DATA GOVERNANCE AND MANAGEMENT TOOLKIT AND LEARNING SERIES

DATA TOOLKIT WEBINAR SERIES

Webinar #3: Data Governance

Series Facilitator: Harmony Johnson sɛƛakəs

February 22, 2021

What are we doing here?

- Organized by self-governing Indigenous Governments (IGs) to provide practical knowledge about data to support Indigenous Governments in their responsibilities

- Today is Session 3: Data Governance
  - Overview of terms and concepts
  - Data context amongst IGs
  - Navigating external data governance
  - Break
  - Establishing internal data governance

- *Session 1: Introduction and Core Concepts*
  - *Ktunaxa Case Study*

- *Session 2: Incorporating Data into Indigenous Governments*
  - *Self-assessment tool*
  - *Change management*

- Session 4 ~~5~~: Designing Social Well-being Indicators and Tracking Change

- Session 5 ~~6~~: Collecting and Analyzing Data

- Session 6 ~~4~~: Data Management and Information Management

Housekeeping

- This webinar will be recorded and posted (in part or in full) publicly to the website – however, you will not be recorded
- Please turn on your video and wave hi
- To ask questions…
  - Through the chat OR
  - Use the hand up function

Some personal notes:

- I apologize in advance if I use the term 'Nation' instead of 'Government'
- I will often be looking at my second monitor
- I will try not to talk too fast
- We will do our best with the technology and may make some mistakes along the way

Zoom

Mute/unmute

Start/stop video

Open the chat

Raise your hand

Key terms for today (*see toolkit glossary)

- **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.

The power of data

- Improve outcomes
- Inform policy, practice, planning and decision-making
- Communicate to citizens
- Fulfill reporting requirements
- Evaluate programs and measure quality
- Celebrate success
- Contribute new knowledge and understandings

Key terms, cont.

Data sovereignty: The ability of an Indigenous Government to access, collect, control, and utilize data about its citizens and territories.

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.

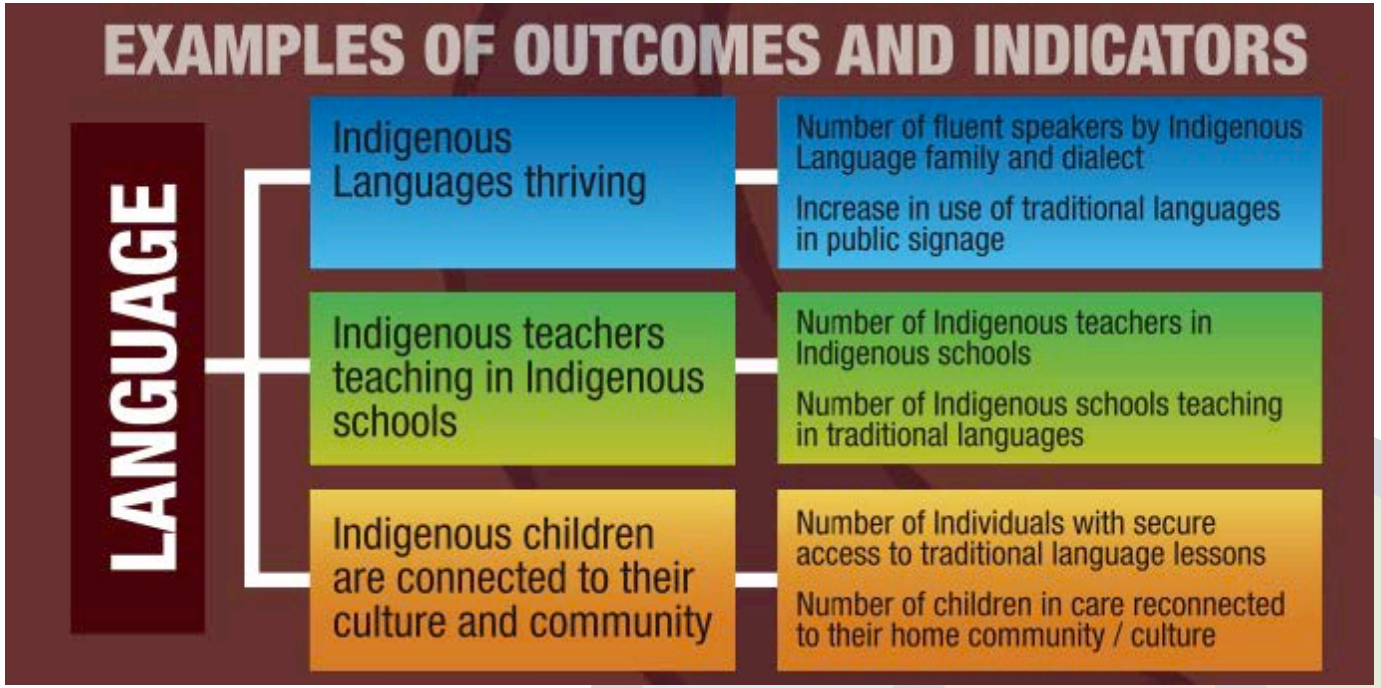
Key terms, cont.

