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Research Brief

Identifying Useful Approaches to the Governance of Indigenous Data

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November 2013

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Introduction

DATA ARE a resource, a descriptive asset. Data can inform planning and decision-making; they can establish track records and measure results; they can enhance accountability and ease compliance. If relevant, of high quality, and used in their proper context, data can serve as a cornerstone of effective governance.

At the same time, governance matters to data. Effective data governance can establish checks to ensure that the data collected support an organization's priorities. It can provide for quality control mechanisms and ensure that the required data are available in a timely way. If more than one organization collects, manages or uses the data, effective data governance can promote mutually beneficial and respectful relationships between the partners.

This research brief seeks to inform efforts to improve the governance of indigenous data shared with or held by governments. Its central examples involve First Nations and the federal government, but it also may be useful to Inuit and Métis in Canada as well as indigenous peoples elsewhere. It is based on an in-depth study of academic and grey literature relating to data governance and on qualitative interviews with key First Nation, federal and provincial government informants.[1]

The research brief first addresses some basic definitions in data governance, then describes a spectrum of models arising from that emerging field. With a particular focus on First Nations, it then turns to indigenous approaches to data governance, which stress the political intentions and ethical foundations that inform any data governance model.

Turning from theory to practice, the brief raises key considerations arising for governments and indigenous groups seeking to negotiate data sharing agreements. It concludes by noting a selection of promising precedents featuring data governance models that support respectful and effective partnerships, as well as key themes that emerged from interviews with staff members involved in some of those initiatives.

What is Data Governance?

WHAT IS DATA? What is governance? We begin with some working definitions.

Data above all describe: they are attributes or characteristics. Data are not simply objective: an interpretive element is present in the decision on which data to collect and use—not to mention which category of people or things data describe (Mitra, 2012; Andersen, 2008). This point about the intention behind data creation and use recedes to the background in

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[1] The longer paper is now under consideration for a special issue of the *International Indigenous Policy Journal* on governance of indigenous information. A draft of the full paper is available on request.

Key Findings

- There are three basic data governance models: hierarchy, partnership, commons
- Indigenous approaches provide an ethical and political orientation for any model
- A number of policy factors are motivating governments to negotiate partnerships involving indigenous data
- Several precedents exist, which respect indigenous approaches as well as government needs and legal constraints

much of the literature on data governance. Yet, as we shall see, it becomes central in speaking of data involving indigenous people.

Governance entails the activity of steering or directing toward a shared goal. As for data governance, it has been defined as:

- A *framework* for decision rights and accountabilities to encourage desirable conduct in the use of data (Wende, 2007);
- The *processes, policies, standards, organization* and *technologies* required to ensure data are available, accessible, high quality, consistent, auditable, and secure (Panian, 2010).

Three actors are involved in data governance: the data producer or creator, the data user and the "governing actor"—or agent that sets and monitors compliance with rules of interaction among producers and users.

Data Governance Models

THE BROADER LITERATURE on data governance allows us to identify three basic models, with variations, for organizing a data governance framework. Each model has its distinct rationale, purpose and benefits. Briefly, the three models are:

- Single-organization data hierarchy
- Data partnership
- Data commons

Single-Organization Data Hierarchy

This model is the central case assumed in much of the literature on data governance. It features an organization, often a for-profit corporation, creating, managing, and using its data to promote its own strategic purposes. The

organization must exist in and comply with an external legal and regulatory environment. But within in its own sphere, its executive can create the data policies, procedures, standards and structures it sees as required to promote effective data governance in a top-down way.

Data governance in this model occurs largely in a self-contained unit. This model *does* allow engagement of external organizations—chiefly in the mode of outsourcing. By outsourcing, an organization transfers key elements of its data management to third parties, which perform them on its behalf. The client organization retains full responsibility and control of the data asset (IT Governance Institute, 2007; Panian, 2010).

Data Partnerships

If the central case for the data hierarchy model is the self-enclosed corporation, the central case for data partnerships might be the public service organization. The past few decades have seen both technological advances and policy shifts calling for more rigorous performance measurement, collaborative governance, and evidence-based policy making. As a result, public service bureaucracies face increasing pressure to gain—often, by sharing—reliable, high-quality data (Yang & Maxwell, 2011).

