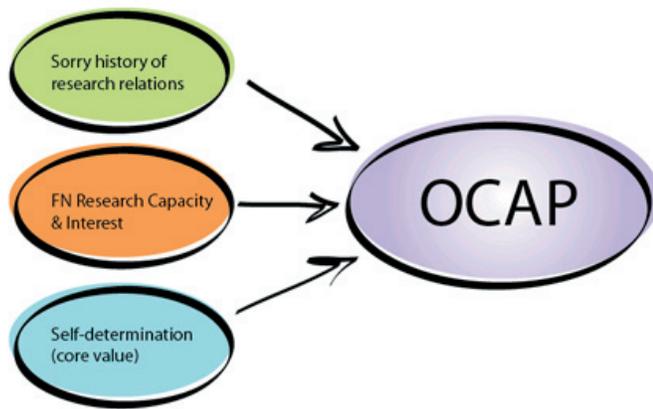
Many Aboriginal people feel that research has been “one-sided [and] that researchers enter communities for motives of personal career enhancement, academic publishing, and/or financial economic incentives, [rather] than supporting community development in improving health and well-being.”⁹ Moreover, First Nations have protested that they have been over-researched.

In recent years First Nations have voiced many concerns about the negative aspects of externally driven research. These include:

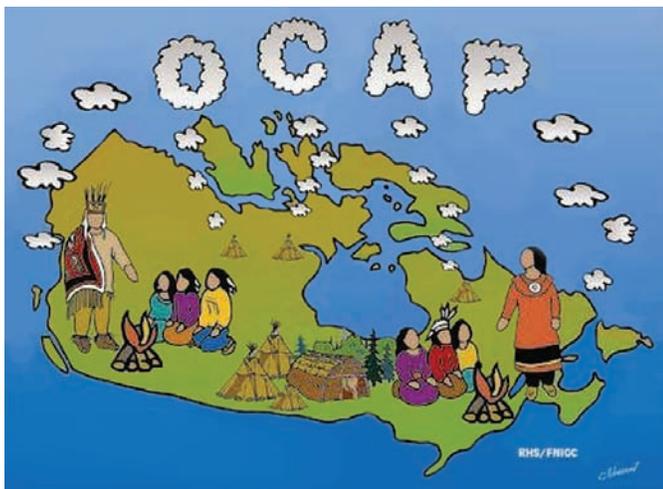
- lack of meaningful community involvement in the research process;
- lack of individual and community benefit from research (irrelevant research, lack of compensation to participants and no local hiring);
- lack of informed community consent (communities not informed of potential risks to health and safety or negative impacts of research);
- pressure to support a project (e.g., “Your people really need this research. How can you deny it to them?”);
- research agendas dictated by personal or academic interests rather than First Nations priorities or interests;
- lack of community ownership of data and research results (no control over analysis, interpretation or reporting; no review or say in who has access to data);
- community stigmatization and stereotyping of First Nations; and,
- lack of respect towards First Nations culture and beliefs, including misinterpretation of traditional knowledge and practices.

The principles of OCAP are, in part, a political response to the “sorry history of research relations between Aboriginal peoples and Canada”,¹⁰ a history based on colonial, oppressive and exploitative research. This response converged with two other historically important elements:

- 1) an increase in First Nations research capacity and involvement; and,
- 2) a widely shared core value of self-determination.



These three things came together to create the conditions for OCAP to resonate and travel quickly across the country like a smoke signal. OCAP is paving the way for the acknowledgement and application of First Nations research processes and models. This will result in more useful, respectful and beneficial research.



What is OCAP?

The principles of OCAP are one aspect of First Nations aspirations towards self-determination and self-governance. The principles represent a comprehensive framework developed by First Nations to bring self-determination into the realm of research and information management. OCAP applies to all research, data or information initiatives that involve First Nations, and encompasses all aspects of research (including funding and review), monitoring, statistics, cultural knowledge and so on. By insisting on the application of the OCAP principles, First Nations are asserting their authority over all research concerning their communities. This includes the right to make decisions about what, why, how and by whom information is collected, as well as how it will be used and shared.

