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## Identifying Useful Approaches to the Governance of Indigenous Data

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# Identifying Useful Approaches to the Governance of Indigenous Data

## Abstract

Questions of data governance occur in all contexts. Arguably, they become especially pressing for data concerning Indigenous people. Long-standing colonial relationships, experiences of vulnerability to decision-makers, claims of jurisdiction, and concerns about collective privacy become significant in considering how and by whom data concerning Indigenous people should be governed. Also significant is the on going need on the part of governments to access and use such data to plan, monitor, and account for programs involving Indigenous people.

This exploratory policy article seeks to inform efforts to improve the governance of data between governments and Indigenous organizations and communities – especially the federal government and First Nations in Canada. It describes a spectrum of models arising from the growing literature on data governance in the corporate and public sectors as well as overarching approaches articulated by Indigenous organizations. After outlining certain practical considerations in negotiating data sharing agreements, the article presents a selection of promising initiatives in indigenous data governance undertaken in Canada, the United States, and Australia.

## Keywords

data governance, information governance, Indigenous data, First Nation data, OCAP, data governance models

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## Identifying Useful Approaches to the Governance of Indigenous Data

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 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.

Speaking of data governance, questions of roles and responsibilities, and processes and protocols come to the fore in any context. Arguably though, these questions become more pressing for government-held data concerning Indigenous people and organizations. Long-standing colonial relationships, experiences of vulnerability to decision-makers, claims of jurisdiction, and concerns about collective privacy become significant in considering how and by whom data on Indigenous people should be governed. Also significant is the on going need on the part of governments to access and use such data to plan, monitor, and account for funds they invest in programs for Métis, First Nation, and Inuit people.

This exploratory policy research article seeks to inform efforts to improve the governance of data between governments and Indigenous organizations and communities, especially the federal government and First Nations in Canada. To this end, the article will first explore basic understandings of data governance, describing a spectrum of models arising from the emerging literature. It will then turn to governance of data involving Indigenous people specifically, considering the central concerns and resulting approaches articulated by Indigenous organizations. After outlining some practical considerations in negotiating a data governance model, it will present a handful of promising initiatives undertaken in Canada, the United States, and Australia. Throughout, it will demonstrate that effective data governance is an important tool, both in rebuilding Indigenous governing institutions and improving Indigenous–government relationships. Further, it will show that mutually useful governance models for sharing Indigenous data *are* achievable—and some have been established already.

This article draws on diverse academic and grey literature on data, information, and information technology (IT) governance as well as on Indigenous perspectives on data and information. It further draws on descriptions – usually on websites – of data governance initiatives in Canada, the United States, and Australia. For Canadian examples, where possible, the article supplements publicly available information with interviews with staff members of the organizations involved. Officials with First Nation communities and organizations interviewed in British Columbia, Ontario, and Quebec appear in Appendix A. Also listed are officials from the Government of British Columbia, Health Canada, and Aboriginal Affairs and Northern Development Canada (AANDC), who agreed to speak about initiatives in which they were involved.

Before proceeding, a few words on limitations. Where this article seeks to gain a broad strokes view of data governance, it does not delve into any particular approach or treat particular legislative and regulatory contexts involving privacy, access to information, and intellectual property. Second, the

promising precedents outlined in the final section should be seen as a sampling – selected to indicate the variety of Indigenous data governance principles to specific circumstances. The Indigenous data governance initiatives now occurring are growing in size and number. They merit more sustained investigation on their own.

### Data Governance: The Basics

“Data” is a term we use so often we often forget our associations with it. At their most basic, data are simply attributes, properties, or characteristics that describe (Mitra, 2012). Data must be distinguished from information, which seeks to render data useful and worthy of notice or concern by interpreting them. Compared to information, data involve a more immediate relationship to what is described. Notably, a subjective intention lies behind their creation and use – most importantly, behind the decision on *which* data to create and use, not to mention *which categories* those data describe. This aspect of data creation has long been emphasized by critiques – among them, Indigenous ones – of political rationalities behind government uses of census data, to take one example (Andersen, 2008; Espey, 2002).

Governance entails the activity of directing or steering (Bevir, 2009; Robichau, 2011). Key sources emphasize governance as an ongoing activity or process. It can occur in multiple spheres: within or between governments, corporations, or non-government organizations, for example. Since the early 1980s, the use of the term in the public context has usually entailed an assumption that authority is (or ought to be) dispersed among actors beyond governments. In this paradigm, governments increasingly depend on other organizations to realize their goals and intentions (Steger & Roy, 2010; Stoker, 1998).

### Data Governance

Much of the literature on data governance draws from the fields of corporate and IT governance. Wende (2007) defined data governance as “the framework for decision rights and accountabilities to encourage desirable behaviour in the use of data” (p. 419). Panian (2010) describes it more broadly, as the “processes, policies, standards, organization, and technologies required to manage and ensure the availability, accessibility, quality, consistency, auditability, and security of data in an organization” (p. 939). In the for-profit context, data governance serves profitability and survival. Its purposes here are:

- To *increase sales* and *retain customers* by developing a deeper understanding of customers;
- To *lower costs* by increasing operational efficiency in business processes and eliminating redundancy; and
- To *ensure compliance* with external regulations and internal policies by streamlining the collection of reporting data and increasing ease of audits.

Of course, these purposes are not fully translatable from the corporate to the public sphere. To the extent that they can be translated, however, one could derive the public goals of *policy and service improvement* by developing a deeper understanding of citizen needs; *cost reduction* by increasing efficiencies and eliminating redundancies; and *ensuring and easing compliance* by streamlining reporting and increasing ease of audits.

## The Agents of Data Governance

Speaking of information governance, Kooper, Maes, and Lindgreen (2011) indicated that there are three central agents: the *producer* or creator of the information, the *user* or receiver, and the “*governing actor*,” or the agent shaping and overseeing the transaction space between the producer and user. Depending on the context, the governing actor could be the board of a company or not-for-profit, or a legislator, policy-maker, or regulator. Though distinct in key ways from information governance, data governance also involves a relationship among these parties, whether they are located in a single organization or different ones.<sup>1</sup>

## Inter-Organizational Data Governance

In the case of multiple organizations, questions of control and ownership move to the fore.

Inter-organizational data governance occurs in a context where one or more agents in the data relationship represent different organizations. One common situation is outsourcing, whereby an organization engages a third party to perform a key function in its data creation or management. Another situation is data sharing. Data sharing opens up an individual organization to a range of possible relationships—from a partnership between two or more organizations, to a larger network or data commons. Importantly, data sharing gives rise to questions of ownership and control that do not arise in an outsourcing scenario. Data sharing arrangements could range from full ownership by one party to partial ownership, to an interest in the data by a preferred user party (Fisher & Fortmann, 2010).

## Components of Data Governance

Beyond the question of ownership in inter-organizational data governance, what areas must a data governance framework address? Data are said to require accessibility, availability, quality, consistency, auditability, and security. Data governance develops these attributes, enhancing the data’s overall value to the organization. Specifically, a data governance framework will:

- Set and enforce standards including definitions and classification systems, development and technical standards, and organizational data models.
- Develop and enforce policies and processes around creation, development, access and delivery, monitoring and measurement, management and auditing of data.
- Set out a data governance structure, including the roles, responsibilities and accountabilities of actors. This extends from planning by executive committees to day-to-day use by data analysts.
- Put in place a suitable technological infrastructure, or a client-focused data integration technology platform that provides built-in capabilities to access, cleanse, transform, deliver, and monitor data (Panian, 2010).

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<sup>1</sup> The authors note an important difference between information and data governance: “where data governance focuses on data assets, information governance is related to interactions” (p. 198).

## **A Spectrum of Data Governance Models**

Drawing on the broader data and information governance literature, the current section describes three basic models of how, in broad terms, a data governance framework could be organized. The intent later on will be to ask how these models might correspond with both Indigenous and government approaches to data governance and sharing.