> Parties in a partnership, by contrast to a hierarchy, jointly govern the data asset.

In its simplest form, a data partnership involves equal parties with reciprocal data needs, equal interest in sharing, similar technical capacity and legal position, and so on. Things are rarely so tidy in practice, but parties in a partnership (by contrast to a self-enclosed hierarchy) *jointly* govern the data asset.

Establishing data partnerships may make sense for a host of reasons. Yet it is not easy, especially if the partners arise from different cultural and legal starting points. There needs to be a perception of mutual benefit on the parts of both producer and user. There also needs to be trust. The producing or sharing party must have confidence that its data is secure, confidential and will not be misused. The recipient party needs to be assured that the data is relevant and of high quality. Formal agreements and joint data governance structures must be created early. Progress should be expected to build slowly at first, as the informal trust and communication channels required take time and effort to develop.

Short of a partnership, single-organization data hierarchies often enlist advisory bodies or committees (Ansell & Gash, 2007). Such arrangements mark an important step beyond a self-enclosed hierarchy. They are not yet a data partnership, though, which is defined by shared decision-making around the data asset.

Data Commons

A third basic data governance model occupies the end of the spectrum opposite to the single-organization data hierarchy. Its central case is a research community. Data commons facilitate use of data as far as possible within a given community (Fisher & Fortmann, 2010). The size of a data commons or sharing network can vary widely, from a few dozen organizations or individuals to thousands—theoretically, to the global community. Even data shared in the commons retains a formal owner, who may choose to sets terms of use in addition to the rules that govern use in the larger community.
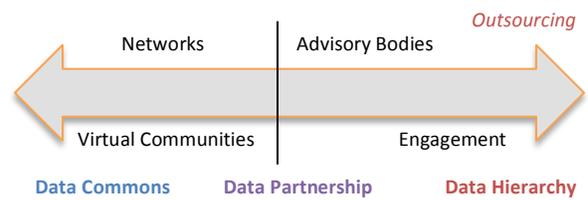

Fig 1. A Spectrum of Data Governance/Sharing Models

The three major data governance models, along with the steps between, might be placed on a spectrum, as above. At the black line and to the left of it—but at no point to the right of it—the data are jointly governed.

Indigenous Approaches to Data Governance

WHY IS A GIVEN DATA SET CREATED? What stories is it used to tell? What stories *should* it tell? Who should do the telling—and how? The broader literature on data governance has allowed us to identify a spectrum of potentially useful data governance models. Most of it, though, does not speak to goals beyond maximizing data utility.

> *"The gathering of information and its subsequent use are inherently political."*
>
> — Report of the Royal Commission on Aboriginal Peoples, 1996

Indigenous approaches to data governance remind us that data can and have been used to achieve all kinds of purposes—among them to categorize and administer entire peoples in an imposed colonial relationship.

The 1996 Report of the Royal Commission on Aboriginal Peoples (RCAP) reminds us of the inherently political aspect of gathering and using information—information that "may or

may not have been relevant to the questions, priorities and concerns of Aboriginal peoples." The Auditor General of Canada has also long questioned the reliability and relevance of much of the data and information the federal government collects from First Nation band councils (OAG 2002, 2011). The impression of limited quality, reliability, value and relevance of much of the data collected was shared by officials interviewed for this project.

Data Needs of Nation-Rebuilding

Speaking of self-government, the RCAP report affirmed that Aboriginal people would need collection and analysis capacities, skills and technologies *within their own governments* to plan and manage government functions. Likewise, the First Nation and tribal council officials interviewed stressed a need for relevant, citizen-focused data as part of their nation-rebuilding efforts.

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A second key point they identified was a need for a fundamental shift in focus. Data collection should be driven by strategic priorities of communities rather than by stove-piped federal programs. High-level standard data could be aggregated and shared with other governments at regional and national levels. The range of areas requiring relevant, high quality data is broad—spanning from health and housing to education, social development, governance and land and resource management.