- **Data governance:** The authority to make decisions with regard to data and the traditions, protocols, processes and institutions through which we engage with data. ***Data governance provides the oversight that ensures important data is identified, of high quality, and processes are in place for its effective management.***

- **Data management:** effective generation, collection, strategic-use, storing, and protection of data and information

Key terms, cont.

- **Outcome:** Measurable statements that let you know when you have reached your goals.
- **Indicator:** A piece of data or a composite of several pieces of data that, tracked over time, measure outcomes.
- **Socioeconomic gaps:** Gaps in socioeconomic outcomes (i.e. health, education, housing, culture and language, and employment) between one group of people and another group of people.



Key terms (*see toolkit glossary)

- **Data steward:** Individual, department, or organization responsible for the storage, protection, and proper use of data. Data stewards implement the decisions of the data governing body.
- **Data custodian:** Custodians are responsible for the technical aspects of data management (i.e. IT personnel).
- **Personal information:** Identifiable information about an individual.
- **Deidentified data:** Data about an individual for which identifying information has been removed and the individual cannot be easily identified.
- **Disaggregated data**: data that has been separated into smaller categories, such as Indigeneity, gender, occupation or educational status.

Self-assessment

Question *If a response to a question is no, mark "not addressed" in the rating column. Please continue to indicate whether the item is high, medium, or low priority to your government in the priority level column.*	Rationale	Rating 1=Fully addressed 2=Somewhat addressed 3=Not addressed	Priority Level 1=High priority 2=Med priority 3=Low priority	Relevant Toolkit Section
Section 3: Data Governance				
Responsibility: Is there a staff and/or a leadership position designated to provide oversight and guidance related to data and decision-making? (In other words, do you connect data to strategic planning?)	*Success in DGM depends on a structure for clear decision-making, and guidance from leadership to staff*			Data Governance > Your Data Governance Framework
Responsibility of data stewards: Do staff understand their responsibilities with data (e.g., how to store data, clean data, and make it useful for decision-makers)?				
Legislation: Does your government have laws or regulations that apply to socioeconomic data governance and management? (E.g., privacy and access to information legislation)	*These provide important guidance for DGM work, and in some cases are legally necessary (e.g. privacy laws)*			Data Governance > Your Data Governance Framework Data Governance > Legislation and the Duty of Privacy Protection

Self-assessment

Department-Level/Administrative Data: Does your government use socioeconomic data from different departments effectively in decision-making? Consider data that might be available in hard copy records and database systems. For example, your financial system might have information about post-secondary support, your program staff may collect data about program participation rates, etc.	*The questions in this section will help you conduct an environmental scan of the internal socioeconomic data your government already has compiled. You need a clear picture of the current data landscape within your SGIG in order to assess needs and gaps.*			Acquiring and Working with Data > Internal Data Sources and Primary Data Collection > Administrative Data
Internal Surveys: Has your government conducted surveys related to socioeconomic outcomes? (For example: health, language and culture, housing, education, employment)				Acquiring and Working with Data > Internal Data Sources and Primary Data Collection > Primary Data Collection
Accessing Data from Other Organizations: Has your government accessed data from other organizations, through online services, a data sharing agreement, or other arrangement? (For example: Statistics Canada, provincial or territorial statistics agencies, the First Nations Information Governance Centre). Is this useful for your government and a high priority?				Data Governance > Data Sharing Acquiring and Working with Data > External Data Sources Building Capacity > Working with Researchers Building Capacity > Capacity Supports

DATA GOVERNANCE

Harmony Johnson & Laurel Lemchuk-Favel

Indigenous peoples and data…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