### **Single-Organization Data Hierarchy**

The previous section addressed data governance primarily in terms of the central case described in the literature: a single organization, often a corporation, that creates and uses data to promote its strategic purposes. That organization must exist within and comply with a legal and regulatory environment largely beyond its control. But within its own sphere, its executive can create the policies, procedures, standards, and structures and acquire the technological infrastructure it sees as required to promote effective data governance in a top-down way. Data governance occurs within a self-contained unit: a single-organization data hierarchy.

In this model, effective data governance exists as a sub-set of the broader corporate governance structure. An executive data governance council or steering committee might be struck, with members representing both IT and business units of the organizations. The executive committee would set top-down data governance goals, ensuring that the data collected and analyzed support the organization's mission and objectives. The executive committee might have a technical data quality management committee reporting to it, chaired by a data steward. This technical committee would be tasked to develop the required standards, policies, processes, and IT recommendations and would directly oversee implementation of the data governance initiative.

### **Outsourcing**

Within the single-organization data hierarchy model, outsourcing allows an organization to transfer delivery of services to third parties, which perform them on its behalf. The decision to outsource might be made when the required talent, capacity, or security exist outside the organization, or the costs of having a third-party perform functions are lower, or the central organization wishes to enhance confidence in the data's integrity by having it created or stored by a third-party (Clark, Zmud, & McCray, 1995). The defining feature of the outsourcing relationship is the client's retention of full control: "while service delivery is transferred, accountability remains firmly with the remit of the client organization" (IT Governance Institute, 2005, p. 7). Or, as Panian (2010) stated, "Although they have moved to a third party, these data remain a core asset of the organization. Even though they sit outside the firewall, the organization cannot relinquish visibility into and control over that data" (p. 942).

As is clear from the above, the outsourcing of data services – even if were to include the entire data creation, management, and storing process – should not be mistaken for a data partnership. On the contrary, this relationship continues and extends the single-organization data hierarchy with the support of a third party hired for that purpose.

## Data Partnerships

The single-organization data hierarchy model possesses certain advantages. Chief among them are its straightforward accountabilities and ability to tailor data creation, management, and storage very closely to the needs of the institution. Yet the model also poses disadvantages, especially in cases where the data pertains not only to the clients, employees, and transactions of the organization, but to the world “out there.” Data are costly to generate and require technical expertise to analyse and administer. Data on broader societal or environmental trends may already exist – in many cases, collected, managed, and stored by government agencies. Access to a data set held by one organization may be necessary for another to fulfill its core functions. Of the many examples, a prominent one has emerged on the international stage: the need to share data among countries for reasons of national or global security.

If the central case for the data hierarchy model is the self-enclosed corporation, the one for data partnerships might be the public service organization. Speaking of information governance, Yang and Maxwell (2011) submit that public service organizations have shifted focus in the past fifteen years from a model emphasizing protection to one of cross-organization sharing. The authors trace this shift to events like 9/11, which laid bare the potentially catastrophic results of information-sharing failures among government agencies. In addition, policy changes since the early 1980s emphasize inter-agency coordination as a means to improve efficiency and client service while reducing waste. Finally, technological changes facilitate organizational exchange of information based on standard transmission and exchange protocols.

Arising from such factors, the second major governance model is the data partnership. In its simplest theoretical form, it involves parties with reciprocal data needs, equal means to meet them, similar capacity and legal position, and so on. Things are rarely so tidy in practice. And yet parties in a data partnership, by contrast to a self-enclosed hierarchy, interact on a horizontal plane. One party may be more powerful, but the other is not a direct subordinate to it. Neither are the parties involved in an outsourcing relationship.

What makes data governance work in a partnership scenario? As basic motivators, there needs to be a perception of mutual benefit of both producer and user and at least a minimally compatible technology. A further major factor is trust. The producing or sharing party must have confidence that the data shared is secure, confidential, and will not be misused (Yang & Maxwell, 2011). The recipient party must have assurance of the data’s quality and credibility. Trust can begin with individuals but should deepen to exist between institutional structures and cultures. A helping factor is leadership. Senior management can provide the vision, guidance, and resources required to initiate and sustain data sharing initiatives. Clarity of roles and responsibilities, respect for autonomy, and appropriate exercise of authority contribute to fruitful sharing. The required staff time and resources required to negotiate and implement sharing relationships is another motivator.

A final factor that can either inhibit or promote data partnerships in a public service context is legislation. On the one hand, a “lack of legislative support to assure the privacy and confidentiality of shared information can impede cross-boundary information sharing in the public sector” (Yang & Maxwell, 2011, p. 170). On the other, explicit support from legislatures and policy-makers is required, or sharing among organizations can “lose its priority status and lack necessary funding and resources to make

projects sustainable” (Yang & Maxwell, 2011, p. 170). Notably, the same legislative supports that can assure sharing between government agencies can also impede sharing of data or information between governments and *non-government* organizations. This has been the experience of Indigenous organizations in Canada.

As the foregoing makes clear, establishing and maintaining information-sharing partnerships—much less data-sharing partnerships—may make good sense for a host of reasons. But it is not easy. In absence of active, ongoing efforts to tend communication and to open policy and legislative channels, the default position appears to be closure. As such, it is crucially important to build up formal sharing arrangements and joint data governance structures. Progress should be expected to build slowly at first, as informal trust and communication channels take time and effort to develop. These points also emerged clearly from the reported experiences of staff of the First Nation and federal or provincial government organizations interviewed for this project.

In terms of organizational structure, data partnerships entail *co-governance* of the data asset. Jointly established executive and technical committees oversee development and implementation of the data governance framework. The partners collect, manage, and share data as determined by protocols and processes they have jointly created.

### **Advisory Bodies**

The above description outlines a full partnership, where decisions surrounding data collection, management, sharing, and other associated procedures are made in a co-governance arrangement. Short of a partnership, organizations could also develop engagement or advisory mechanisms with no decision-making power. Public organizations such as Statistics Canada, for example, seek advice not only to improve their data products and their relevance but also to educate clients, stakeholders, and the public about them.

Advice-seeking forums can take many forms. These can range from virtual engagement techniques, to information and engagement workshops, to working groups or task forces, to permanent advisory committees. More lasting forums approach the partnership model. However, the defining feature of a collaborative governance partnership is that “participants engage directly in decision-making and are not merely ‘consulted’ by public agencies” (Ansell & Gash, 2007). As such, the use of advisory bodies, while they represent a step toward a data partnership model, should not be mistaken for one.

### **Data Commons**

The third basic model appears at the opposite end of the spectrum from the single-organization data hierarchy. It is the data commons and its central case may be the research community. Within the confines of a given community, the rationale behind the commons model is to facilitate data sharing as far as possible. The data commons also cultivates a community of mutual discussion, exchange, and group-sourcing to ensure quality and usefulness. Its centerpiece may be a shared infrastructure or platform that allows members to upload data, which are then compiled, archived, and distributed. The size of a community or network can vary widely, from a few dozen organizations or individuals to thousands. In the limit, the data commons is the global public—where it is very costly, if not impossible, to control the use of a data set once released into cyberspace.

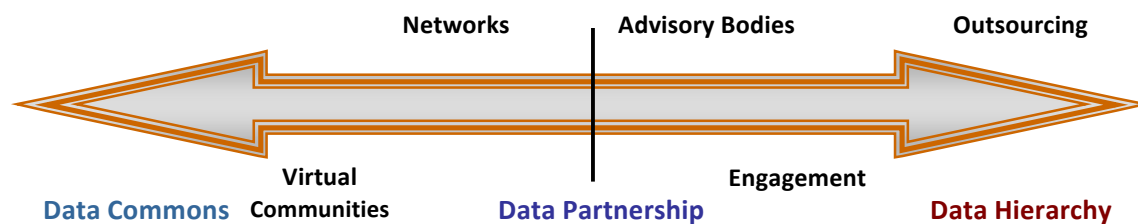


Fisher and Fortmann (2010) noted the increasingly common practice of sharing data in digitally distributed collections and virtual communities. Applying the theory of common property rights to sixteen case studies of data sharing in a commons situation, the authors found that successful sharing tended to feature clearly defined boundaries, appropriation rules, and collective choice arrangements to ensure that both producer and user benefit.