The RHS affirms that the principles of OCAP best express the “necessary authorities, structures and processes for First Nations self-determination and self-governance over their individual and collective data, information and knowledge.”¹¹ Moreover, the RCAP Report highlighted that “capacity building and control in the areas of research and information are clearly linked to Nation re-building, the implementation of self-government and the assertion of First Nations rights to self-determination.”¹²

OCAP is a way to participate in a First Nations created environment that promotes the pursuit of beneficial research and its ethical application.

The OCAP principles are defined as follows:¹³

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 [or possession].

Control: The aspirations and rights of First Nations to maintain and regain control of all aspects of their lives and institutions include 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 people 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: 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 breach or misuse. This is particularly important when trust is lacking between the owner and possessor.

How OCAP Can Benefit Your Community

Insisting on the OCAP principles is a way to turn a good research idea into a good research process. The increasing assertion of OCAP principles is causing researchers – especially external researchers – to be more open-minded and flexible in their research plans.

Research must respect the privacy, protocols, dignity and individual and collective rights of First Nations. It must also derive from First Nations values, culture and traditional knowledge.

OCAP allows First Nations to not only judge the merits of a proposal, but also to put forward conditions so that good research ideas can be done in a good way. All stakeholders in a research project stand to gain from OCAP-compliant research:

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.¹⁴

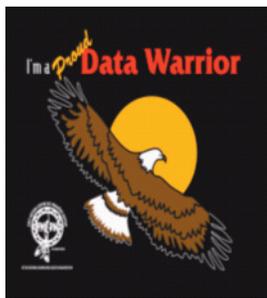
OCAP can benefit your community by:

- insisting that First Nations rights in the realm of research be recognized (community empowerment);
- rebuilding trust in research;
- creating a more holistic approach to research;
- improving data quality, relevance and value to the community;
- supporting meaningful capacity development and empowerment among First Nations;
- ensuring community consent to and control over the research process (including the interpretation and reporting of results);
- insisting on community ownership of the research results and data;
- supporting appropriate compensation and recognition for all project participants and contributors;
- protecting First Nations and their communities against stigmatization and stereotyping; and,
- protecting traditional knowledge.

The following figure illustrates culture permeating every aspect of an OCAP-based research process. The model suggests that OCAP and capacity are mutually reinforcing, and that they lead to more relevant research results. This, in turn, empowers communities and individuals to make more informed decisions that ultimately lead to improved health and well-being for community members.



OCAP and capacity development go hand-in-hand. Research capacity enhances a community's ability to assert OCAP, which, in turn, creates new opportunities for capacity development. In this perspective, the development of a community-driven First Nations health research infrastructure is seen as a long-term benefit of OCAP.



Those who promote and believe in OCAP are sometimes known as Data Warriors. The FNC offers three-day training on the effective use of health data for community planning. The sessions are popularly known as "Data Warrior Training".

How First Nations Can Assert OCAP

Many First Nations have begun to assert control over all research concerning them in order to ensure that it is done in an ethical manner—one that reflects and respects their community values and processes. They are initiating steps to manage research by putting in place the necessary regulations, procedures and oversight mechanisms, often including some kind of research committee.

One approach that has gained momentum is the development of community research protocols, policies or ethical guidelines such as a community code of research ethics.¹⁵ These documents typically regulate all research concerning the community and its members. A well developed, respected and enforced code of research ethics can be an important tool in asserting self-determination over research. It can prevent inappropriate research and the misuse of existing data while also encouraging positive

research. Research can be very good, and in the health field, good research can improve health.

A community code of research ethics and related processes can increase public awareness of First Nations rights in relation to research, influence change, and improve the culture and practice of research in general. The result should be better, more useful and relevant research—the kind that promotes positive change for the benefit of the community. FNC's *Considerations and Templates for Ethical Research Practices (2006)* provides a template for developing a code of research ethics, as well as other tools.

A variety of strategies have been effective in asserting the OCAP principles. Some useful practices include:¹⁶

- 1) Holding community consultations to find out the issues and research priorities of the community; Speaking with Elders and leaders.
- 2) Becoming informed of what other communities are doing and what strategies they are adopting. Build on successful First Nations initiatives and processes.
- 3) Setting up a committee to develop research guidelines and protocols.
- 4) Developing culture-based frameworks, methods, tools, training, review and reporting strategies.
- 5) Developing a community code of research ethics, guidelines, policies or by-laws to guide all research activities and researchers.
- 6) Developing criteria for evaluating research proposals. (See the attached *Appendix A* for a list of useful questions to ask when reviewing research proposals.)
- 7) Establishing a Research Review Board to review research proposals.
- 8) Negotiating the research relationship and management of the research project, including the goals and objectives, methodology, data collection process, control and access of the data, data stewardship and analysis, dissemination of the research results and their publication.

