FNIGC | CGIPN

First Nations Information Governance Centre
Le Centre de gouvernance de l'information des Premières Nations

The First Nations Principles of OCAP® and Data Sovereignty

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National Gathering on Unmarked Burials: Indigenous Data Sovereignty and Community Control over Information and Knowledge

January 18, 2023

To Share This Morning

- About FNIGC and a bird's eye view of the work
- First Nations data and the OCAP® principles: what are they?
- Research and data governance harms: colonial relations
- Rebuilding and reclamation: First Nations Data Sovereignty in Action

First Nations Information Governance Centre

- Building on the mid-1990s work to develop the Regional Health Survey and the OCAP® principles
- First Nations non-profit, incorporated in April 2010 with a special mandate from the Assembly of First Nations Chiefs in Assembly (#48–2009)
- Guided by principles, research ethics, and a cultural framework developed by First Nations, for First Nations
- Nations come together through regional processes; regions come together to do national-level work

About FNIGC

VISION

The FNIGC envisions that every First Nation will achieve data sovereignty in alignment with its distinct worldview.

MISSION

With First Nations, we assert data sovereignty and support the development of information governance and management at the community level through regional and national partnerships. We adhere to free, prior and informed consent, respect nation-to-nation relationships, and recognize the distinct customs of nations.

Education, Training, & Capacity

- First Nations data sovereignty
- Information governance & management
- OCAP®
- First Nations Data Governance Strategy (FNDGS)

Research

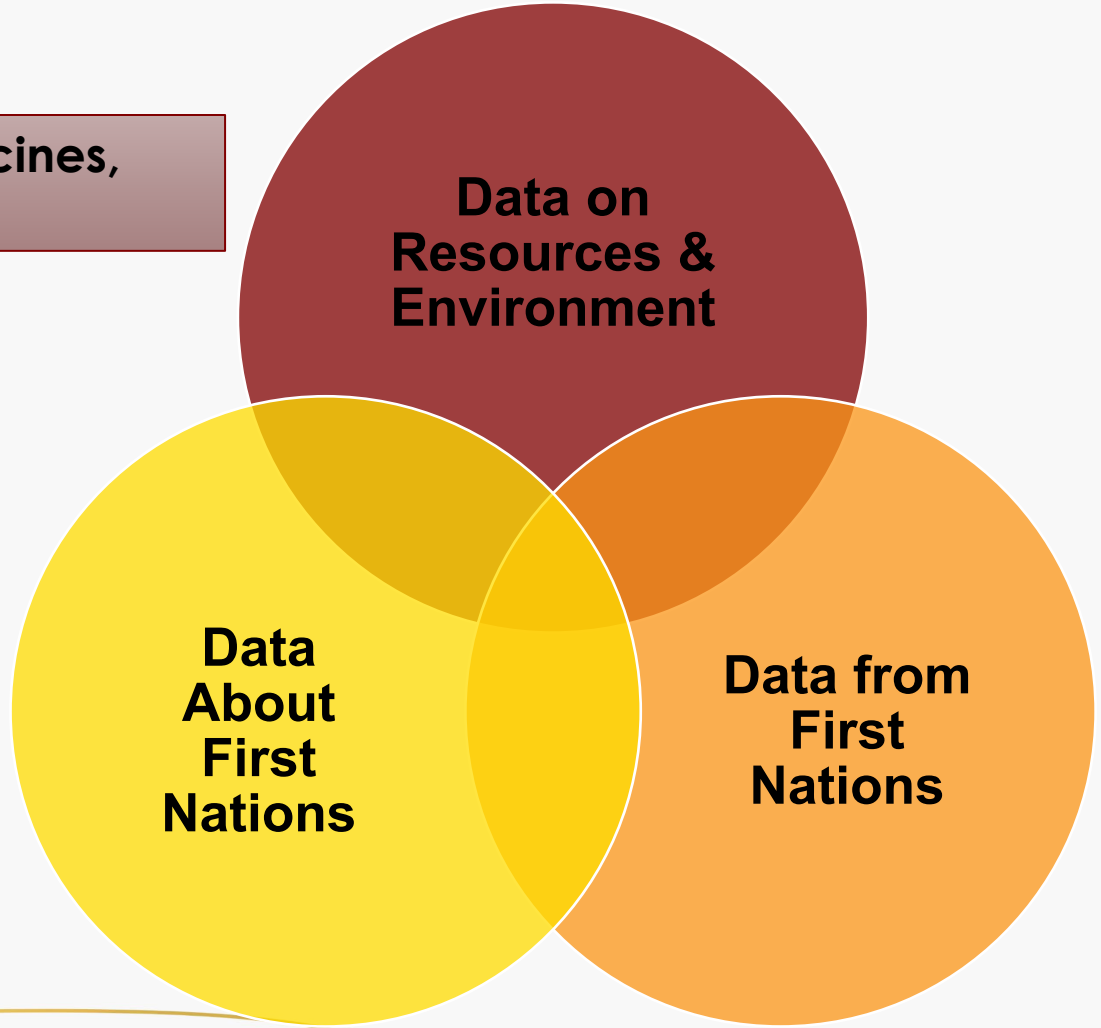
- Research on data sovereignty and information governance
- Topical research that aligns with FNIGC strategic direction and established principles and priorities