For even data sets shared in the commons retain a formal owner and do not come without their rules of use. Fair use policies might require “payment” by users in the form of acknowledgement of the source or co-authorship by the producer. Data sites might be password-protected and accessible only to registered users. Producers might have immediate use rights, or an ability to analyze and publish results from the data before sharing with the community.

### A Continuum of Data Governance Models

In concluding this review, we might place the three major models—along with the steps between them—on a spectrum. At the one end is the single hierarchical organization, governing its data with a close focus on its own institutional needs. At the other is the theoretically limitless data commons, which promotes accessibility of data in a given community, subject to limited constraints. In the middle is the data partnership, where governance by a single-organization gives way to genuine co-governance—shared decision-making—of the data asset. At the black line and left of it, but at no point to the right of it, ownership becomes an issue for negotiation.



**Figure 1: A Spectrum of Models of Data Governance and Sharing**

To this point, the article has drawn on the broader Western-based literature on data governance. It has identified some basic definitions, key actors, and required components of a data governance program. It has addressed the central purposes of a data governance regime, with its overarching goal of maximizing the value derived from the data resource. Finally, it has described a spectrum of data governance models, presenting three basic arrangements and intermediate stages.

Turning now to indigenous approaches to data governance, the article explores themes that were notably absent from the literature examined to this point. Why is a given data set created? What stories is it used to tell? What stories should it tell? Who should be doing the telling and how? Beyond the secondary goal of maximizing value, Indigenous approaches to data governance address questions of the spirit and intent that inform any specific data governance model.

## Indigenous Approaches to Data Governance

It might be fitting to begin this section with a story. In his book, *The Inconvenient Indian*, Cherokee author Thomas King (2012) described his memories of the occupation of the Washington headquarters of the Bureau of Indian Affairs in 1972. During the seven-day occupation, some members of the American Indian Movement ransacked the building and destroyed BIA files. King (2012) recalled:

At first none of us wanted to believe the reports of vandalism...

Destroying BIA files might have had some symbolic power, but the loss of those records also had the potential to hurt tribes, to set them back in their negotiations with the government, to allow Washington to drag its feet. The damage didn't make much sense...

Many years later, at a conference in Phoenix, I ran into a guy who had been in the BIA building during the occupation. I made the mistake of sharing my opinion about the destruction, and we almost wound up in a fight. "You weren't there," he told me, "so you don't get it. You didn't see the files. Our lives were in those files. The bastards had us locked up in folders". (pp. 148 - 149)

King's story reminds us of a feature of data that appears nowhere in the broader data literature, namely: data can be, and have been, used to fulfill all manner of purposes, among them to categorize and administer peoples in an imposed colonial relationship. The story further conveys, in stark terms, the ambivalent relationship many Indigenous people continue to have toward the data that federal and other governments create about them. On the one hand, such data are necessary, at very least, to provide archival evidence of prior injustices or to establish ongoing needs and priorities. On the other hand, they are artefacts of a fraught historical relationship—one that was undeniably oppressive in the past and remains marred by colonialism to this day.

### The Lingering Effects of Colonialism

Recalling the connection noted earlier of information and the data that support it to the intentions of its creators and users, we consider the oft-cited statement in the Report of the Royal Commission on Aboriginal Peoples (RCAP, 1996a):

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. (p. 4)

The data gathering refers relates to a variety of areas, among them administration of the Canada census, federal or provincial programs and services, or, for First Nations people on reserve, the federal Indian registry and other administrative requirements of the *Indian Act*. Beyond being *not* useful, the data collected to support these activities may in fact undermine the ability of Aboriginal governments to define and meet their own data needs by supplanting them with the data needs and demands of external governments.

Speaking of programs delivered on reserves, the Auditor General of Canada has long noted the questionable value and relevance of the data and information that the federal government—in particular, AANDC—collects from First Nations as a condition of their funding arrangements. Successive reports have made at least three criticisms:

- The Department collects far too much information focussed on outputs. This results in an excessive reporting burden, increased costs, and inefficiencies.
- The information collected, in the form of reports required as a condition of program funding, is of limited use either to First Nations or to government administrators and does not provide adequate information on outcomes.
- Collection requirements are dictated to First Nations rather than based on discussion with them. The information collected does not reflect community priorities and there is little feedback on its basis (Auditor General of Canada 2002, 2004, 2008).

Despite modest improvements, the Auditor General's (2011) status report remarks that the situation now remains largely unchanged. The same impression was reflected in interviews with First Nation administrators for this project.

### **The Data Needs of Nation Rebuilding**

The observations noted above should not leave the impression that Indigenous leaders and administrators do not perceive a need for high quality, relevant data. On the contrary, as the interviews conducted for this project indicate, such data are crucial to rebuilding Indigenous nations and communities. Speaking of the movement toward self-government, the RCAP report affirmed a need for Aboriginal people to collect and use quality data in order to plan and implement their governments:

For Aboriginal people, knowing how political, demographic, social and economic changes will affect their nations and having in place data collection vehicles that provide a community and nation level aggregate picture will be essential to Aboriginal government implementation and planning processes. (RCAP, 1996b, p. 349)

The RCAP further stressed that Aboriginal people need the required skills and technologies *within their own governments* to design, plan, and manage government functions and operations. For their part, the First Nation and tribal council officials interviewed for this project stressed their need for relevant, high quality, and integrated data as part of nation rebuilding in areas ranging from health to social development to governance and land management.

Within the broader purpose of self-determination and nation rebuilding, many themes that emerged from discussions with First Nation representatives bore a striking similarity to themes from the broader literature on data governance presented earlier.<sup>2</sup> Specifically, interviewees noted:

- A need to integrate disparate data sources – now dispersed in siloed programs and jurisdictions – around the individual First Nation citizen to optimize investment.
- A need to cast indicators and performance measures in terms of the strategic objectives, visions, and cultural or historical self-understandings of communities, rather than in those of government programs.
- Where possible, a need to consolidate information from multiple existing sources to introduce efficiencies, reduce reporting burdens, and improve compliance. Ideally, the data would be brought together from all levels of government and either owned or easily accessed by the First Nation partner.
- A need to provide the IT infrastructure and technical personnel required to ensure the coordination of data around nations and citizens.

A final key point that emerged from the interviews was the need to shift the focus of indicators from *eliminating problems* to *identifying desired end states*, then measuring progress toward the end goals rather than addressing gaps and deficits.

### **Ownership, Control, Access, and Possession**

It was noted earlier in this article that questions of ownership arise as soon as data is shared. As the observations of the RCAP and Auditor General make clear, First Nations and other Aboriginal organizations indeed share data with other governments. Much of these data are administrative and dispersed across programs and jurisdictions. Some are from censuses or surveys, collected and owned by Statistics Canada or other agencies or private organizations. Some of the data arise from university or independent researchers engaging in research projects.

The most explicit assertion of ownership and control of data concerning Indigenous people arose around survey and research data, although it holds deep implications for administrative data as well. That assertion involves the First Nation principles of “Ownership, Control, Access and Possession,”

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<sup>2</sup> Of particular importance to the observations presented on this page were personal communications with Gwen Phillips, Ktunaxa Nation, January 11, 2013; Nancy Gros-Louis McHugh and Richard Gray, First Nations of Quebec and Labrador Health and Social Services Commission in Quebec, January 23, 2013; and Michelle DeGroot, Miranda Kelly, and Joseph Mendez of the First Nations Health Authority in British Columbia, February 2013.

recently trademarked by the First Nations Information Governance Centre (FNIGC) as OCAP™.<sup>3</sup> An Assembly of First Nations (AFN, 2009) publication describes the principles as follows:

- **Ownership** refers to the relationship of a First Nations community to its cultural knowledge, data, and information. The principal states that a community or group owns information collectively in the same way that an individual owns his or her personal information.
- **Control** asserts that First Nation communities and representative bodies are within their rights to control research and information management processes which affect them, including all stages of research projects, research policies, resources, processes, frameworks, data management, etc.
- **Access** refers to the right of First Nations people to access information and data about themselves and their communities regardless of where these are held, and to make decisions regarding access to their collective information.
- **Possession** refers to the actual custody and holding of the data. It is distinguished from ownership for being more literal in its understanding.

