



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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Table of Contents

Introduction.....	1
The Origin of OCAP.....	2
Research Legacy	2
What is OCAP?.....	4
How OCAP Can Benefit Your Community.....	5
How First Nations Can Assert OCAP	6
Initiatives that Reflect OCAP.....	7
OCAP is a Way Forward.....	8
What Lies Ahead for OCAP?.....	10
Endnotes.....	12
Bibliography	14
Appendix A: Questions to Ask When Reviewing Research Proposals.....	15
Appendix B: Strategies for Asserting OCAP in your Community	18

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.

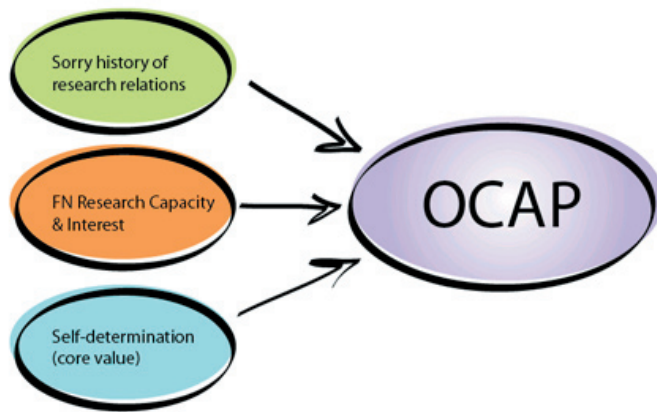
Many Aboriginal people feel that research has been “one-sided [and] that researchers enter communities for motives of personal career enhancement, academic publishing, and/or financial economic incentives, [rather] than supporting community development in improving health and well-being.”⁹ Moreover,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

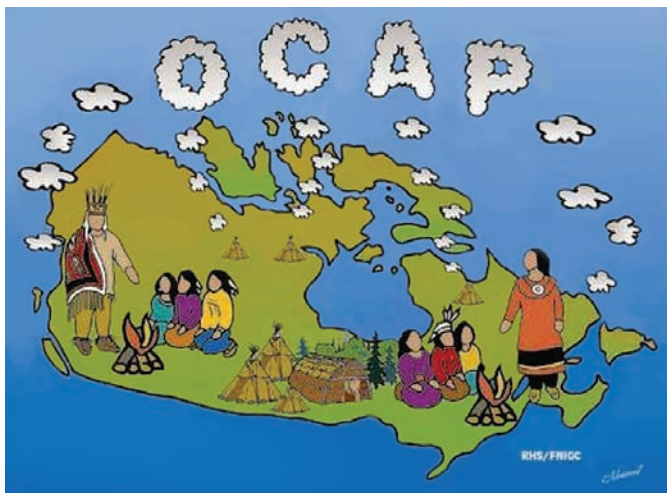
- lack of meaningful community involvement in the research process;
- lack of individual and community benefit from research (irrelevant research, lack of compensation to participants and no local hiring);
- lack of informed community consent (communities not informed of potential risks to health and 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

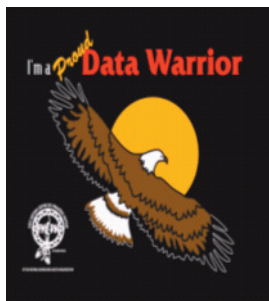
OCAP can benefit your community by:

- 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.