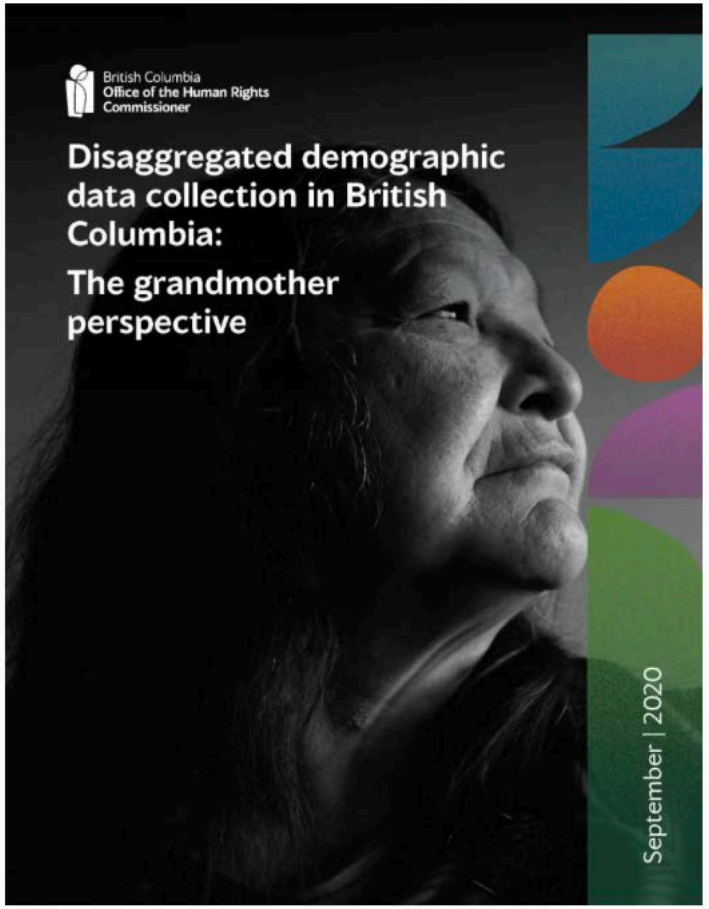
UNDRIP, OCAP®, self-government agreements emphasize the data sovereignty of Indigenous Governments

External Governments & Data: Current State

- Multiple government sources for data in health, social and education database, among others.
- The data environment is fractured
- Only high level analyses often available to external parties
- 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” issues
- “Cell size” issues limit access to and use of data
- Data is not timely

External Governments & Disaggregated Data

- In responding to requests for data, external gov’ts will typically provide 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 some provinces are committing to more disaggregation of data.