(First Nations may wish to decline participation in research processes that do not respect OCAP or their research protocols.)

9) Building research skills among people in your community or organization.

A checklist of suggested actions is provided in *Appendix B* to assist First Nations communities in asserting their OCAP rights.

Initiatives that Reflect OCAP

Whether they refer specifically to OCAP or not, the number of policies and processes that reflect the principles continues to grow. The following are just a sample.

The RHS Code of Research Ethics

The RHS Code of Research Ethics (2005), developed by the First Nations Information Governance Committee, establishes a framework of principles and procedures to guide all partners of the RHS in accomplishing the mandate and objectives of the survey. The *Code* outlines the responsibilities of each partner through all aspects and phases of the survey (and spin-off research) to its conclusion. The policy statement echoes the cornerstone of OCAP, and recalls the recommendations of the RCAP:

It is acknowledged and respected that the right of self-determination of the First Nation includes the jurisdiction to make decisions about research in their communities.¹⁷

It further states:

the benefits to the communities, to each region and to the national effort should be strengthened by the research. Research should facilitate the First Nation 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. The First Nations Information Governance Committee promotes making the most of the funding opportunity on behalf of First Nations. We will reclaim the original foundations of our health and healing.¹⁸

Kahnawá:ke Schools Diabetes Prevention Project (KSDPP) Code of Research Ethics

The KSDPP's Code of Research Ethics (1996) guides the research partners: the Kanien'kehá:ka community of Kahnawá:ke, community based researchers of the Kateri Memorial Hospital Centre, the Kahnawá:ke Education System, and researchers from McGill University and the Université de Montréal.

Embodying the principles of community-based participatory research, the Code ensures that the community is a full partner throughout the entire research process. It outlines the obligations of each of the partners in all phases of the project, from the design of the research through to the publication of results. The Code recognizes and respects the "sovereignty of the Kanien'kehá:ka of Kahnawá:ke to make decisions about research in Kahnawá:ke."¹⁹

The Code further states that the "benefits to the community as a whole and to individual community volunteers should be maximized by the researchers. Research should empower the community to support community goals of health and wellness, to promote healthy lifestyles, improve its self-esteem and to fulfill its traditional responsibility of caring for the Seventh Generation."²⁰

Mi'kmaq Ethics Watch Model

The Mi'kmaq Ethics Watch Model: Principles and Guidelines for Researchers Conducting Research With and/or Among Mi'kmaq People (2000) was developed by the Grand Council of the Mi'kmaq to protect Mi'kmaq peoples and their knowledge. These principles and protocols, including a formal review process, help to ensure that outside organizations follow the highest standards of research, with sensitivity and respect to Mi'kmaq people and their communities. They will also ensure that the right of ownership of Mi'kmaq knowledge and heritage rests with the appropriate Mi'kmaq communities.

Assembly of the First Nations of Quebec and Labrador Research Protocol

The First Nations of Quebec and Labrador Research Protocol, published by the Assembly of the First Nations of Quebec and Labrador, was developed in cooperation with various regional organizations. The research protocol is a tool for First Nations and organizations to support them in activities related to research. It promotes the development of research skills. It aims to “promote a precise and well-informed ethical form of research, whose whole process respects the will of the First Nations involved.”²¹

The American Tribal Participatory Research Approach

In the United States, the Indian Health Service offers funding for Native American Research Centers for Health (NARCH). These centres include participation from American Indian/Alaska Native (AIAN) organizations, including scientists and health professionals, responsible for securing funding, building capacity and strengthening partnerships. Taking a Tribal Participatory Research (TPR) approach, this American funding program provides funding directly to the Tribal organization and not an academic institution. The TPR approach

facilitates the active involvement of AIAN communities in the research process, from conceptualizing the issues to be investigated to developing a research design, and from collecting, analyzing, and interpreting the data to disseminating the results. [It] emphasizes the inclusion of community members and the social construction of knowledge.²²

OCAP is a Way Forward!