Ownership, Control, Access and Possession

As indicated earlier, questions about ownership, access and control arise as soon as data is shared. Indigenous individuals and communities indeed share data with external governments—whether in the form of census and survey data, research data or administrative and program data. In the early 1990s, some indigenous organizations began to develop principles to guide their sharing. Most notable are the principles of Ownership, Control, Access and Possession, trademarked in 2012 as OCAP™ by the First Nations Information Governance Centre (FNIGC).

The OCAP™ principles have been described as a "political response to colonialism and the role of knowledge production in reproducing colonial relations" (Espey, 2002, 6). One of their major concerns is to ensure the collective ownership and privacy of data and information collected about small, easily identifiable First Nation communities and their members (FNIGC, 2011). A second motivation is to ensure that research and analysis conducted by external researchers will actually benefit communities. First Nations people have been treated as research objects in ways that have misrepresented and even physically harmed them. Community control of research processes is thought both to preclude such harm and to ensure the accuracy and relevance of any resulting products—as well as to build research capacity in First Nation communities.

The access principle of the OCAP™ framework becomes especially critical for First Nations and regional organizations seeking to access and use administrative data held by other governments. Interviews with First Nation

officials, including organizations with formal sharing agreements, indicate that access to government-held data on their members remains a chronic concern. The possession principle reflects a commitment physically to hold the data on a First Nation-controlled server. This principle supports both First Nation community-level capacity and the community's claim to jurisdiction over its data.

Developed through a First Nation health survey, the OCAP™ principles are specific to First Nations. That said, a review of indigenous approaches to data governance in the United States and Australia revealed similar issues, objectives and protocols in those countries too.

Key Practical Considerations

MOVING FROM THEORY to practice, how might indigenous data governance approaches fit with the spectrum of models discussed earlier?

Indigenous Considerations

Taken at their face, principles requiring First Nation ownership and control of research data might be seen to entail a single-organization data hierarchy—only located in a First Nation community/organization rather than in other governments. Looking more carefully, though, the OCAP™ principles themselves emerged through the Regional Health Survey, a survey whose national-level results were shared with Health Canada via a licence-to-use agreement. Further partnerships featuring co-governance of data and reflecting the OCAP™ principles also exist. Finally, it would at least be imaginable to see a data commons set up for a well-defined community agreeing to be guided by OCAP™ or similar principles.

Recalling that the data governance models outlined earlier did not speak to ultimate ends, the reverse would also appear to apply: indigenous approaches to data governance may not appear on the spectrum of models at all. Rather, they could be seen as providing a political and ethical orientation supporting indigenous self-determination and respect, which should animate any model pursued.

In this case, the overriding consideration on the indigenous side might be: does a given data governance arrangement—whether a hierarchy, partnership or data commons—satisfy the spirit and intent of the indigenous code, protocol or principle? Beyond this, does it meet the specific data needs that motivated the agreement?

Government Considerations

One commentator has observed that "OCAP for the dominant culture goes unnoticed" (Espey, 2002, 27). That the government party should own data collected about citizens—indigenous or otherwise—is often simply assumed. Further, the hierarchical structures of departments and ministries have long favoured a top-down model of governance in most areas, including those of data governance.

> Privacy and access to information laws often heavily prescribe sharing of data collected by governments.

In addition, privacy and access to information laws, as well as laws related to public health and vital statistics often heavily prescribe the limits of sharing of data collected by governments. Government officials negotiating data-sharing agreements need to be well informed of the legal backdrop of their negotiations.

Despite the very real constraints of laws and the weight of public service hierarchies and culture, key factors also promote data partnerships and sharing. Beyond the general factors noted in the section on partnerships, there is also the unique relationship between the federal Crown and indigenous governments and organizations. Program and service delivery for indigenous people depends on productive partnerships (AANDC, 2012). Added to this dependence are recognitions of self-government and the policy goal of increased autonomy for indigenous communities. These factors would call for increasing reliance on data partnerships, rather than assumed control of indigenous data by the government party. Partnerships, as such, would acknowledge the major concerns and protocols of the indigenous partners—just as they would the legal constraints of the government ones.

