

DATA GOVERNANCE

Harmony Johnson, sełakəs, Tla'amin Nation

Overview

- Key understandings
- A complex history
- Current context and needs
- Establishing data governance processes internally
- Establishing data governance processes for external data

Data Scope and Functions

Improve Population Health Outcomes

Gather, monitor, track core health indicators

Operational Needs

Support the day to day business

Strategic Decision Support

Inform routine strategic planning and performance



Advocacy

Inform policy and funding proposals

Evaluation

Collect data to inform program and operational evaluation

Research

Contribute to research projects

Key terms

- **Data:** Qualitative or quantitative information that is collected for reference or analysis, and includes stories, facts, measurements, values, qualities, or observations. The collection, analyses and interpretation of data and information is a basic activity of government.
- **Database:** Collection of data organized in a computer system to be accessed and managed.

Key terms, cont.

- **Data sovereignty:** The assertion by an Indigenous Government, of ownership over their people's unique identity as an Indigenous Nation, including ownership of the data and intellectual property that relates to their distinct society including their language, culture, worldview, history and land stewardship.
- **Data governance:** The exercise of data sovereignty, through a variety of control mechanisms, including the development of standards to describe data quality, negotiation of data sharing agreements, drafting of protocols, policies and procedures to manage data access and possession and developing mechanisms to measure systems performance.
- **Data management:** Effective generation, collection, strategic-use, storing, and protection of data and information

A complex history

- Oral v. written tradition
- It has historically been harmful to ‘be counted’
- External determination of what (and how) gets measured, counted and reported
- No tangible benefit to – and in fact theft from – many communities
- Studies focus on problems and portray First Nations as poor, sick, dependent, violent, vulnerable

Protecting our rights

United Nations Declaration on the Rights of Indigenous Peoples... **maintain, protect and develop:**

- Intellectual property
- Identity & Nationhood
- Cultural heritage, traditions, customs
- Traditional knowledge
- Science & technology

OCAP®

Ownership: An Indigenous Government owns information collectively.

Control: Indigenous Governments must control how information about their citizens and communities is collected, used and disclosed.

Access: Indigenous Governments must have access to data about their citizens and communities and have the right to make decisions regarding who can access their collective information.

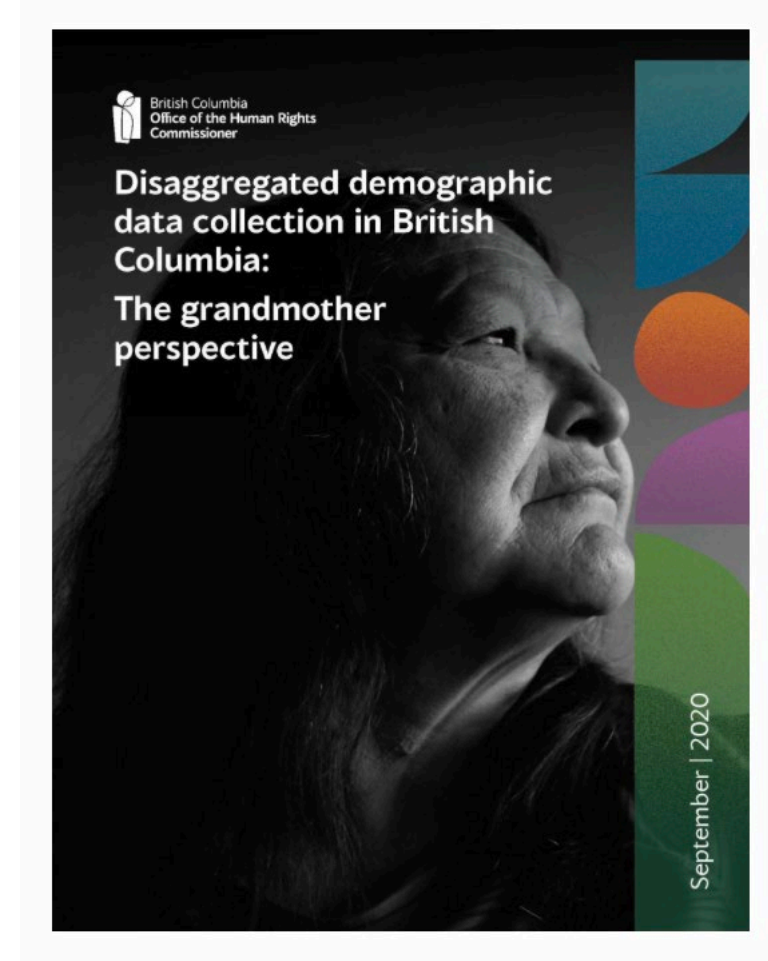
Possession: Data must be in the jurisdiction and stewardship of Indigenous Governments.