National Surveys

- Regional Health Survey (RHS) – ongoing
- Early Childhood, Education & Employment Survey (FNREES) – 2016
- Labour & Employment Development Survey (FNLED) – present

What is First Nations Data?

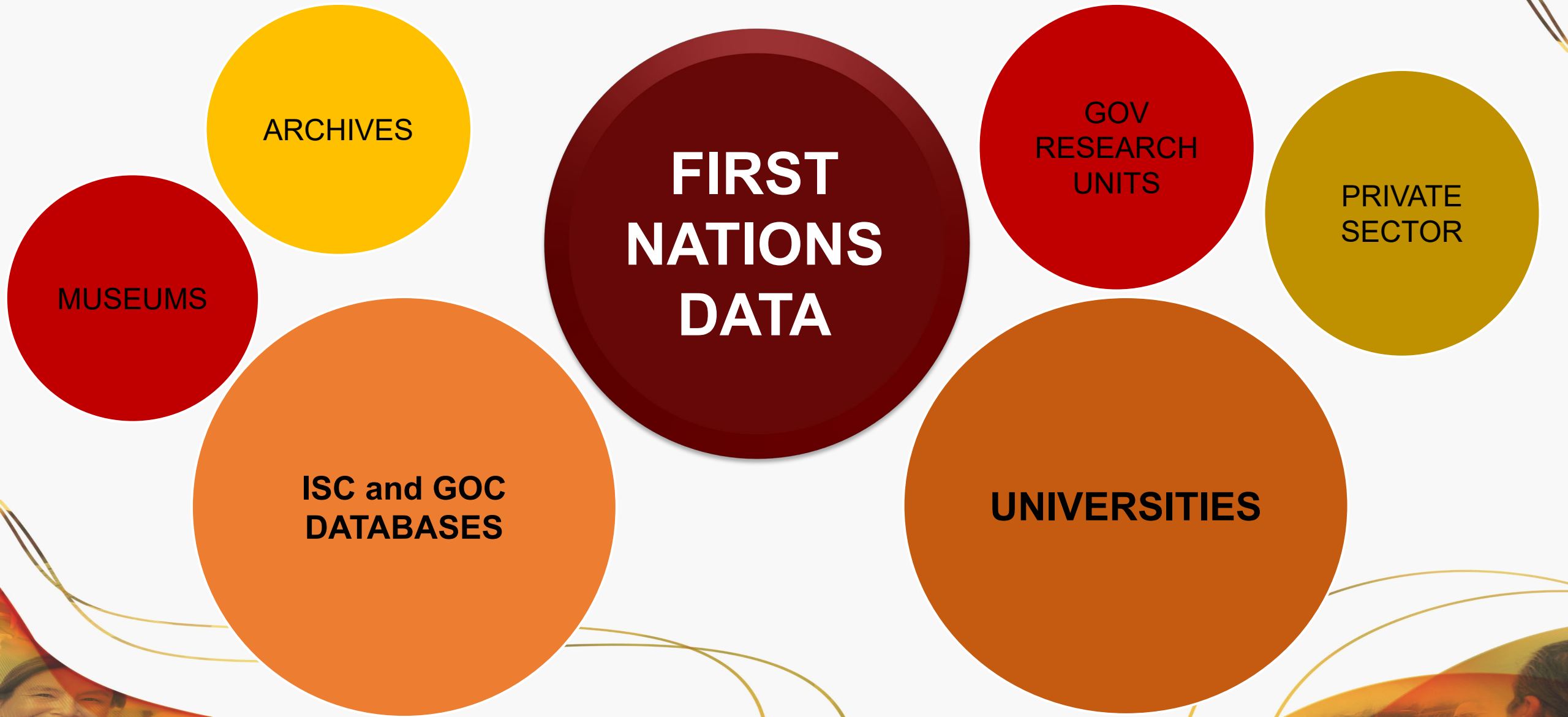
Lands, Waters, medicines, animals, etc.