There have been some concerns about OCAP, mainly expressed by non-First Nations researchers and government representatives.

“...protect [your community’s traditional knowledge] and ensure that it reaches only people who will appreciate its worth, meanings, and uses. People have a right to protect their intellectual property.”
(Masuzumi and Quirk, 1993)

Some perceive OCAP as being an obstacle to doing research and gaining entry to First Nations. Certainly, OCAP affirms the right of First Nations to accept or refuse research concerning their communities. However, it is not simply a means for automatically saying “no”. Instead, OCAP is a way to turn a good research idea into a good research process and allows beneficial research to happen in a beneficial way. It affirms the right of First Nations to exercise their voice and control over research, as well as make decisions on research that affects their communities.

OCAP helps to identify worthwhile research and ensure better research processes. It asserts the right of First Nations to decide not only whether research should happen, but also how it should be done for the benefit of their communities. To the overall mainstream research community, this may take some getting used to. It challenges researchers to change their accustomed ways of conducting research with First Nations. For example, they must carefully consider community research protocols, conflicting worldviews, and the time needed to build trusting relationships, all of which are fundamental in successful research undertakings with First Nations.

Some may argue that research and knowledge do not belong to anyone and can therefore be collected freely. Yet, some practitioners of science carefully guard data and refuse to share it with the individuals or groups from whom they collected it. Moreover, at the conclusion of the research, researchers have released results publicly without full regard for the privacy and other rights of the people who supplied the data.

While academic freedom is an important principle, it does not amount to free rein. Canadian laws establish many kinds of protections and conditions for the ownership, safeguarding, dissemination and use of data and intellectual property. In asserting OCAP principles, First Nations are hardly being unreasonable; they are simply being assertive, particularly in safeguarding their information and their knowledge. For some, this assertiveness will take some getting used to. Through OCAP, First Nations remind the practitioners of science that ‘free knowledge’ is a guiding principle and not an absolute.

Under Canadian law, individuals have privacy rights that include protection of their personal information and data. The FNC's Privacy tool kit provides detailed information. OCAP rights are *in addition* to individual rights. OCAP-based policies can protect collective or community information in much the same way that privacy policy and legislation protects individuals. This is sometimes referred to as "collective privacy".

Collective privacy can be asserted through policies that formally require community consent for data collection, data access and disclosure, sharing or reporting of data or results. Collective privacy applies to data already held in government or academic databases, as well as to new research.

Personal privacy provides individual protection. Collective privacy is for the community or Nation. It is a jurisdictional issue, consistent with cultures that value both individual and collective self-determination.

Lastly, First Nations have been unfairly criticized as lacking the research capacity and formal credentials to perform high quality and scientific research. On the contrary, Western assumptions about quality research often filter out precisely those research approaches that would be effective and relevant in First Nation settings. In fact, research that relies on Indigenous knowledge and ways of knowing is usually stronger methodologically because the bias from outside (i.e. non-Indigenous) interpretation is lessened. For this reason, First Nations researchers are often the best choice to research their own peoples. Community-based researchers have a greater understanding of their communities, and can contribute much knowledge, strength and validity to the research.

First Nations are demanding that they are actively involved throughout the entire research process, from the design phase to the analysis and dissemination of the findings. They want to make decisions and have more control over the research that affects them. Although it is difficult for many external researchers to adapt to this new way of doing research with First Nations, it is a reality they must accept. Through OCAP, First Nations not only have a stake,

but they are demanding a key role in the whole research process!

OCAP is a way to say "yes" to beneficial research and "no" to research that is not relevant or results in harm.

What Lies Ahead for OCAP?

Researchers and governments today are increasingly recognizing that if they want to do research involving First Nations, they have to respect OCAP. OCAP is here to stay. The term OCAP is now heard not only in First Nations meetings but also in classrooms, at conferences and within federal, provincial and territorial government offices. Expectations of First Nations are changing quickly and university researchers are updating their ways of doing business. A growing number of academic research centers are beginning to recognize and acknowledge OCAP. In June 2005, the RHS National Coordinator articulated the following goals for strengthening OCAP and improving First Nations research over the next few years:²³

- enhanced research capacity in all First Nations;
- First Nations communities and organizations being identified as authors or co-authors in publications;
- research funding criteria changed to facilitate community access;
- establishment of First Nations research ethics review processes; and,
- First Nations research conducted from within a cultural framework and university curricula incorporating cultural framework training.