Current state of federal & provincial data

- Multiple government sources and databases in health, social and education, among other sectors
- The data environment is fractured (doesn't "talk" to each other)
- First Nations or Inuit surveys vary in coverage, timeliness and trending
- Data may not exist in the general population as comparators
- Data collection is not aligned with Indigenous need, reality, priority
- Variable accuracy due to Indigenous "identity"
- "Cell size" issues limit access to and use of data
- Data is not timely

Commitment to more disaggregated data

- Data which has been disaggregated to allow the identification of Indigenous information is a strong tool for promoting systemic change by highlighting inequities with the dominant population and being a catalyst for policy and program change.
- Government of Canada and Province of BC are committing to more disaggregation of data.

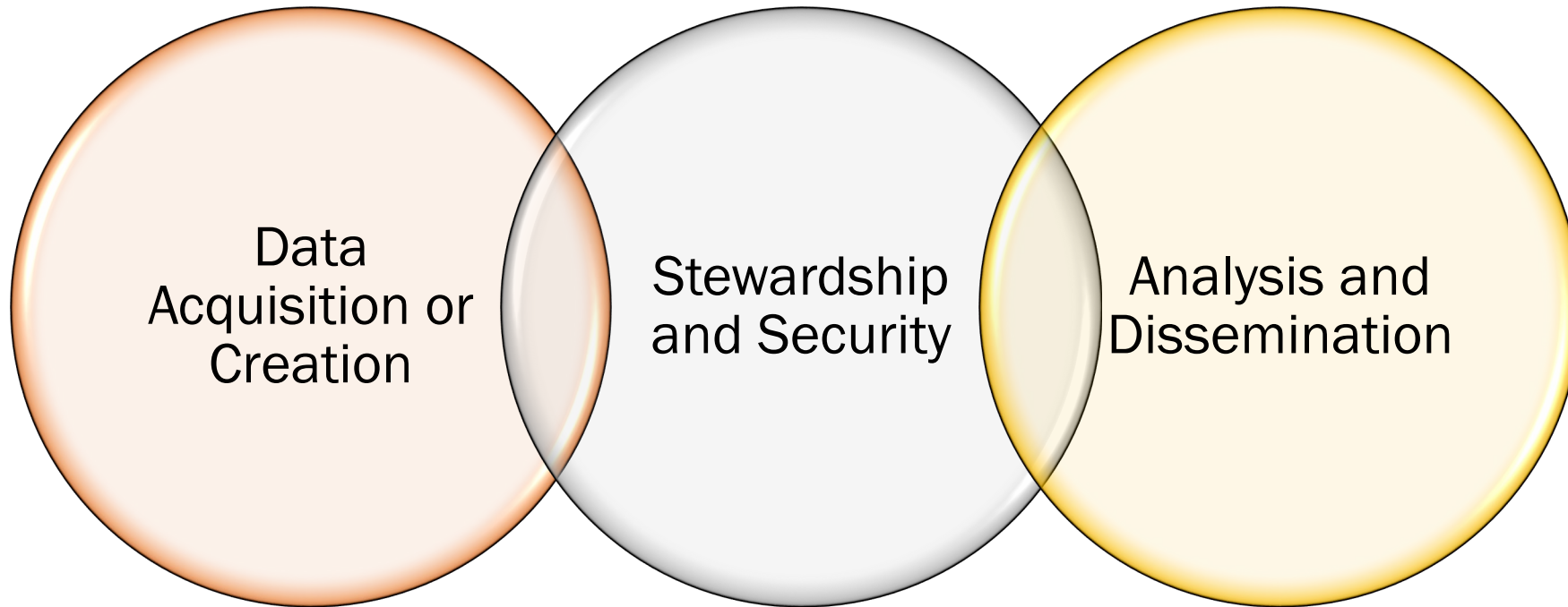


What do Indigenous Governments need?