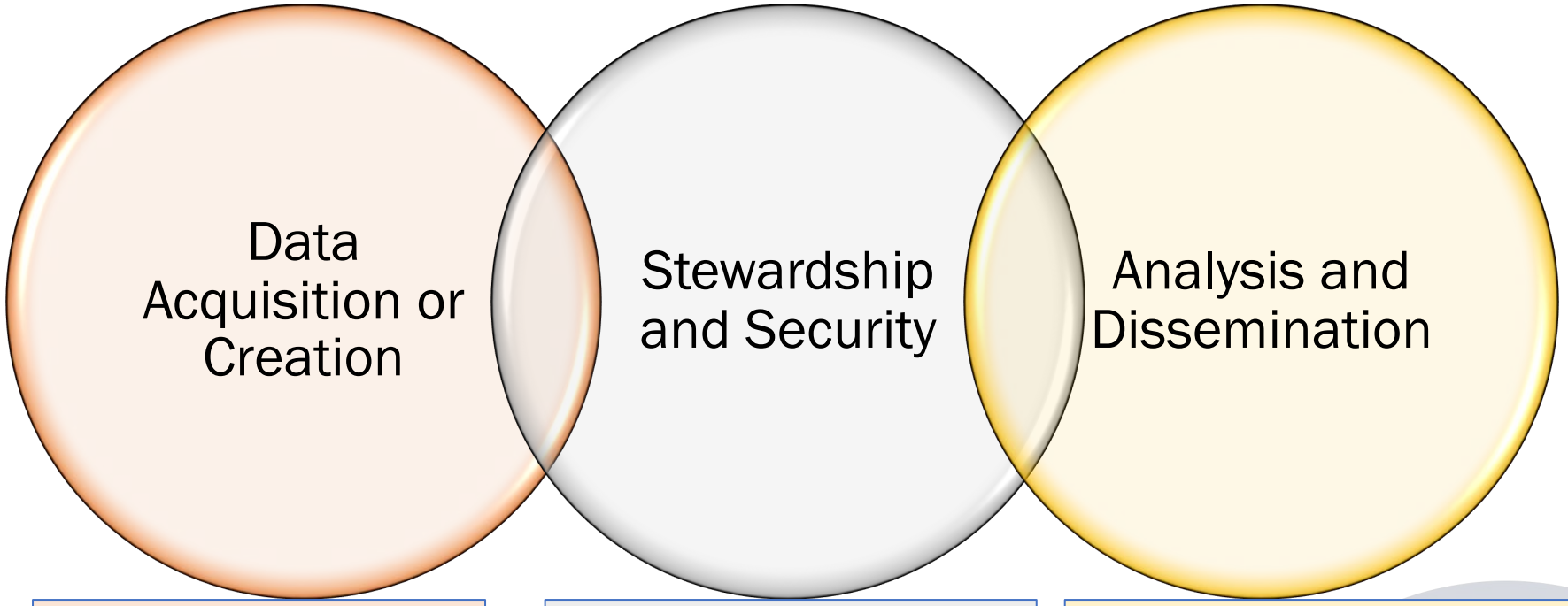


What do IGs need?

- Data that matters to them (e.g. connection to culture and community)
- Recognition of data sovereignty
- 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
- 'Deficit data' to 'close the gap'

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

Life Cycle of Data Governance



- 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

EXTERNAL DATA GOVERNANCE PROCESSES

Harmony Johnson and Laurel Lemchuk-Favel

Key Process Barriers

- Indigenous-specific data is not available
  - Can't identify data which is Indigenous - Indigeneity not recorded as a data field and there is no other way to determine Indigenous data records
  - Data resides in private health 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

Overcoming barriers collectively as IGs

- Seek a comprehensive data access process which is consistent with the spirit and intent of self-government agreements and with OCAP®
- Undertake review & standardize data now held now by IGs
- Consider new data creation through surveys that support both individual and collaborative needs
- Participate in existing First Nations and Inuit surveys (e.g. RHS)
- Consider opportunities to collaborate on data collection and management infrastructure

Accessing IG data

- Where is the data held? With an Indigenous data steward or within government entity?
- P/T data stewards may have data protocols worked out with government and can assist with a gov't data request process
- Work within applicable data access processes of the data steward and/or government. 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

Information-Sharing Agreements

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.

ISA 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

Available Datasets – Early Childhood Development

- Hospitalization data
- Physician Fee for Service data
- Specialty provincial and territorial databases
- First Nations surveys
- Inuit surveys
- Non-insured health benefits
- Canadian Chronic Disease Surveillance System
- Education