First articulated in 1998, the OCAP™ principles are specific to First Nations – although their creators acknowledge possible parallel principles elsewhere. A seminal 2002 article describes them as “a political response to colonialism and the role of knowledge production in reproducing colonial relations” (Espey, 2002, p. 6).

The principles arose through the development and administration of the First Nations Regional Health Survey (RHS), a national health survey conducted on and by First Nations people on reserves. The FNIGC, whose core staff members have overseen administration of the RHS over the past sixteen years, describes the motivation behind their emergence as follows:

In the 1990s, First Nations were increasingly dissatisfied with Canadian privacy and access to information laws that did not meet their needs and aspirations. First Nations believed they had been “researched to death” with little or nothing to do with the information that was collected from them and taken out of their communities. The First Nations principles of OCAP (Ownership, Control, Access and Possession) were initially coined as “OCA” in 1998 as a framework for asserting self-governance over information related to research... The “P” for

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<sup>3</sup> At a workshop delivered in January 2013 to AANDC staff, staff of the First Nation Information Governance Centre indicated that the trademark was acquired to protect the acronym OCAP (Ownership, Control, Access and Possession) from improper and unauthorized use. The presenters indicated that the acronym should be referenced in documents as OCAP™. This will be the approach taken here. However, at least one First Nation official interviewed questioned the decision to trademark the principles – with the justification that it is individual First Nation communities, not a national First Nation organization, that own the principles and determine their meaning in practice.

possession was later added as a mechanism to support the previous three principles. (First Nations Regional Health Survey, 2011, p. 14)

A major concern animating OCAP™ has been to ensure the collective ownership and privacy of information about First Nation communities. Existing federal and provincial laws protect individual privacy but do not acknowledge, let alone protect, communal or collective privacy. As communities that are comparatively small and easily identifiable, First Nations can be and have been stigmatized by publications based on information about them. The OCAP™ principles seek to address by asserting ownership, by the First Nation community, of data concerning its members.

A second motivation relates to ensuring that research conducted by external researchers benefits communities. Historically, First Nations people have been treated as objects in ways that have disempowered, misrepresented, and even brought physical harm to them. As a means to reverse such practices, the principles seek to ensure community control of the research processes. They provide a framework requiring researchers to gain permission from the community's political leadership before commencing work, and to work in close partnership with members at all stages, including sharing and publishing results. Control of the process is thought ultimately to improve the accuracy and relevance of the final products and also to build research capacity where it is required, within First Nations themselves.

The access principle of the broader OCAP™ framework becomes critical for First Nations and regional organizations seeking to access and use the administrative data and records held by other governments. Interviews with First Nation officials, including those in organizations with formal data sharing agreements with other governments, indicated that access to government data on their citizens remains a chronic concern. Noted with particular frequency was difficulty in accessing data from the Indian Registry, as well as provincial and federal government health data, due to privacy and health data-specific laws and policies. A further concern cited concerns cases where information held by another government is shared with external parties without consent or knowledge of the First Nation partner.

The possession principle reflects a commitment physically to hold the data assets on a First Nation-controlled server. Some First Nation officials interviewed emphasized the need to hold and use data *at the community level*. One reason cited was economic. Adherence to OCAP™ principles at the community level provides First Nation members with opportunities for skilled jobs and professional development, rare in many remote communities. A second reason is nation rebuilding. Data owned, held, and accessed by communities are more readily available for use in strategic planning, monitoring, and reporting to the membership at that level. Third, where First Nation communities are the rights-holders, including of the inherent right of self-government, they are the primary rightful owners of their data. An interviewee from a Northern Ontario tribal council serving nine remote communities stressed this point on the example of education data. Schools in each community hold and interpret key program data themselves, with remote backup. In this case, the issue is to ensure that capacity to manage and analyze the data exists, and remains, at the community level. In a related community-centred vein, an Assembly of First Nations (AFN, 2007) publication stated: "Quite simply it is the First Nation community whose data or information is at stake that decides what these principles really mean" (p. 5).

Of central importance to understanding the OCAP™ principles is that they arose as part of a broader assertion of jurisdiction by First Nations to govern their own affairs. Self-governance of data both supports and reflects the purpose of self-determination more broadly. Consistent with this intent is the expanding application of the principles from research-related information to program and administrative data and even to IT infrastructure.

## Other Jurisdictions

This review of Indigenous approaches to Indigenous data governance focused mainly on First Nations in Canada, but also examined some approaches in the United States and Australia. It revealed similar issues and related objectives among Indigenous peoples in the other two jurisdictions as well.

In the United States, for example, the Indigenous First Archivists Circle (FAC, 2007), *Protocols for Native American Archival Materials*, recognized the “sovereign governments and associated rights of Native American communities” (p. 4). Similar to the OCAP™ principles, the protocols challenge the ideal of unfettered access to archival resources:

Archivists and librarians taught to champion intellectual freedom and unfettered access to resources may be troubled by the notion that in Native American and other Indigenous communities knowledge can be collectively owned and that access to some knowledge may be restricted as a privilege rather than a right. These views of information are not irreconcilable, given that archives and libraries often contain restricted materials, classified materials, secret materials, or materials that may not be accessed until some future date. (FAC, 2007, p. 3)

Also in the United States, Fisher and Ball (2003) described a “tribal participatory research model” that facilitates active involvement of American Indian and Alaska Native communities in health research. Collaborations between researchers and tribal governments engage community participants in all aspects of the research, from conceptualizing the issues to be investigated to developing a research design, and from collecting, analyzing, and interpreting the data to disseminating the results. A recent project initiated by the Crow and Montana State University used the same method to gain water quality data to address health issues in the community. Crow tribal members describe their research in a way that resonates strongly with First Nation experience in Canada:

Crow tribal members, like members of other Tribes, are sensitive about participating in research as we have been researched repeatedly with little or no benefit to the Tribe. This experience was different because Tribal members initiated the work, the data are useful to us and we are solving the problems we have identified. The fact that the impetus for this research originated with the community continues to be the single most important factor in the overall success of our Crow Water Project (Cummins et. al, 2010, p. 167).

In Australia, the Australian Library and Information Association (2012) published the *Aboriginal and Torres Strait Islander Protocols for Libraries, Archives, and Information Services*. First developed in 1995, the protocols were endorsed by the Aboriginal and Torres Strait Islander Library, Information and Resource Network. Recently updated, the protocols have been called “ground-breaking” by Native Indian archivists in the United States. Also asserting Indigenous ownership of their archival information, the protocols uphold restricted access to knowledge of a secret or sacred nature.

## **Practical Considerations**

The Indigenous approaches to data governance described in the last section are highly consistent. They all cite concerns about collective privacy concerning community information, as well as about misuse and potential harm caused by data created in a context of ongoing power imbalances. As an antidote, the approaches propose a governance framework ensuring that any data created and the resulting analysis benefit Indigenous communities. The OCAP™ principles entail an additional claim of political jurisdiction of First Nation governments over data and information concerning their citizens.

At this point, it is useful to ask: How might Indigenous approaches fit with the continuum of data governance models outlined in earlier sections? Which data governance models fit within the overarching framework provided by OCAP™ and related principles?

## **Indigenous and First Nation Considerations**

Taken at their face, First Nation ownership and control of data might be seen to entail a single organization data hierarchy, only located in a First Nation organization rather than in other governments. Given the assertion of political jurisdiction, this initial perception would be understandable. And, yet, the OCAP™ principles themselves emerged through a survey whose national-level results the FNIGC intended to—and did in fact—share with Health Canada via a licence-to-use agreement. Data partnerships reflecting the OCAP™ principles also exist, as will be seen in the next section. Finally, it is at least imaginable to have a data commons with a well-defined virtual community agreeing to be guided by OCAP™ principles and protocols developed within them. The adoption of a commons model would depend on how widely the Indigenous party would like to see data concerning its members accessed and used.