- Data that matters to them
 - Their own indicators
 - 'Deficit data' to advocate for equity
- Recognition of data sovereignty → ownership & access to data about their Citizens
- Data which are accurate, reliable, timely, clear, comparable and coherent over time, supported by relevant protocols, systems and structures
- Standardization of community data collection systems
- Collectively we also need to continue to produce provincial / population reports

This may require navigating external data governance processes to gather information about citizens and territories AND setting up internal data governance processes to ensure proper decision-making about data use.

In practice



- IGs have validated the collection of data
- IGs shape the methodology and process
- IG governance & decision-making throughout

- Data is stored securely
- Alignment with OCAP & applicable legislation
- Handled by identified personnel only
- Information Sharing Agreements with partner organizations

- Analysis from wellness paradigm, aligned with community interests
- IG involved in analysis
- Intellectual property owned by IG
- Analysis protocols and policies exist to support privacy & confidentiality
- Report approval involves IG
- Presentation to IG first

Internal data governance processes

Internal data governance framework

Vision

```
graph TD; A[Vision] --> B[Principles]; B --> C[Law & Policy]; C --> D[Governance Structure]; D --> E[External Partnerships]
```

Principles

Law & Policy

Governance Structure

External Partnerships

Vision

- A vision statement boldly describes the future desired state of data integration into your IG – “what” and “why”

Our Government governs and protects all of our data and information wherever it resides, enabling data's full potential as a strategic asset to better understand and actionably support the needs, priorities, and plans of our Citizens, Government, and partners.

Principles

- Principles describe the standards that the IG will apply to shape data decision-making

- Our Government governs all our Data, regardless of where it is stored
- All analyses and publications will be culturally appropriate and reflect our world view
- Data will have actionable benefit for the well being of our Government and Citizens
- Data is treated in a secure and protective manner regardless of where it is stored
- Our Government will promote the creation, maintenance, disclosure and storage of data within its own environments whenever feasible
- Our Government will protect the privacy of individuals
- Data will be of quality – accurate, reliable, clear, comparable, timely, coherent

Data Governance Law and Policy

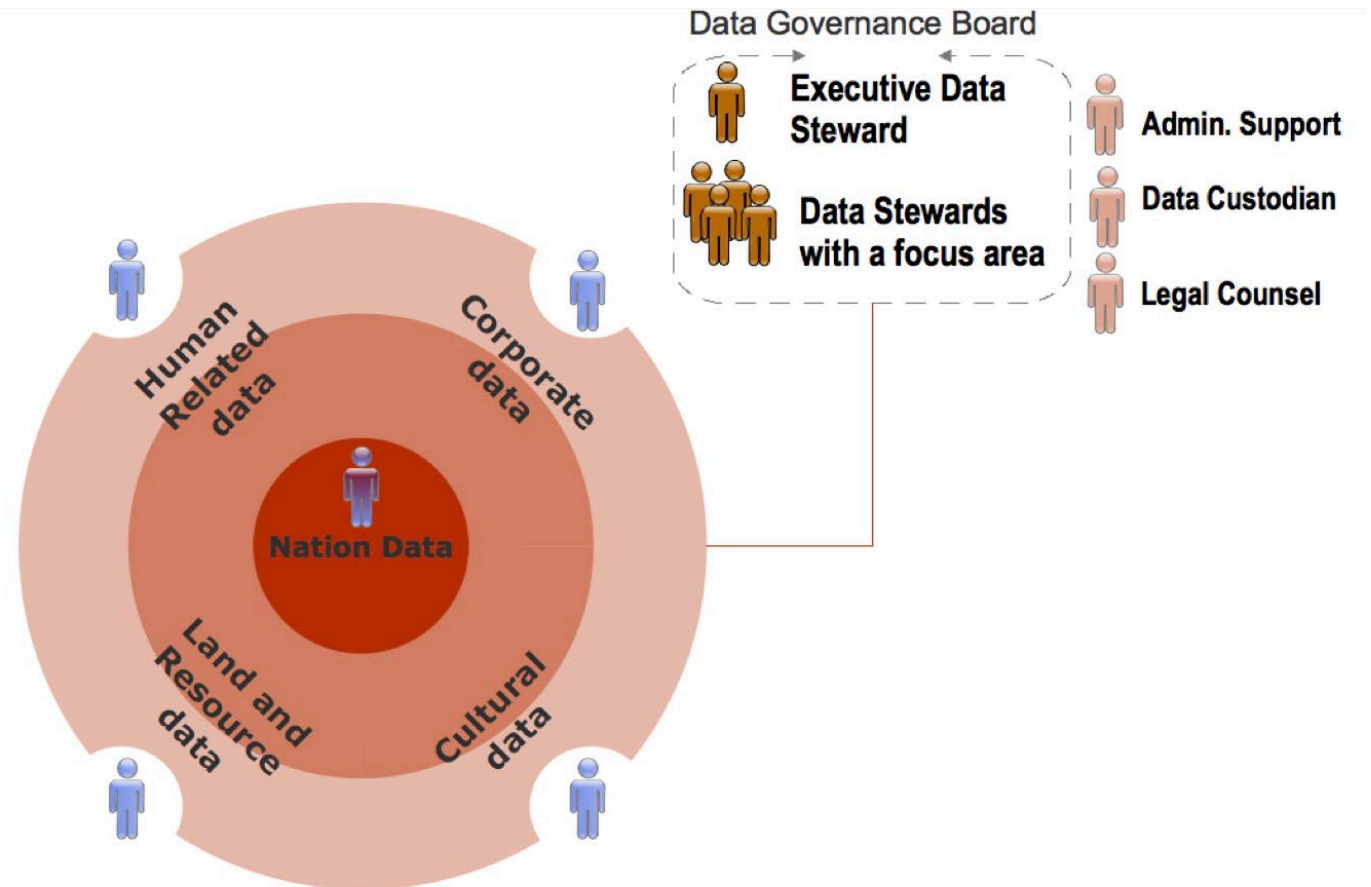
- Guidance for appropriate, consistent use and management of data
- Law and policy often describe data governance principles and structures, as well as:
 - Appropriateness – Analysis and publication is aligned with Indigenous worldview, meets their definitions of quality, and follows established process
 - Availability – ensuring that data is available and easy to consume by those that require it and provide for data access request and research processes
 - Usability – ensuring data is clearly structured, documented and labeled, enables easy search and retrieval, and is compatible with tools used
 - Security & Privacy – ensuring data is classified according to its sensitivity, and defining processes for safeguarding information and preventing data loss and leakage – including specific requirements for protection of personal information