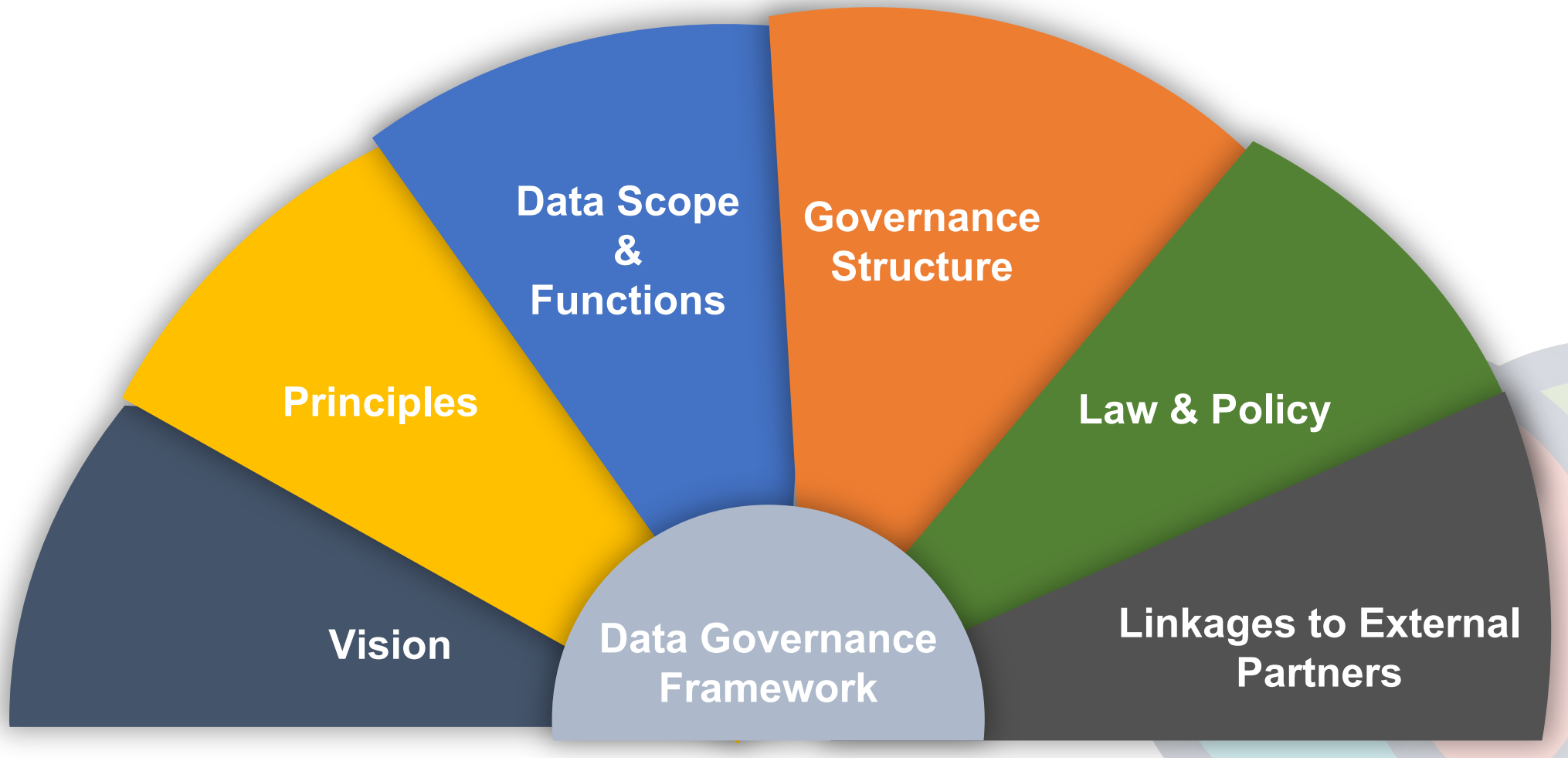
Potential ECD Indicators

Administrative	Survey	Education
• Substance use during pregnancy • Cigarette use during pregnancy • Hypertension during pregnancy • Diabetes • Antenatal care • Teen pregnancy • Healthy birthweight • Breastfeeding during birth admission • Dental hospitalization • Asthma in children • GP attachment • Hospital utilization • Physician user rate • Emergency Department user rate	• Teen pregnancy • Exposure to mould • Safe drinking water • Breastfeeding • Child injury • Balanced meals • Aboriginal Head Start • High school diploma • Diploma, certificate, post-secondary completion • First Nations language • Cultural activities • Oral health • Prenatal exposure to alcohol • Speech and language proficiency	• Foundational skill assessment • Early Development Index

BREAK

INTERNAL DATA GOVERNANCE PROCESSES

Harmony Johnson and Laurel Lemchuk-Favel


Vision
Principles
Data Scope
&
Functions
Governance
Structure
Law & Policy
Linkages to External
Partners
Data Governance
Framework

Vision

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

Sulingituk 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
- The Sultingituk Government will promote the creation, maintenance, disclosure and storage of data within its own environments whenever feasible
- The Sultingituk Government will protect the privacy of individuals
- Data will be of quality – accurate, reliable, clear, comparable, timely, coherent