Other people have other ideas as well. What do you think is needed? Where should we go now? Although the OCAP road may be bumpy at times, the prospect of more respectful and useful research makes the ride worthwhile.

Glossary of Terms Related to Research and OCAP²⁴

Accountability: The obligation to demonstrate and take responsibility for performance in light of agreed upon expectations.

Aggregate data: Data that is presented or collected in a grouped or a summarized form (e.g., community average income as opposed to each individual's income).

Capacity building:²⁵ Increasing the ability of individuals, communities and nations to learn and to do. Capacity building implies the capacity to work with external agencies, organizations, institutions and governments to share knowledge and experiences. Capacity building in health planning can involve developing and applying governance models, making informed decisions, strategic planning, identifying and setting priorities, evaluating, managing human and fiscal resources, and assuming responsibility for success and failure of health programs and interventions.

Collective privacy: Personal privacy provides individual protection, while collective privacy is for the community, nation or group. Keeping certain traditional cultural practices private is a long-standing practice based on an understanding of collective privacy. Collective privacy can be asserted through policies that formally require community consent for data collection, data access and disclosure, sharing or reporting of data or results. Collective privacy applies to data already held in government or academic databases, as well as to new research.

Collective rights: The concept that the members of a community, nation or other group have rights as a collective, in addition to their rights as individuals. In the context of First Nations research and information, these rights may include ownership, control, access and possession of First Nations research and information, as well as cultural and Indigenous (traditional) knowledge and intellectual property rights.

Data: Facts, observations or measures that have been recorded, but not put into any meaningful context.

Data linkage: Also called “data matching.” A method of bringing together the information contained in two or more databases. For example, mortality data might be linked to hospital records.

Data steward: A manager or trustee who has responsibility or is in possession of data banks/repositories of personal information.

Data warrior: Term used to describe those dedicated to protecting First Nations information and upholding the OCAP principles.

De-identified data: Data that excludes any information that can personally identify the research participant/subject. For example, data from which the names, addresses, date of birth and health care numbers have been removed. The data may still include information about individuals, but the individuals cannot be identified.

Health:²⁶ A state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.

Indigenous (traditional) knowledge:²⁷ An ancient, communal, holistic and spiritual body of information and understanding that encompasses every aspect of human existence. Indigenous knowledge can be unique to a specific culture, collectivity, nation and territory. Knowledge is passed on through traditional teachings, ceremonies, healing practices and everyday living.

Information: Data that have been arranged in a systematic way in order to yield order and meaning. While counts of hospital visits each day might be considered data, knowing that the number on weekdays is higher than the number on weekends is information.

Inherent right:²⁸ A right that abides in a person and/or a collectivity and can not be given or taken away. Aboriginal rights are inherent to all Aboriginal peoples in Canada and are passed down from generation to generation.

They stem from the recognition that Aboriginal peoples are the original occupants of this land, and are often broadly defined as the right of independence through self-determination in respect of governance, land, resources and culture.

Knowledge: Information in the mind in a context that allows it to be transferred into action (see Information).

Participatory research: Participatory research is a systematic inquiry that includes the active involvement of those who are the subject of the research. Participatory research is usually action-oriented, where those involved in the research process work together to define the research, collect and analyze the data, produce a final product and act on the results.

Personal information: Information about an individual(s) that directly identifies the individual(s), or contains personal details that indirectly reveal their identity.

Raw data: A set of information or data that has not been statistically manipulated or analyzed.

Research ethics: A system of rules or standards which distinguish between acceptable and unacceptable research practices. Health research ethics guidelines usually deal with issues such as: the nature of the relationship between the researcher and the subject; ownership of and access to data; conflict of interest; consent to research; privacy and confidentiality; and measures to preserve human dignity.