General Considerations

Some general points to consider in negotiating data relationships:

- What is the overarching purpose of sharing or linking the data? Are the purposes of the parties that wish to share data compatible, providing a basis for collaboration?
- What are the data needs of the respective parties? Who should own the data set and why? Who should hold it and why? Who access it, and under what conditions?
- What are the respective responsibilities of the data producer(s) and user(s)?
- What committees—governing, technical, advisory—are required to govern the data? Who should sit on these committees?
- What technical capacities are required to collect, manage, store and/or analyze the data? Where should they be located?

Promising Precedents

ORGANIZING THE DETAILS of data governance arrangements occurs in the specific data relationships. The past ten to fifteen years have seen a host of initiatives in the governance of indigenous data. These projects feature diverse and often creative uses of indigenous principles in ways that also accommodate the data needs of government partners. Appendix A describes nine sample initiatives, as well as key themes emerging from interviews with officials involved in a number of them. These officials raised trust-building, commitment, legal advice and assistance, and technical expertise in creating data linkages as key requirements for sharing data in practice. They also stressed the resulting reward: more complete data files, resulting in an improved ability on all sides to meet the needs of indigenous citizens.

Conclusion

EFFECTIVE DATA GOVERNANCE is a key component of planning, decision-making and accountability. Arguably, it is even more critical in an indigenous context—given the fraught relationship with external governments, longstanding socio-economic stresses, and task of rebuilding their governing institutions that indigenous communities now face.

Respectful, mutually useful governance models of indigenous data *are* achievable. Some have been established already. It is hoped that more such precedents will arise in this long-contested area—helping, in a concrete way, to rebuild indigenous nations and communities and also to improve indigenous/Crown relationships.

Appendix A: Promising Precedents in the Governance of Indigenous Data

The following list of initiatives draw from examples in Canada and Australia. They represent a small sampling of initiatives that acknowledge indigenous approaches while also meeting the needs of government and other parties. Much more detailed information on each initiative is available in the longer paper.

Survey and Research Data	Purpose	Governance Model	Principles & Protocols	Further Information
First Nation Regional Health Survey (Canada)	Survey seeking to provide reliable data/information on the health and wellbeing of First Nations people while acknowledging the need for First Nations to control their health information.	Governed and delivered by the FNIGC and 10 regional organizations; sharing of national-level data through licence to use agreement with Health Canada.	RHS Code of Research Ethics, featuring OCAP™ principles; respects relevant privacy legislation.	http://www.fnigc.ca/our-work/regional-health-survey/about-rhs.html
Surveys on Aboriginal Peoples (Canada)	Voluntary survey on demographic and socio-economic characteristics of Aboriginal populations in Canada. Focus in 2011 on education and employment.	Delivered in 2011 by FNIGC for First Nations, by Statistics Canada off-reserve. Steering committee of funding federal government departments, tripartite technical advisory body.	OCAP™ principles for First Nation community data; Statistics Act for Aboriginal people outside First Nation communities, as with prior surveys delivered by Statistics Canada.	http://www.aadnc-aandc.gc.ca/eng/1321384019753/1322059098232 http://www.fnigc.ca/our-work/fnreees/about-fnreees.html
Aboriginal and Torres Strait Islanders Data Archive (Australia)	Archive seeking to ensure respectful collection, storage, preservation and sharing of data relating to Aboriginal and Torres Strait Islander peoples.	Data sets stored at Australian National University. Individual depositors set access conditions to protect interests of their Indigenous research associates and/or own academic interests.	General ATSIDA protocols for the preservation, access, reuse and repatriation of research data relating to Aboriginal and Torres Strait Islander communities; any indigenous protocols specific to the community a data set concerns.	http://www.atsida.edu.au
Health Data Sharing	Purpose	Governance Model	Principles & Protocols	Further Information
First Nations Health Authority Tripartite Data Quality & Sharing Agreement (British Columbia)	Agreement aiming to improve the quality of First Nations health data, and facilitate data sharing. Agreement allowed for the creation of a First Nations Client File using an annual extraction of Indian Registry data transferred to the BC Ministry of Health.	Tripartite Data and Information Planning Committee with members from FNHA, Health Canada and BC Ministry of Health oversee implementation of agreement; FNHA is secretariat; BC Ministry of Health is custodian of data transferred from Indian registry.	First Nations Health Information Governance: structure, process and protocols as defined in the Agreement; relevant federal and provincial legislation.	http://www.fnha.ca/what-we-do/health-knowledge-and-information/data-management http://www.fnhc.ca/pdf/BC_Tripartite_Data_Quality_and_Sharing_Agreement_-_SIGNED_COPY.pdf
Tui'kn Partnership Unama'ki Client Registry (Nova Scotia)	Longitudinal population registry of five Cape Breton First Nations. The Registry allows extraction of population level health data from provincial administrative/clinical registry systems. It links band community electronic medical records, provincial	Each party controls and owns the data they contribute. 6-member Unama'ki Client Registry Data Access Committee reviews all data requests for purposes beyond the data sharing agreement. Registry data is stored off-site by a trusted third	OCAP™ principles (with modified possession principle); relevant federal and provincial legislation.	http://www.tuikn.ca