Languages, cultures, knowledge, stories, songs, ceremonies

Demographics, housing, health, labour, education, etc.

Where is First Nations Data?



First Nations Principles of OCAP® - a framework for asserting data sovereignty

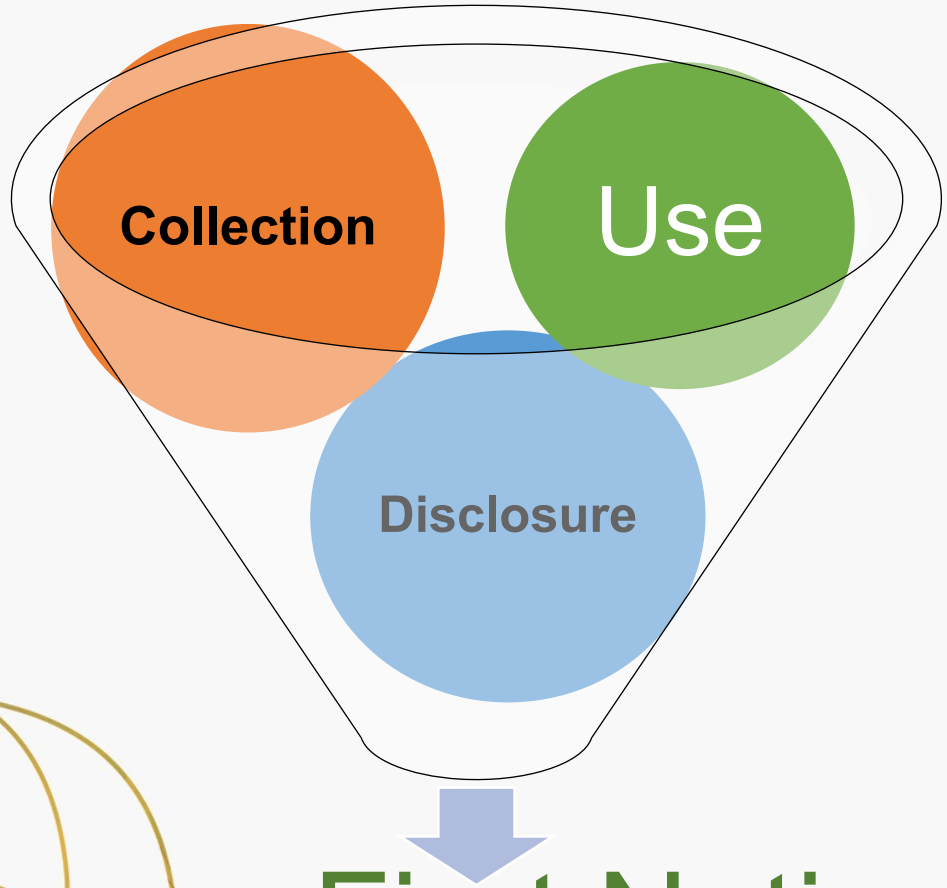
- Ownership, Control, Access and Possession

1. Collection, protection, use, and sharing of First Nations data
2. Benefits community while minimizing harm
3. Self-determination, and preservation and development of culture

Ownership

Data about First Nations resources, environment
Data about First Nations
Data from First Nations