Research partnership agreement: A document that represents a formal summary of rights, responsibilities and good faith between the parties entering into a partnership to jointly conduct research. Information explaining the roles and responsibilities of all partners in all aspects of the research is outlined in the agreement. All parties involved in the research partnership sign the agreement.

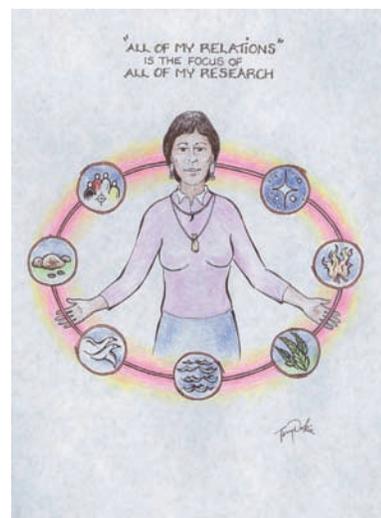
“Right to Dissent”:²⁹ Partners in a research project can agree on a “right to dissent” clause in their research agreement. This clause ensures that all

partners have an equal voice in the oral and written communication of research results and is helpful in cases where there is disagreement. It gives the disagreeing partner the right to include a description of why they disagree, and/or an alternative interpretation in the publication or communication. This also allows the public to read both interpretations and decide for themselves which one they agree with.

Self-determination: The opportunity and ability to direct one’s own life, without the interference of an external entity. For an individual, it includes the freedom and the resources to make economic, health and personal decisions in one’s own best interests. For a community, it is the ability to create an environment that supports the well-being of its members. For a nation, it is sovereignty over its lands, resources and its citizens, including the ability to govern itself according to its values, culture, and traditions, and based on its legal, political, social, economic, and cultural systems, in order to create an environment that supports the well-being and prosperity of its citizens. Evidence suggests that individual self-determination is a determinant of health.

Sovereignty:³⁰ Supreme power or authority of a people over their interests and territories, independent of the control of other governments or other external entities.

Self-government: The ability of a people or a nation to govern themselves according to their values, cultures and traditions, and based on their legal, political, social, economic and cultural systems.



Endnotes

Please note that cartoons were commissioned by the FNIGC – RHS. Logos were used with permission.

¹Cathryn George of the Association of Iroquois and Allied Indians is credited with the original acronym “OCA”. The “P” (Possession) was added to establish that RHS First Nations data should remain in the hands of First Nation authorities in order to respect First Nations’ principles and protect their collective information.

²First Nations Information Governance Committee (FNIGC) is the new committee name given to the previous First Nation and Inuit Regional Health Survey National Steering Committee. The name change reflects the broadened mandate and range of issues that years of work on the RHS had brought into focus. The FNIGC address issues such as university research, government data collection processes, health information systems and initiatives, research ethics, development of First Nations research infrastructure, etc...

³The initial RHS included the Inuit of Labrador and was titled the First Nations and Inuit Regional Longitudinal Health Survey. The 2002/03 RHS survey included First Nations on-reserve/communities only and is called the First Nations Regional Longitudinal Health Survey. The Inuit have opted for Inuit specific research initiatives.

⁴First Nations Regional Longitudinal Health Survey, First Nations Centre, *Our Voice, Our Survey, Our Future: The “Survey of Choice” by First Nations in Canada. Presentation to the United Nations Workshop on Data Collection and Disaggregation on Indigenous Peoples* (Ottawa: National Aboriginal Health Organization, 2004), p. 4.

⁵Ibid. p.14.

⁶Ibid p.5.

⁷Royal Commission on Aboriginal Peoples, *Report of the Royal Commission on Aboriginal Peoples, Volume 3: Gathering Strength* (Ottawa: 1996), p.4.

⁸Durst, D., *Partnerships with Aboriginal Researchers: Hidden Pitfalls and Cultural Pressures* (Regina: Saskatchewan Institute of Public Policy, 2004), p.2.

⁹Assembly of First Nations, *An Aboriginal Health Info-structure: Social/Political Operational Issues*, Background Paper (Ottawa: Assembly of First Nations, 1998), p. 28.

¹⁰First Nations Centre, *Ownership, Control, Access and Possession (OCAP) or Self-Determination Applied to Research: A Critical Analysis of Aboriginal Research Practice and Some Options for Aboriginal Communities*, paper first prepared for the First Nations Information Governance Committee, Assembly of First Nations (Ottawa: National Aboriginal Health Organization, 2005), p. 3.