Recalling that the data governance models outlined earlier did not speak to ultimate ends, the reverse would also apply: Indigenous approaches to data governance likely do not appear on the spectrum of models at all. Rather, they provide a political and ethical orientation upholding Indigenous self-determination and respect, which should animate any model pursued. In this case, the overriding consideration on the Indigenous side might ask the following: Does a given data governance arrangement—whether a data hierarchy, partnership or 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**

But what of the government party in the data relationship? Before turning to promising precedents, we briefly consider priorities, issues, and challenges on the government side.

One commentator observed that federal and provincial communities already have OCAP™ – although “OCAP for the dominant culture goes unnoticed” (Espey, 2002, p. 27). The Government of Canada owns all data produced by Statistics Canada and that agency controls the data creation and analysis process. Apart from this, the Crown (whether federal or provincial) has historically owned, controlled, and possessed all data assets of their individual departments and ministries as a matter of course.



Through laws and policies governing privacy, confidentiality, and access, both federal and provincial governments control access to the information and data they hold.

Within this broader framework, assuming government ownership on behalf of Canadians or provincial residents, government departments and ministries are no strangers to the data hierarchy model. Indeed, even internally, they often find it difficult to overcome barriers to data partnerships. Factors that inhibit a more collaborative approach to data governance include:

- A long-standing view of *ministerial accountability* as vertical control in a given government department or agency, existing to serve and protect the interests of the (publicly accountable) political leadership. This understanding of accountability works against horizontal sharing arrangements.
- A resulting *administrative culture* that has evolved to favour risk aversion and top-down coordination of initiatives, rather than horizontal coordination in a partnership relationship.
- A limited scope of *fiscal instruments* through which to promote partnerships. Both procurement contracts and annual contribution agreements emphasize cost containment as well as a high degree of control, rather than partnership, as a function of public accountability (Allen, Juillet, Paquet, & Roy, 2001).

The pronounced hierarchical structures of government departments and ministries have historically favoured a top-down control model in *most* decision areas, including in data governance. To the three factors noted above could be added privacy legislation, which allows sharing of data containing personal information on a “need-to-know” basis within and across governments, but inhibits the ability to share with organizations considered non-governmental, such as First Nations and their regional organizations.

And yet equally weighty factors promote co-governance arrangements. In some ways, these factors may be ascendant. Ansell and Gash (2007) remind us that collaborative governance, involving shared decision-making between governments and external parties, came about as a response to the failures in implementation of top-down initiatives and as a positive response to the growing knowledge and institutional capacity outside government. Allen et al. (2001) observed, “nearly everything about the connected (or digital) state requires horizontal governance” (p. 94). They argue that governments have been forced to adapt to horizontal models or risk becoming both irrelevant and inefficient. Added to this is a heightened need for relevant, high quality data as part of a concerted push toward evidence-based policy-making and results-based management of programs. In this sense, the question that has evolved in the past fifteen years is not whether, but *how* public organizations—which were not designed for horizontal governance—can nonetheless achieve it.

### **Data Relationships with Aboriginal Governments and Organizations**

Certain features of the relationship between the federal government and Aboriginal governments and organizations add further impetus to the argument for data partnerships.

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 with communities (AANDC, 2012). In a practical sense, therefore, responsibility for the outcomes of programs and services delivered is shared. Both Aboriginal organizations and the federal government require relevant data to demonstrate their progress in improving outcomes. Added to this are recognitions of self-government and the policy goal of increased autonomy for Indigenous communities.

Taking the program reality and the policy impetus together, the Government of Canada would appear to be aiming at a partnership with First Nations and Aboriginal organizations, with a momentum favouring increased autonomy on the Aboriginal side. It would be strange indeed if the federal government were to continue pursuing a self-enclosed data hierarchy model in the governance of data on Aboriginal people; such a model supports neither its program delivery structure nor its long-term policy goals. But a partnership, to be a partnership, would need to acknowledge the major concerns and protocols of the Indigenous partners—just as it would the legal constraints of the government ones.

## **Summary**

The literature on data and information governance consulted in the first half of this article suggested that there is no one correct model of data governance. Whatever approach is adopted, the data created and used should support the strategic goals pursued. This principle could apply to a single organization or to a group of organizations seeking to realize shared goals. The Indigenous approaches reviewed underscore the overarching political and ethical intentions of the actors, along with the processes that realize and reinforce them. Government considerations revealed an ongoing struggle of factors. Strong historical, institutional, and legal factors still favour a single-organization data hierarchy. However, this model has faced repeated challenges in past decades. Specific to data governance involving Aboriginal people, both the program delivery model and policy goals of the federal government suggest the suitability of a partnership model over a hierarchic one.

What data approaches would facilitate creation, use, and analysis of data in a way that supports Indigenous governance of Indigenous information, yet provides partners with the data access and privacy assurances they require? Such questions can be answered only in the concrete. To that end, the next section provides examples of recent data governance initiatives involving governments and indigenous communities that have answered such questions—provisionally, at least—with the sense of benefiting both parties.

## **Promising Precedents**

Within the past 10 to 15 years, a host of initiatives in indigenous data governance have arisen. They feature diverse, often creative, uses of Indigenous approaches in ways that also accommodate the needs government partners. Drawing from the Canadian, American, and Australian contexts, the projects profiled below integrate increased attention to Indigenous approaches in relationships between governments and Indigenous groups. They also indicate some of the challenges that remain.

The projects profiled are a mere sampling of the wide variety of new data governance initiatives that now exist. They were selected for featuring either strategic use of data to promote the autonomy, capacity, and governance of indigenous communities, or for evincing a shift from hierarchic data governance by governments to a more collaborative partnership model. Where possible, the author interviewed staff

members in the initiatives undertaken in Canada and received commentary on draft profiles. It should be noted that, with some exceptions, formal evaluations had not yet been conducted for the initiatives profiled. As such, it is not yet clear whether the results the parties anticipate will be achieved in practice.

The initiatives profiled below feature three survey and research data relationships, four health data sharing initiatives, and two IT and data infrastructure initiatives.

## **Survey and Research Data Use Arrangements**

### **1. First Nations Regional Health Survey (Canada)**

The longest-standing example of a new orientation toward Aboriginal data is the First Nations Regional Health Survey (RHS), developed in the mid-1990s. Funded by Health Canada. The RHS was designed, implemented, and disseminated by participating First Nations in 1997, 2002 to 2003, and 2008 to 2010. Its delivery agent, the First Nations Information Governance Centre (FNIGC), has a licence-to-use agreement with Health Canada to guide its access and use of the national level RHS data. Ownership, control, access, and possession of the RHS data remain with the First Nations. The initiative, in other words, is “OCAP™ compliant.”

The current organization of the RHS reflects ongoing capacity building led by First Nation organizations at national, regional, and community levels. Formerly a committee of the Assembly of First Nations, the national-level FNIGC was federally incorporated in April 2010. Ten regional partners provide oversight, implement the survey, and hold the data collected in their regions. Local community members, who are recruited and trained by regional coordinators, carry out fieldwork. Local political leaders must also be on board: no recruitment of fieldworkers or survey participants can occur without the consent of the community leadership via a band council resolution. The regional data centres report to regional political leadership.

The RHS data is now housed at the FNIGC and regional data centres. The organization has developed a number of protocols, codes, and guides to protect the quality, integrity, and community accessibility of the data. The RHS has undergone reviews assessing the quality of its design, collection, and dissemination and has gained consistently high marks from external reviewers. Perhaps most notable is a review of the Phase I 2002 to 2003 survey by the Harvard Project on American Indian Economic Development, which concluded:

Compared to other national surveys of Indigenous people from around the world, the 2002/2003 RHS was unique in First Nations ownership of the research process, its explicit incorporation of First Nations values into the research design and in the intensive collaborative engagement of First Nations people and their representatives at each stage of the research process. All of this was accomplished under considerable resource constraints. (Harvard Project on American Indian Economic Development, 2006, p. iv)

According to staff members at the FNIGC, a strong partnership with Health Canada has emerged over the survey cycles. In the experience of the Health Canada project manager interviewed, the licence-to-use agreement has been effective in accommodating requests for a range of health information needs, including official requests for statistics to more programmatic analyses designed to target improved

health promotion activities (FNIGC, 2011; Rene Dion, Health Canada, personal communication, February 7, 2013).