Control

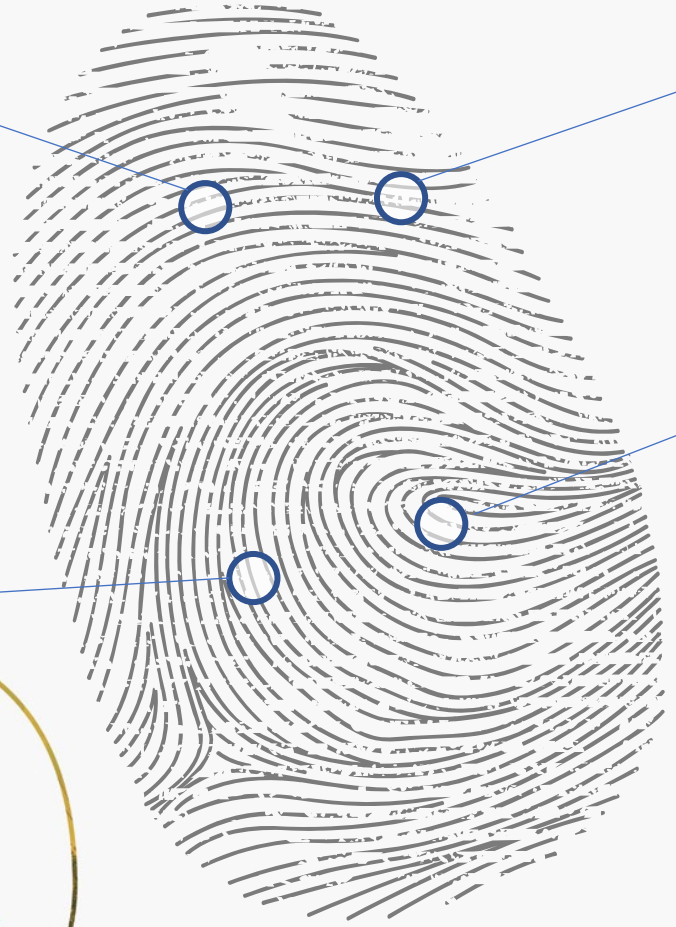


First Nation Control

Access

Who has Access

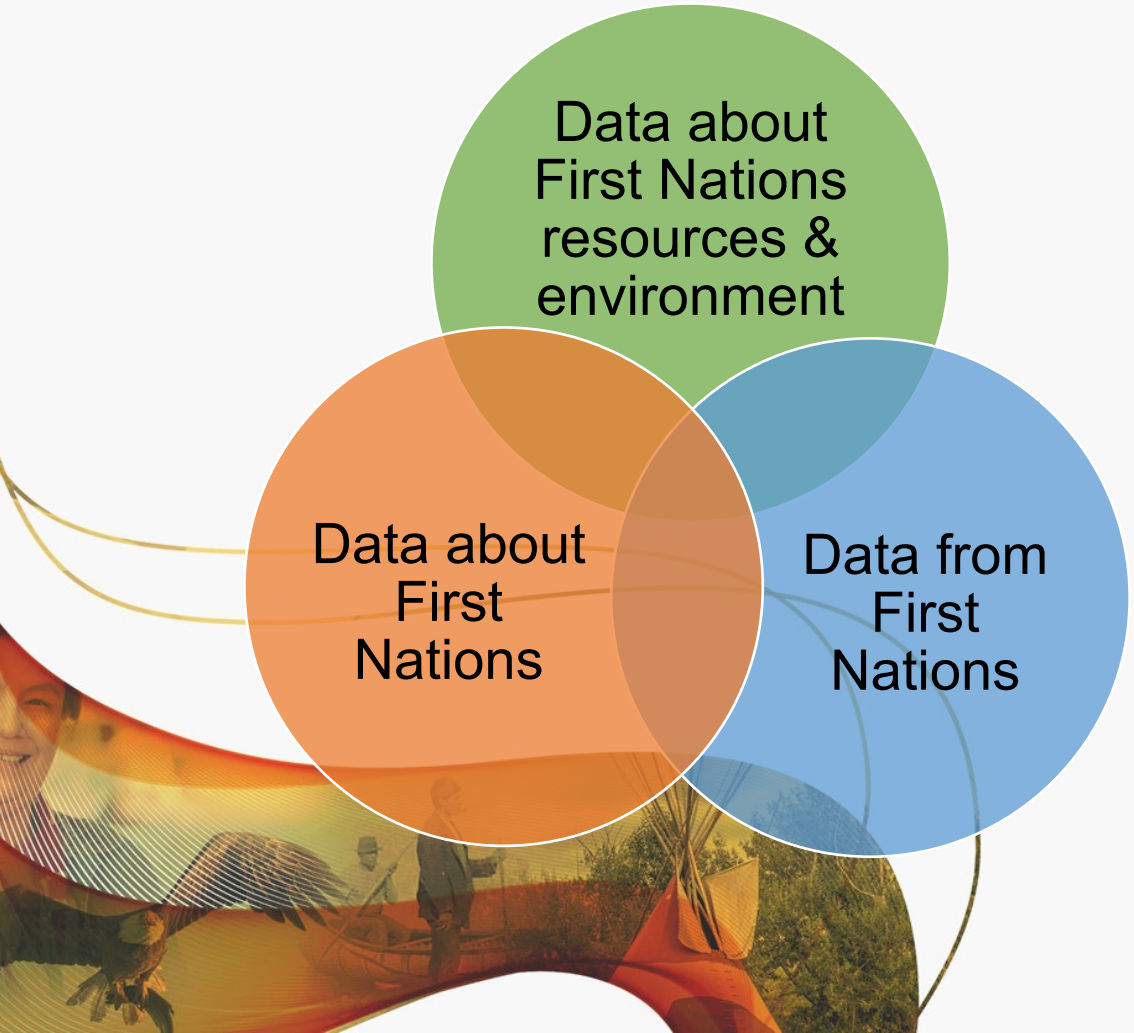
Limitations of Access



Who does not have access

Conditions of Access

Possession


Data about First Nations resources & environment
Data about First Nations
Data from First Nations

Colonial Research (and less visible) Colonial Information Governance

Nuu-Chah-Nulth Arthritis Study

- Between 1982 and 1985, University of British Columbia researcher Dr. Richard Ward took 883 vials of blood from the Nuu-chah-nulth people.

- Received $330K from Health Canada to study arthritis amongst the Nation's people
- His study failed to yield any significant findings.
- In 1986 moved to the University of Utah, then Oxford University.

He took the blood samples with him.

- Collected research grants and furthered his own academic career.
- Loaned samples to other researchers for other studies.
- blood samples were used to produce hundreds of papers in areas as diverse as HIV/AIDS and population genetics
- Used the blood samples to support his theories about migration across the Bering Strait - disrespecting and undermining the Nuu-chah-nulth Creation stories.

INEFFECTIVE USE OF FIRST NATIONS DATA

Data collected from First Nations have not been used effectively to improve the lives of First Nations people.

2018 Auditor General's Report states that INAC and ESDC are requiring data from First Nations but not using it effectively to improve the lives of First Nations.

> *"They are not measuring and reporting on progress to close socio-economic gaps. Lack of performance indicators to determine if programs are effective. Recommend that FNS are engaged on decision-making and getting better, more accurate information."*

Legislative Barriers to First Nations Data Sovereignty

Privacy Act

- The *Privacy Act* is the law that sets out privacy rights in an individual's interactions with the federal government - how the government collects, uses and discloses personal information.
- The Act does not recognize or protect *Collective privacy.*

Access to Information Act

- Provides public access to government information via Access to Information & Privacy (ATIP) requests
- Almost any information provided by First Nations or that Canada collects can be released to the public (names and personal identifiers are removed).