	health data, and federal Indian registry data.	party on behalf of all partners.		
First Nations of QC and Labrador Health and Social Services Commission, Common Surveillance Plan Initiative (QC)	Project to develop and implement a health surveillance plan based on plan of Quebec Ministry of Health and Social Services, but specific to Quebec First Nations. their cultural distinctiveness and realities.	Project in development. Seeking required data from federal and Quebec governments. Member First Nation health directors will be able to access their communities' results through a web surveillance portal.	OCAP™ principles. Provincial privacy and health legislation said to be a barrier to obtaining data.	http://www.cssspnql.com/en/areas-of-intervention/research-sector/surveillance-state-health
IT and Data Infrastructure	**Purpose**	**Governance Model**	**Principles & Protocols**	**Further Information**
First Nation Technology Council (BC)	Mandate to facilitate the development and use of technology to support nation rebuilding of 203 First Nations in BC.	Developed in 2002 as a committee of the First Nations Summit in BC. Now endorsed by First Nations Summit Society, Union of BC Chiefs and BC Assembly of First Nations.	Seeks to develop tools and the competencies that are First Nation owned and developed at a reasonable cost.	http://www.fnbc.info/information-management-0
The First Mile	Project provides an online meeting space where First Nations can share stories on how their communities have taken ownership and control of IT in their communities.	Developed out of a 2010 study of broadband networks in First Nation communities. Now part of a SSHRCC-funded study launched in 2013.	Applies the OCAP™ principles to IT infrastructure and technology development. Stresses local ownership and management of First Nation information and communication technologies, which are usually provided at much higher cost by external service providers.	http://www.firstmile.ca http://fn-innovation-pn.com/background.aspx

Common Themes

The following common themes arose from the interviews with staff members involved in several of the data governance and sharing initiatives featured above.

- Regardless of the model pursued, in negotiating data sharing arrangements, trust-building as well as frequent contact is crucial to working through the privacy and capacity issues that will certainly arise.

- At the operational level, both commitment and technical capacity to begin to implement data linkages is required. Such capacity is often in short supply on both government and indigenous sides.

- There was a distinction among the sharing initiatives on the question of political support: some started small and built up slowly, seeking support from senior decision-makers as they progressed; others were initiated through high-level political accords which were then progressively implemented.

- First Nation data sharing arrangements varied in their interpretation and embodiment of the OCAP™ principles. The First Nation partners appeared to support approaches that allowed for compromise with partners, as long as they were assured that the "spirit and intent" of the principles were preserved.

- Some examples feature local, regional and even national level stewardship of data by a First Nation organization. Other initiatives are tightly focused on the community level. Regardless, staff at all organizations interviewed noted their priority to ensure that communities themselves could access and have a voice in the governance of the data that concerns them specifically.

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