For the Phase III data, Health Canada will work with the FNIGC to explore the possibility of establishing regional-level agreements to access results to inform region-specific program management and decision-making.

## **2. The Survey on Aboriginal Peoples (Canada)**

As the fourth generation of a survey conducted since 1991, the Aboriginal Peoples Survey (APS) was developed to collect information that is not covered in the Canada Census (Statistics Canada, 2012). Its evolution reflects movement toward more targeted, useful, and complete information for policy-makers on the one hand and greater respect for the principles underlying First Nation governance of information on the other.

The first three generations of the Aboriginal Peoples Survey were developed and implemented by Statistics Canada, informed by an advisory committee comprised of the national Aboriginal organizations. In 2006, the Assembly of First Nations withdrew its support from the survey, citing concerns about the collection and ownership of the data. The survey was not delivered on First Nation communities that year, resulting in a loss of valuable data on the on reserve population.

In the lead-up to the fourth generation survey, the funding departments (AANDC, Employment and Social Development Canada, and Health Canada) established a more limited, thematic focus on priority areas of employment and education. At the same time, the funders deepened their relationship with the FNIGC, an organization with a now long-established relationship with Health Canada and proven capacity to deliver a major national survey. The result has been two delivery partners for the Surveys on Aboriginal Peoples, two related but distinct surveys that focus on education and employment. In 2011, Statistics Canada delivered the fourth generation Aboriginal Peoples Survey off reserve while the FNIGC is preparing to deliver the First Nations Regional Early Childhood, Education and Employment Survey (FNREEES) in First Nation communities.

The surveys' governance structure features a steering committee of funding partners, a tripartite technical advisory committee, and a secretariat provided by AANDC. Two key features of the data relationship reflect the First Nation governance of First Nation information. First, within certain broad parameters established by the funding parties, the FNIGC, together with participating regions and communities, has determined the content of the FNREEES survey. Second, AANDC will never own this survey data. Informed by the prior work of Health Canada, the department is now seeking to negotiate national and regional data access and use agreements for both RHS and FNREEES data tables.

## **3. Aboriginal and Torres Strait Islander Data Archive (Australia)**

Created in 2008, the Aboriginal and Torres Strait Islander Data Archive (ATSIDA) is a research data management facility designed to ensure storage and preservation of data relating to Aboriginal and Torres Strait Islander peoples. ATSIDA seeks to collect scattered research data on Aboriginal people, to manage it according to appropriate protocols, and to make it available for secondary analysis. A node of the Australian Data Archive, the datasets are stored at the Australian National University and managed

by the University of Technology of Sydney library according to protocols created with the Jumbunna Indigenous House of Learning (ATSIDA, 2014a).

Of the initiatives examined here, this one comes closest to a data commons. The archive obtains datasets through direct deposits by individuals and organizations. Depositors set access conditions to protect the interests of their Indigenous research associates and their own academic interests. Restrictions imposed by a depositor might be due to the pending publication of research papers based on the dataset or may be imposed in accordance with Indigenous cultural protocols specified by the community the dataset concerns. Requests for access to a restricted dataset can be submitted for the depositor's consideration. Unrestricted datasets permit use without specific authorisation.

Along with principles of respect, trust and engagement, the protocols state an explicit intention to stimulate research: "ATSIDA encourages and promotes use of its data archive to stimulate new research ventures and insights that benefit Aboriginal and Torres Strait Islander communities" (ATSIDA, 2014b, Engagement, para. 3). According to its website, ATSIDA (2014c) works closely with Aboriginal and Torres Strait Islander communities to repatriate their materials "through a recognized cultural centre or community organisation (such as a language or knowledge centre) that has a computer terminal available for approved users. Responsibility to monitor access to the materials by individuals will devolve to the community organisation" (para. 6). ATSIDA also works with university researchers to provide information relating to their research, with higher education institutions to identify datasets and research projects of national interest, and with governments to influence policy concerning Indigenous data, research, intellectual property, and moral rights.

The author was unable to find material presenting Aboriginal or Torres Strait Islanders perspectives on the ATSIDA archive. Further research examining whether this model meets requirements on the Indigenous side would have to seek out and incorporate those perspectives.

### **Indigenous Health Data Governance Initiatives**

#### **4. First Nations Health Authority, Tripartite Data Quality and Sharing Agreement: British Columbia (BC, Canada)**

The First Nations Health Society was created in 2009, evolving into the First Nations Health Authority (FNHA). Together with the First Nations Health Council, the FNHA evolved out of a series of agreements with provincial and federal governments preparing for the assumption by a First Nations organization of federal health programming for First Nations in BC. The province-wide organization gained its mandate from 203 chiefs in British Columbia, making the FNHA the first organization of its kind in Canada.

Among other things, the FNHA is mandated to collect and maintain clinical information and patient records and develop protocols with the BC Ministry of Health and the BC Health Authorities for sharing patient information; to plan, design, manage, deliver, and fund the delivery of First Nations health programs; and to enhance collaboration among First Nations health providers to address service delivery issues and improve efficiencies and access to health care (Canada, British Columbia, First Nations Health Society, 2011). In October 1, 2013, all programs and associated data for Health

Canada's First Nations and Inuit Health Branch (FNIHB) British Columbia region were transferred to the FNHA, which now interacts directly with FNIHB headquarters in Ottawa.

On April 16, 2010, the First Nations Health Society (2010) signed the First Nations in BC Tripartite Data Quality and Sharing Agreement (TDQSA) with the Government of British Columbia and the federal government. A central purpose of this agreement is to improve the quality of First Nations health data, to facilitate data sharing, and to ensure that these data are "appropriately compiled, used and shared by the Parties in accordance with the principles set out by this Agreement and in relevant legislation" (First Nations Health Society, 2010, Section 3.1). The agreement allowed for the creation of a First Nations Client File using an annual extraction of Indian Registry data held by AANDC and transferred to the BC Ministry of Health, which would act as the data custodian. Terms of the data transfer and custodianship are set out in a memorandum of understanding between the BC Ministry of Health and AANDC.

Both the Tripartite Data Sharing Agreement webpage (First Nations Health Council, n.d.) and interviews with staff members at the FNHA and Health Canada indicated that *access* to First Nation client data remains of paramount concern on the part of First Nations, along with the understanding and support of both governments to build the capacity of First Nations to implement the principles of OCAP™ (Michelle DeGroot, Joseph Mendez, Miranda Kelly, personal communications, February 18 & 19, 2013; Shannon Waters, Health Canada (BC Region), personal communication, February 4, 2013). A second motivation has been to enhance governance in the health area in First Nations: "Because research drives policy development, First Nations need to be armed with accurate information to effectively plan and implement programs and services at a community level" (First Nations Health Council, n.d., para. 4).

The Tripartite Data and Information Planning Committee, which is tasked to improve the quality and sharing of First Nations health data, facilitate data sharing (including data linkages), and ensure proper use of First Nations data held by federal and provincial partners, oversees the implementation of the TDQSA. Staff members at the FNHA provide secretariat support to this committee, whose three voting members represent FNHA, Health Canada, and the BC Ministry of Health. The committee works mainly by consensus.

In the views of the First Nations Health Authority personnel interviewed, relationships with their government counterparts are strong and improving, although some issues still arise. The issues are due in part to frequent staff turnover in partner organizations, as well as to the limits on the number of individuals with the access and expertise required to perform data linkages. Awareness building of the First Nations priorities and concerns require ongoing orientation efforts with provincial partners. One staff member interviewed stressed the importance of the high level political agreements to ensure that momentum is maintained when progress begins to stall on technical issues. Others emphasized a need for fairly frequent, in-person meetings to build trust and communication and ensure that the partners hold each other to account.