Library & Archives of Canada Act

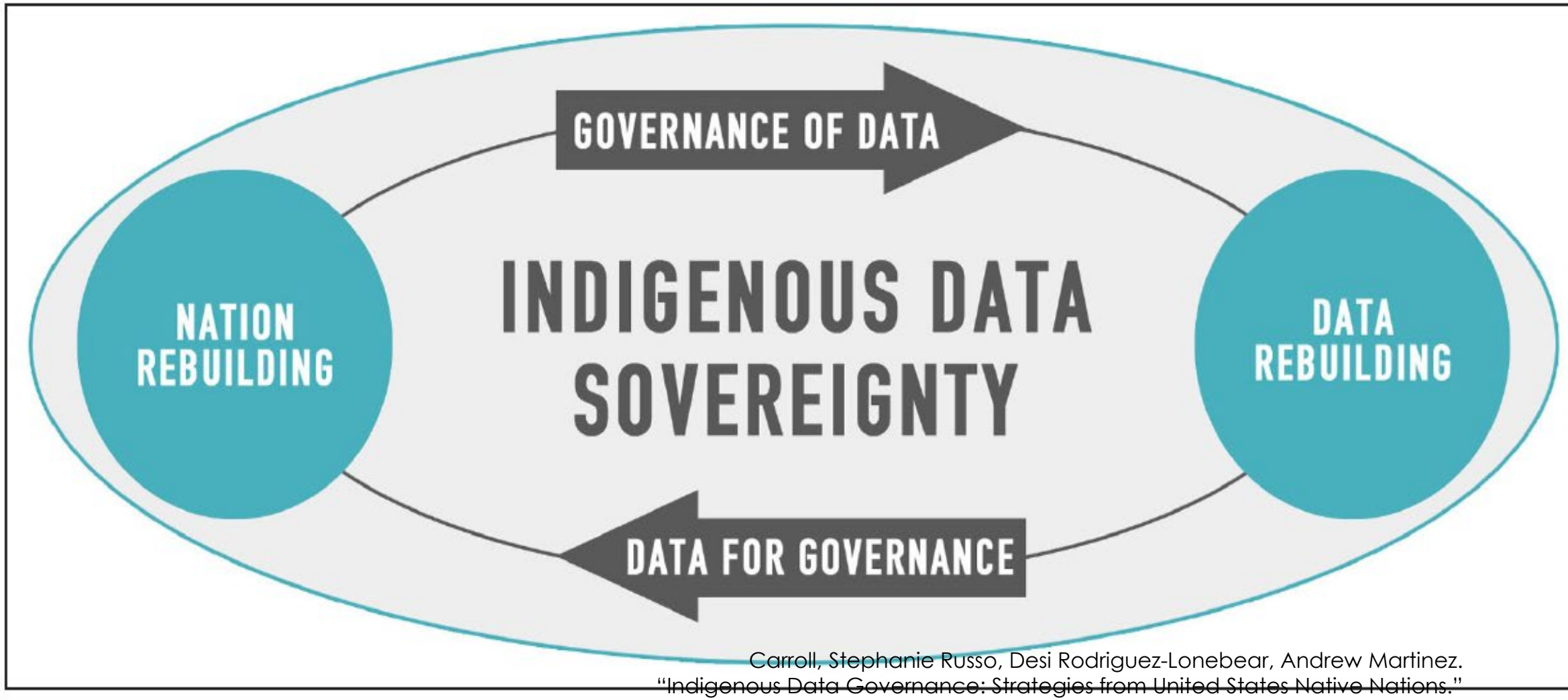
- Mandates that all records in the control of federal departments or institutions be transferred to Archives when no longer in use.
- Once this happens, even personal information becomes vulnerable to ATIP requests (20 years after death).

Rebuilding and reclamation: First Nations Data Sovereignty in Action

First Nations Data Sovereignty

- A people's data and information are a people's collective resource
- First Nations, as sovereign nations and rights holders, have an inherent right to govern their peoples, lands, and resources.
- These rights are confirmed in Section 35 of the Canadian Constitution, Section 25 of the Canadian Charter of Human Rights, and the UN Declaration on the Rights of Indigenous Peoples (UNDRIP)
- **These rights are operationalized by the right of a First Nation to exercise authority over its data & information.**
- **First Nations data sovereignty means First Nations data is governed by First Nations laws, protocols, and policies.**

Data for governance ←→ Governance of data



Carroll, Stephanie Russo, Desi Rodriguez-Lonebear, Andrew Martinez. "Indigenous Data Governance: Strategies from United States Native Nations." Data and Governance: The Interdependence of Nation Rebuilding and Data Rebuilding .*Data Science Journal* 18(1)p.31. DOI: 10.5334/dsj-2019-031. .

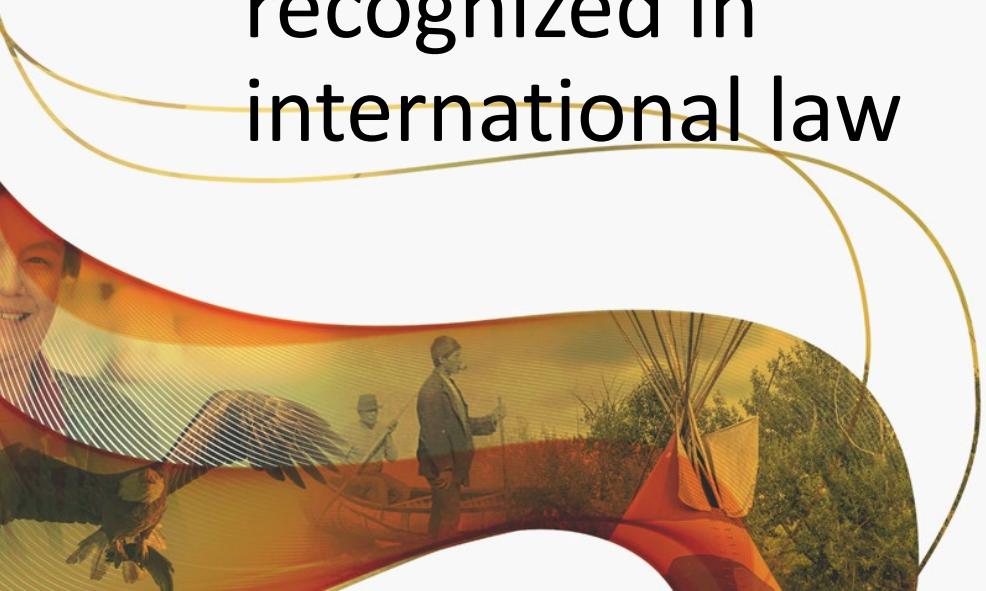
Reclaiming knowledge and the right to information