Governance Structure - Basic

Data governance board:

- Executive data steward
- Data stewards: represent the governance of data categories of interest to the IG
- Subject matter experts as needed

Board manages and protects data in accordance with the Data Governance Framework, policy, law



External data governance processes

Key Process Barriers

- Indigenous-specific data is not available
 - Can't identify data which is Indigenous
 - Data resides in private services
 - Data has not been collected from Indigenous communities
 - Data collection not based on Indigenous needs and priorities
- Barriers exist to accessing Indigenous data – even on an anonymized basis
- Current agreements and processes are not aligned with UNDRIP or OCAP[®]

Accessing data as an Indigenous Government

- Where is the data held? With an Indigenous data steward or within government entity?
 - Indigenous data stewards may have data protocols worked out with government and can assist with a data request process
- Work within applicable data access processes. Understand their governance protocols.
- Navigate data access request
- Enter into Information-Sharing Agreement if applicable

Data Access Request

1. Requestor information
2. Project overview – purpose, background, partners
3. Description of data requested
4. Knowledge dissemination plan
5. Data security and privacy
6. Risks and concerns

ISAs

An information sharing agreement (ISA) documents what information will be shared amongst who and for what purpose. An ISA can also set out the way information is shared.

Sample Table of Contents

- Preamble
- Definitions
- Objectives
- Information / Data to be Shared
- Use of information / Data
- Information / Data Sharing Mechanism
- Data Ownership
- Publication and Dissemination
- Confidentiality and Security
- Information Retention and Disposal
- Intellectual Property
- Duration and Renewal
- End / Termination of Agreement

Overcoming barriers collectively

- Work together on a collective and comprehensive data governance agreement which is consistent with UNDRIP and OCAP®
- Consider opportunities to collaborate on data collection and management infrastructure and technical expertise – e.g. regional data centre
- Undertake review of & standardize data now held now by communities (e.g. on a Nation basis)

Final thoughts

- It takes time to develop a mature data governance framework and the work is never done
- Start with broad leadership and management support and acceptance
- Consider starting with a small project to demonstrate what is involved and the value of the work
- Use templates, models and existing tools to save time and money
- There are major opportunities now to work ***collectively*** to ensure Indigenous data sovereignty is upheld through agreements and regional data governance capacity