Specific to the OCAP™ principles, FNHA staff members stressed a need to engage in a sustained discussion at the community level: what OCAP™ means; what province-wide standards should be in place; what data should be owned, held, or controlled by communities or by their mandated health

organization, the FNHA; and what data should remain with its partner institutions (regarding the First Nations Client File, for example: the FNHA does not yet have the capacity to house the file). In addressing such questions, the organization wishes to honour the spirit and intent of OCAP™ in their own context. That context requires them to work in close coordination with provincial authorities, consider their own capacity and strategic priorities, and bring community voices to the fore in governing First Nations health data and information.

Due to concerns of their federal government partners, the TDQSA does not reference the OCAP™ principles. However, it does include the following definition of First Nations health information governance:

“First Nations Health Information Governance” is a component of First Nations Health Governance and refers to a structure, process and protocols by which First Nations in B.C. have access to First Nations Data and are influentially involved in decision-making regarding the culturally appropriate and respectful collection, use, disclosure and stewardship of that information in recognition of the principle that such information is integral to First Nations policy, funding and health outcomes. (First Nations in BC Tripartite Data Quality and Sharing Agreement, 2010, p. 3)

In the view of the officials interviewed, this definition protects the spirit and intent of the principles in health information governance discussions with their partners.

## 5. Tui'kn Partnership (Nova Scotia, Canada)

The Tui'kn Partnership includes the Eskasoni, Membertou, Potlotek, Wagmatcook, and Waycobah First Nations of Cape Breton, Nova Scotia. The Partnership emerged from a Primary Health Care Transition Fund project called the Tui'kn Initiative (2004 - 2006), which had the goal of creating a platform for joint planning and collaboration on issues of mutual interest and concern to the five First Nation communities on Cape Breton Island. Working together and in partnership with the district health authorities, the Nova Scotia Department of Health, First Nations and Inuit Health of Health Canada, and Dalhousie University, Tui'kn leveraged the size, talent, scope, and resources to better shape the philosophy, planning, funding, and delivery of primary health care services.

Since that initial project, the communities have collaborated on more than 30 initiatives since 2006. These all build on Tui'kn's shared vision of achieving *health status and outcomes that are equal to, or better than, the overall Canadian population* (Tui'kn Partnership, 2012). The bands take turns hosting and administering health projects on behalf of the Partnership.

To support their health monitoring, planning, and evaluation needs, Tui'kn has partnered with the Nova Scotia Department of Health and Wellness (NSDHW), Health Canada, and academic partners to develop an Unama'ki Client Registry. Completed in 2010, the Unama'ki Client Registry is a unique longitudinal population registry of five Cape Breton First Nations. It allows extraction of population-level data from provincial administrative and clinical registry systems for use by the bands in their own health planning and in their planning efforts with other health organizations.

According to the project manager interviewed for this report, it was a lengthy process to complete the privacy impact assessment on the registry and to negotiate a data sharing agreement between the five Bands and the Nova Scotia Department of Health (Stacey Lewis, Tui'kn Partnership, personal communication, March 1, 2013). Not only the newness of the process, but the number of parties and complexity of the data required prolonged the negotiations.

On the questions of control and possession, the project manager indicated that each party controls the data that is contributed to the registry. Although the registry data is stored off-site by a trusted third party on behalf of all partners, OCAP™ principles are reflected in the policies, procedures, and access structures governing the registry data.

Access to the Client Registry for purposes beyond those outlined in the data-sharing agreement must go to the Unama'ki Client Registry Data Access Committee. The Committee's six members include the First Nation health directors and one member from the Nova Scotia Department of Health and Wellness. The Committee reviews all requests in a process that is said to be respectful of both OCAP™ principles surrounding First Nations data and the Department of Health's legal and policy requirements surrounding the Nova Scotia Health Card Registry.

The registry is now used by Cancer Care Nova Scotia, Reproductive Care Program of Nova Scotia, and Cardiovascular Health Nova Scotia to produce reports on indicators that were identified as important by the communities. Each First Nation receives a report from each provincial program, and the Partnership as a whole receives a regional report with data aggregated across the five communities. The reports belong to the First Nations and are not to be used for other purposes without their permission. The First Nations have also received chronic disease and health care utilization reports developed on contract by the Population Health Research Unit at Dalhousie University.

With information extending from 2000 to 2010, the First Nation partners have just produced a series of health bulletins developed to communicate some of the key findings from the health indicator reports to a broad audience including health care providers on and off reserve, chiefs and councils, community members, planners, and policy-makers. Communities are using information from the health indicator reports to establish their future priorities and to inform community health plans. The provincial parties, for their part, have also learned more about the health status of First Nations people and developed relationships with their First Nation community counterparts.

According to the project manager interviewed, the Tui'kn Partnership's efforts have advanced to date through the persistence of its partners and their shared intention to remove roadblocks as they arise. One inhibitor to achieving a level playing field in negotiating data sharing agreements and pursuing data linkages is the lack of access to legal, privacy, and technical expertise on the First Nation side. By contrast, government partners are able to draw on significant in-house legal, technical, and privacy expertise.

## **6. Common Surveillance Plan Initiative: First Nations of Quebec and Labrador Health and Social Services Commission (FNQLHSSC, Quebec, Canada)**

Due to the relatively small size, dispersion, and health characteristics of First Nation communities, the surveillance of First Nations health and health determinants is a major challenge. The role of the



FNQLHSSC is to “assist Quebec First Nations and Inuit communities and organizations in defending, maintaining and exercising their inherent rights in ... health and social services, support them in developing and implementing these programs, and help them gain greater control over the data and information pertaining to First Nations people and services” (First Nations of Quebec and Labrador Health and Social Services Commission [FNQLHSSC], 2009, p. 7). To this end, the FNQLHSSC began in 2009 to develop and implement a health surveillance plan specific to Quebec First Nations.

The health surveillance framework is based in part on the common plan developed by the ministère de la Santé et des Services sociaux du Québec (MSSS). Although it lacks the specific indicators to develop it, the plan also draws on the health measurement framework of the EAGLE (Effects on Aboriginals from the Great Lakes Environment) project, which identified health indicators specific to First Nation communities and focused on holistic quality of life measures rather than health determinants. The inventory developed by the FNQLHSSC focuses on selected indicators that can be compared with other jurisdictions, but are also consistent with the cultural and historical background as well as data and reporting needs of Quebec First Nations. It combines indicators where possible, using such sources as the Canada Census, First Nations identifier, health surveys, vital statistics registries, health services utilization data, specific surveillance systems, and other information systems. Most of the data required to make the surveillance plan operational is stored in statutory databases owned by the Government of Quebec.

The initiative was designed, among other things, to assist individual First Nations in developing their community health plans. Member First Nation health directors will be able to access their communities' results through a web surveillance portal. Yet, the project also has a number of additional potential users. Health Canada, as a partner, will have access to regional-level results of the surveillance. Other organizations interested in improving Quebec First Nations health might consult the project to obtain information on health trends. All external users will be subject to application of the OCAP™ principles.

In this, as in other data-related initiatives, staff members at the FNQLHSSC cited challenges similar to those experienced by the other First Nation regional organizations canvassed here (Nancy Gros-Louis McHugh and Richard Gray, FNQLHSSC, personal communication, January 24, 2013). A specific difficulty was accessing provincially held health data due to stated conflicts with provincial privacy, health, and access to information legislation. Because the FNQLHSSC is not a public agency under the Quebec health system, it is not permitted to access the provincial health database. A further difficulty has been a lack of stable funding for the surveillance project to date, as well as absence of shared vision in speaking with federal partners. Staff members remain hopeful for a shift in mindset that will allow their counterparts see First Nation band councils as more than administrators of federal programs. For its part, the Quebec First Nations leadership is said to be aware of their need for more complete health data for their planning; many have put into place the required protocols and privacy protections for information at the community and nation levels.