¹¹First Nations Regional Longitudinal Health Survey, *Our Voice, Our Survey, Our Future: The “Survey of Choice” by First Nations in Canada*, p. 11

¹²Ibid. p.12.

¹³First Nations Centre, *Ownership, Control, Access and Possession (OCAP) or Self-Determination Applied to Research: A Critical Analysis of Aboriginal Research Practice and Some Options for Aboriginal Communities*, p 2.

¹⁴Ibid. p.25.

¹⁵For more information see First Nations Centre, *Considerations and Templates for Ethical Research Practices* (Ottawa: National Aboriginal Health Organization, 2006).

¹⁶Some of the steps have been taken from the First Nations Centre, *Ownership, Control, Access and Possession (OCAP) or Self-Determination Applied to Research: A Critical Analysis of Aboriginal Research Practice and Some Options for Aboriginal Communities*.

¹⁷First Nations Information Governance Committee, *First Nations Regional Longitudinal Health Survey, Code of Research Ethics- Revised Draft* (Ottawa: Assembly of First Nations, 2005), p. 3

¹⁸Ibid. p. 3.

¹⁹Kahnawake Schools Diabetes Prevention Project, *KSDPP Code of Research Ethics* (Kahnawake Territory, Mohawk Nation: 1996), p.2.

²⁰Ibid. p.2.

²¹Assembly of the First Nations of Quebec and Labrador, First Nations of Quebec and Labrador Health and Social Services Commission, *Assembly of the First Nations of Quebec and Labrador Research Protocol* (Quebec: First Nations of Quebec and Labrador Sustainable Development Institute and the Commission on Human Resources Development for the First Nations of Quebec, 2005), p.3.

²²P.A. Fisher and T.J. Ball, “Tribal Participatory Research: Mechanisms of a Collaborative Model”, *American Journal of Community Psychology* Vol. 32, 3-4 (2003), pp. 207-16.

²³First Nations Regional Longitudinal Health Survey, First Nations Centre, *The Cry of the Data Warrior in Canada*, a presentation to International Network of Indigenous Health Knowledge and Development 2nd Bi-Annual Meeting, Vancouver, Canada (Ottawa: National Aboriginal Health Organization, 2005) pp. 37-38.

²⁴Taken from the FNC Training Session – *How to Use Data for Effective Community Health Planning*. Sources include: John M. Last, *A Dictionary of Epidemiology, 4th Edition*, (New York: Oxford University Press, 2001) and Office of National Surveillance, Health Protection Branch, Health Canada, *Proposal to Develop a Network for Health Surveillance in Canada*, (Ottawa: Public Works and Government Services Canada, 1999).

²⁵Definition adapted from: Louise Mailloux and Peter Gillies, *Inuit Health Information Initiative Discussion Paper* (Ottawa: Pauktuutit Inuit Women’s Association and Inuit Tapirisat of Canada, 2001), p. 24.

²⁶Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19-22 June, 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organization, no. 2, p. 100) and entered into force on 7 April 1948.

²⁷Definition adapted from: Simon Brascoupé and Howard Mann, *A Community Guide to Protecting Indigenous Knowledge* (Ottawa: Indian and Northern Affairs Canada, 2001), p.3.

²⁸Definition adapted from: M. Battiste and J.Y. Henderson, *Protecting Indigenous Knowledge and Heritage: A Global Challenge*, (Saskatoon: Purich, 2000), pp. 212–213 and “Aboriginal Rights”, *The Canadian Encyclopedia* (Historica Foundation of Canada, 2006). Retrieved from <http://www.thecanadianencyclopedia.com/index.cfm?PgNm=TCE&Params=A1ARTA0000015>

²⁹First Nations Centre, *Ethics Tool Kit: Information to Share from the First Nations Centre of the National Aboriginal Health Organization* (Ottawa: National Aboriginal Health Organization, 2003), p. 10.

³⁰Definition taken from: de Wolfe, Gaelan Dodds, et al., *Canadian Dictionary 2000 Edition* (Toronto: Gage Educational Publishing Company, 2000).