Data Scope and Functions

Improve Population Health Outcomes

Support Sulingituk to gather, monitor, track core health indicators

Operational Needs

Support the day to day business of Sulingituk primary care centre

Strategic Decision Support

Inform renewal and monitoring of Sulingituk strategic plan

Advocacy

Inform policy and funding proposals

Evaluation

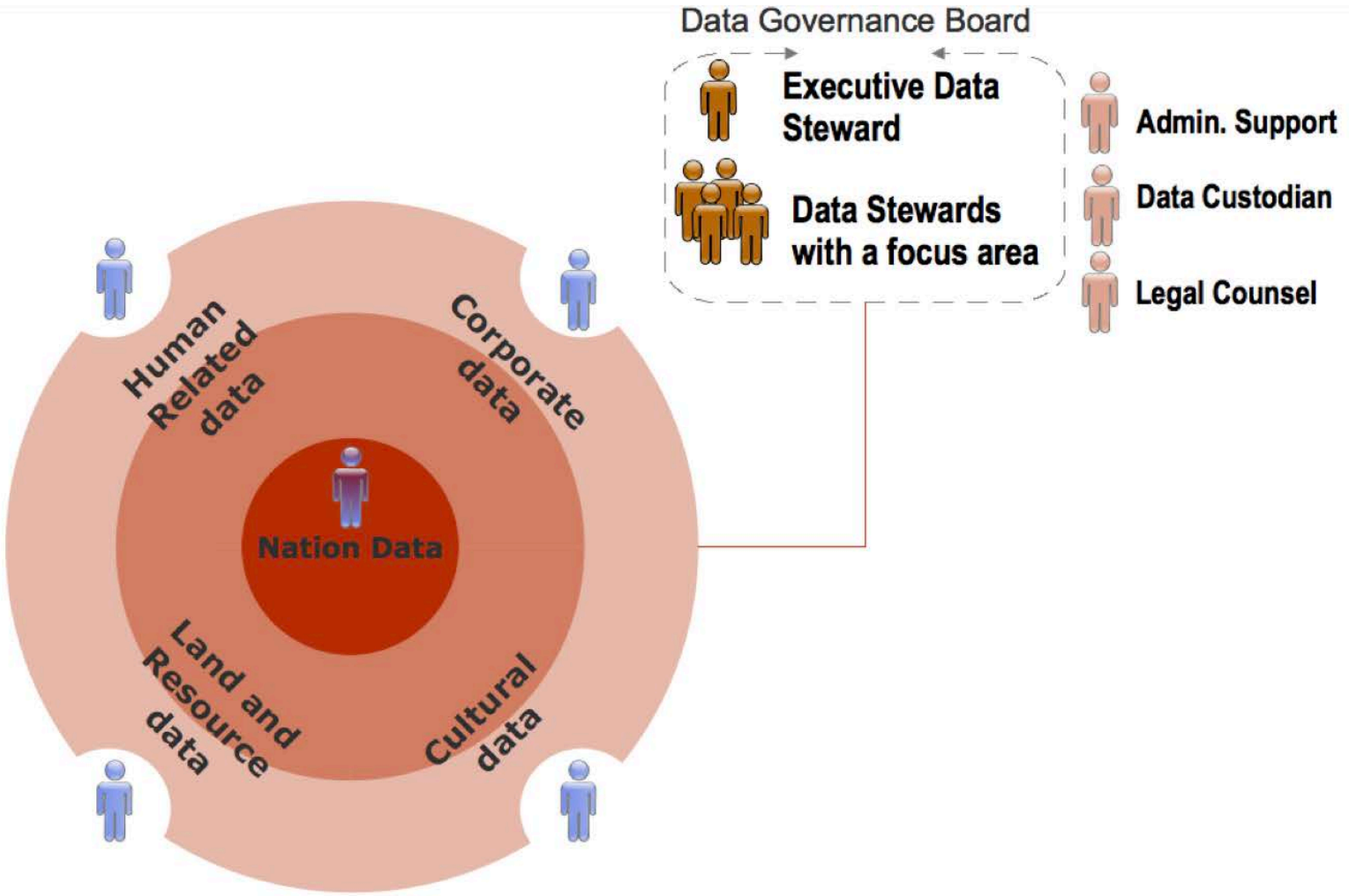
Collect data to inform five-year evaluation of Sulingituk programs

Research

Contribute to Sulingituk research projects

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



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

Final Thoughts on all of this information

- It takes time to develop a mature data governance framework
- 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 (e.g. the toolkit!) to save time and money
- Use the advisor support available to you to get started based on your specific context
- Future webinars will focus on highly related aspects – including indicator development and data collection

Closing

- Next Webinar March 9
  - Session 4: Designing Social Well-being Indicators and Tracking Change
- Utilize the advisors to support your work – contact Mieke at mcoppes@Nvisiongroup.ca
- Please briefly complete the pop-up poll, *"How would you rate the usefulness of this webinar?"*
- For more information: https://indigenousdatatoolkit.ca