## **7. Northwest Portland Area Indian Health Board (and EPI-Center) (USA)**

In 1972, a group of tribal leaders from Idaho, Oregon, and Washington came together to discuss their nations' health issues and to determine how they might work together to address them. The leaders noted that it was often an enormous challenge to obtain health data at tribal level and that tribe-specific

data was frequently incomplete, inaccurate, and insufficient. The lack of accurate data hindered tribes' ability to manage health services and implement appropriate public health measures. They created the Northwest Portland Area Indian Health Board (NPAIHB), an intertribal organization serving 43 federally recognized tribes in the tri-state region with each member tribe appointing a delegate (Harvard Project on American Indian Economic Development, 2004).

The NPAIHB addresses the need to generate tribe-specific data and provide accurate data on health services and facilitate knowledge sharing between tribes. It provides expertise in health-related services but also facilitates advocacy, health promotion and disease prevention, data collection and management, and empowers its tribes to create and manage effective health care systems specific to individual community needs. The website indicates that the organization is now involved in at least two record linkage projects: the Northwest Tribal Registry Project, designed to increase the quality of disease surveillance health data on American Indians and Alaskan Natives; and the Improving Data & Enhancing Access – Northwest (IDEA-NW) Project (Northwest Portland Area Indian Health Board, 2013).

The organization is recognized throughout the United States and was granted a Harvard Project on American Indian Economic Development Honoring Nations Award in 2003 for having played a crucial role in improving the health status of its member tribes. One of NPAIHB's main successes was the development of the Northwest Tribal Epidemiology Center (EPI-Center) in 1997 to facilitate health-related research, surveillance, and training to improve the quality of life of American Indians and Alaskan Natives. As the first and largest tribal epidemiology center in the United States, the NPAIHB Epi-Center trains member tribes in data collection, relevant statistical analysis software, and data management. It regularly implements innovative programs to enable tribes to work increasingly independently and to customize their own programs. In turn, NPAIHB relies on the center's work with tribes in the design and implementation of effective health promotion and disease prevention programs.

### **First Nation IT and Data Infrastructure Initiatives**

The following two examples address the IT infrastructure component of any effective data governance program. They apply, in an innovative way, First Nation approaches to information and data governance to IT infrastructure.

#### **8. The First Nation Technology Council (BC, Canada)**

The First Nation Technology Council (FNTC) serves 203 First Nation communities in British Columbia. Developed in 2002 as a committee of the First Nations Summit, the FNTC aims to partner in every region of the province to continue its mandate of providing technical capacity development, high-speed connectivity, information management systems and practices, and technical services and support. Its goal is to facilitate the development and use of technology in the broadest sense to support nation rebuilding of First Nations in BC. Where most First Nations in BC are very small, the FNTC seeks to develop tools and competencies that are First Nation owned and developed and come at a reasonable cost (FNTC, 2013a).

In conjunction with the FNTC, the Sto:lo Nation developed UNIFICATION, a citizen-focused IT system to assist in managing First Nations' social information concerning education, housing, and

employment statistics, among other areas. The application was also designed to make reporting and planning activities required by AANDC more efficient and less time consuming. Thus far in BC, several communities are implementing UNIFICATION for information management, data integration, and community planning. Through this initiative, First Nations can integrate their data in a way that focuses on individual citizens and at the same time ensure more accurate and reliable reporting (FNTC, 2013b; Sue Hanley, former coordinator of the First Nations Technology Council, personal communication, January 23, 2013; Gwen Phillips, Ktunaxa Nation, personal communication, January 11, 2013).

## 9. The First Mile Project (Canada)

The First Mile project applies the OCAP™ principles to IT infrastructure and technology development through telling stories of First Nation self-determination in technology development (First Mile, 2013). It builds on a 2010 study of broadband networks in First Nation communities. That study stressed the importance of local ownership and management of First Nation information and communication technologies, which are usually provided at higher cost by external service providers. Consistent with an OCAP™ approach to research, the First Mile approach supports the community leadership to make decisions about the development and deployment of broadband networks in their communities (O'Donnell, Kakekaspan, Beaton, Walmark, & Gibson, 2011). A main component of the First Mile project is an online meeting space where First Nations can share stories about how their communities have taken ownership and control of technologies.

The First Mile project is now part of a new Social Sciences and Humanities Research Council of Canada (SSHRC) funded study, formally launched in February 2013. The First Nation Innovation project features Keewaytinook Okimakanak (KO), a tribal council providing IT support to nine remote First Nations in Ontario, Atlantic Canada's First Nation Helpdesk, the First Nations Education Council in Quebec and the University of New Brunswick. The goal of this partnered research project is to focus on how remote and rural First Nation communities are using broadband networks and ICT to improve their communities, social and economic development and services (First Nations Innovation Project, 2013; Brian Beaton, former KO-KNET Coordinator, personal communication, February 5, 2013).

### Common Themes

Although very diverse, the examples cited above present some common themes. Among them:

- Regardless of the model pursued, in negotiating data sharing arrangements between governments and First Nations organizations, trust-building as well as frequent contact among the parties appears to be key to addressing the legal, policy, and capacity challenges that will certainly arise.
- At the operational level, both commitment and the technical capacity required to begin to implement data linkages is required; such capacity is often in short supply on both government and First Nation sides.
- There was a distinction among the sharing initiatives to approaches on the question of political support: some started small and built up slowly, seeking support from senior levels

as they progressed; others were initiated through high-level political accords that were then progressively implemented.

- The 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, as long as they were assured that the spirit and intent of the principles were preserved.
- Some examples feature local, regional, and even (in the case of the RHS and FNREES) national level stewardship of First Nation data. Other initiatives are tightly focused on the community level. That said, staff at all organizations interviewed noted their priority to ensure that communities gain access to and have a voice in the governance of the data concerning them.

### **Conclusion**

The profiles presented above represent only a small number of initiatives addressing Indigenous data governance. To keep the task manageable, the article has addressed some higher profile examples, which has meant that many local, lesser-known community-based initiatives went unaddressed. Many worthy examples—taken in particular from the health area—could not be included here. Very little research exists examining these and other initiatives. This gap merits further research attention, given the centrality of data both to the nation-rebuilding efforts of Aboriginal peoples and the broader relationship between Indigenous peoples and the Crown.

The potential policy implications of the governance of Indigenous data are at once deep and far ranging. How, for example, might a partnership model promote the long announced goal of reducing the reporting burden of Aboriginal communities and organizations in Canada? How might it guide the sharing of documents and archives surrounding residential schools? How might it interact with current government-wide initiatives, at both provincial and federal levels, supporting open data and open government?

These are all topics for a future day. This one – which brings together models of data governance described in academic and corporate literatures on data and information governance with Indigenous approaches – concludes an open invitation for readers to offer comments and critiques. As an early, exploratory policy research piece in a complex intercultural area, this article will certainly have provoked as many questions as it has provided answers.

## Appendix A: List of Interviewees

Name	Title	Organization
Brian Beaton	KO-KNET Coordinator	Keewatinook Okimakanak
Peter Cunningham	Assistant Deputy Minister, Partnerships & Community Renewal Division	Government of British Columbia
Mariana Diacu	Ministry of Advanced Education, Innovation and Technology	
Carroll Dena	Ministry of Children and Family Development	
Chris Bechard	Ministry of Jobs, Tourism and Skills Training	
Denise Sandison Michael Ross	Ministry of Social Development	
Michelle DeGroot	Executive Director, Health Actions	First Nations Health Authority
Joseph Mendez	Vice-President, Innovation and Information Management Services	
Miranda Kelly	Health Planner, Health Knowledge and Information	
Rene Dion	Manager, Health Information and Policy Coordination	Health Canada
Richard Gray	Manager, Social Services	First Nations of Quebec and Labrador Health and Social Services Commission
Nancy Gros-Louis McHugh	Manager, Research Sector	
Sue Hanley	Former Coordinator	First Nations Technology Council

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<b>Name</b>	<b>Title</b>	<b>Organization</b>
Stacey Lewis	Project Manager	Tui'kn Partnership
Gwen Phillips	Director, Governance Transition	Ktunaxa Nation
Diana Proesser	Policy Analyst, Performance Measurement	Aboriginal Affairs and Northern Development Canada
Shannon Waters	Director of Health Surveillance, First Nations & Inuit Health Branch	Health Canada, BC Region

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