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Appendix A - Questions to Ask When Reviewing Research Proposalsⁱ

There are fundamental questions that a First Nation may want to consider in deciding whether or not to approve a research proposal. Answers to the following questions may help decide the worth of a proposed project or could suggest how the project could be modified in order to be acceptable. You may want to ask the following questions when deciding the worth of a research proposal:

1. What are the major health/social/economic/environmental issues that this research will address?

2. Are these issues a priority for your community?

Yes No Maybe

3. Will this project result in new information about this issue that benefits your community or that benefits others?

Yes No Maybe

4. Has a similar research project already been conducted in your community, or elsewhere to your knowledge?

Yes No

If yes:

What was the outcome?

Was your community satisfied with the process? Why or why not?

Is there a good reason why another, similar project should be conducted?

5. Have community members been involved, or are they going to be involved, in key phases of this research project? Check the ones that, in this case, have or will involve members of your community.

Project planning and design

Data collection

- Data analysis and interpretation
 - Decisions on project outcomes (e.g. what type of final reports)
 - Assisting in preparation of final reports
 - Editing and/or approving the final report
 - Other: _____
-
-

6. In what ways does the project involve people in your community? Check the examples below that apply.

- Researchers or research assistants
 - Interpreters
 - Field guides
 - Participants (e.g. in interviews, focus groups, etc.)
 - Members of a project steering committee or working group
 - Other: _____
-
-

7. How will this project benefit your community? Some potential benefits are listed below; check the ones that apply.

- Direct economic benefits to community members (e.g. as paid researchers or participants)
- Indirect economic benefits (e.g. outside researchers will spend money in the community, research may raise the profile of the community and attract other visitors, etc.)
- Training, education or capacity-building for community members
- Results may help community members to make more informed choices
- Results may validate or justify community need(s) in order to support future funding and programs
- Results may support change at a higher level (e.g. provincial/territorial or federal policy)
- Other: _____

8. What are the potential harms or risks of the project? Check any that apply.

- Invades personal or collective privacy
 - Involves sensitive issues that might upset people
 - Violates or conflicts with community or cultural values, ethics or behaviours
 - Involves a lot of (unpaid) time for leaders or other community members
 - May disrupt other important projects or issues in the community
 - Results might portray the community in a negative way
 - Environmental impacts
 - Other: _____
-
-

9. Do the benefits of the project outweigh the risks?

___ Yes ___ No ___ Maybe

10. Have the researchers agreed to abide by a Code of Research Ethics (if your community or region has one), OR has the project been approved by an Ethics Review Board?ⁱⁱ

___ Yes ___ No

ⁱAdapted from Assembly of First Nations, *Template for a Community Code of Ethics in Research and Data Sharing Protocols* (Ottawa: Author, 1999).

ⁱⁱSome First Nations, municipalities or regions have developed a Code of Research Ethics to regulate or guide research in their community or area. Also, most universities, research and funding agencies require that affiliated project proposals be reviewed and approved by an Ethics Review Board. For more information of research ethics, please refer to *Ethics in Health Research* (2003) and/or *Considerations and Templates for Ethical Research Practices* (2006), available from the First Nations Centre of the National Aboriginal Health Organization.

Appendix B - Strategies for Asserting OCAP in your Community

First Nations communities have created and applied a variety of strategies for asserting the OCAP principles. The list below provides suggestions to help you develop an OCAP strategy that serves the needs and interests of your community. You can check the examples that your community has already accomplished, or that you want to accomplish in the future.

- Develop and implement independent community-based, community-paced practical research projects.
- Hold community and Elder consultations to determine research priorities.
- Learn about and build on First Nations initiatives and processes that were successful elsewhere.
- Develop culture-based frameworks, methods, tools, training, reviewing and reporting strategies.
- Develop a community code of research ethics, guidelines, policies or bylaws (see FNC's Considerations and Templates for Ethical Research Practices for more information).
- Develop criteria for evaluating research proposals.
- Establish a research committee or review process to assess research proposals.
- Negotiate the research relationship and management of the research project, including the goals and objectives, methods, hiring, training, control and access to the data, analysis, interpretation and dissemination of results.
- Develop research skills in your community or organization.
- Refuse to participate in research that does not respect OCAP or community values or interests.

Other: _____



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