"While colonial states are able to assert data sovereignty as a given, Indigenous peoples or their political entities are only recently staking their claims in the data space…part of the broader decolonization project" (Oguamanam, 2019).

Oguamanam, Chidi, 2019, *Indigenous Data Sovereignty, Retooling Indigenous Resurgence for Development,* Centre for International Governance Innovation, CIGI Papers No. 234 – December 2019, retrieved from: https://issuu.com/cigi/docs/no.234

United Nations Declaration on the Rights of Indigenous People (UNDRIP)

- "that **[I]ndigenous individuals** are entitled without discrimination to **all** human rights recognized in international law



- **[I]ndigenous peoples possess collective rights** that are indispensable for their existence, well-being and **integral** development as peoples".

Indigenous peoples…

"have the right to **self-determination**. By virtue of that right they freely determine their political status and freely pursue their **economic, social and cultural development.**" (Article 3)

"in **exercising** their right to self-determination, have the right to **autonomy** or **self-government** in matters relating to their internal and local affairs…" (Article 4)

"have the right to **maintain and strengthen** their **distinct** political, legal, economic, social, and cultural i**nstitutions**…" (Article 5)

Data sovereignty: unspoken but essential element of these rights.

Asserting and Respecting First Nations Data Sovereignty Together

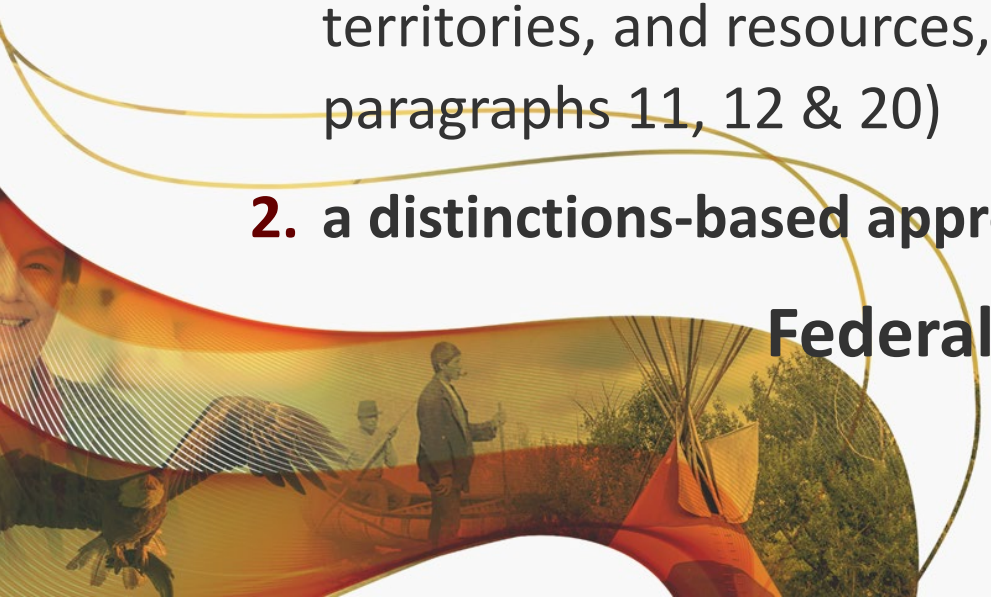
United Nations Declaration Act (UNDA)

"Act is to be construed as **upholding the rights of Indigenous peoples** recognized and affirmed by section 35 of the Constitution Act, 1982…

Confirms that the **Declaration is a source of interpretation of Canadian law**, (Preamble paragraph 17)

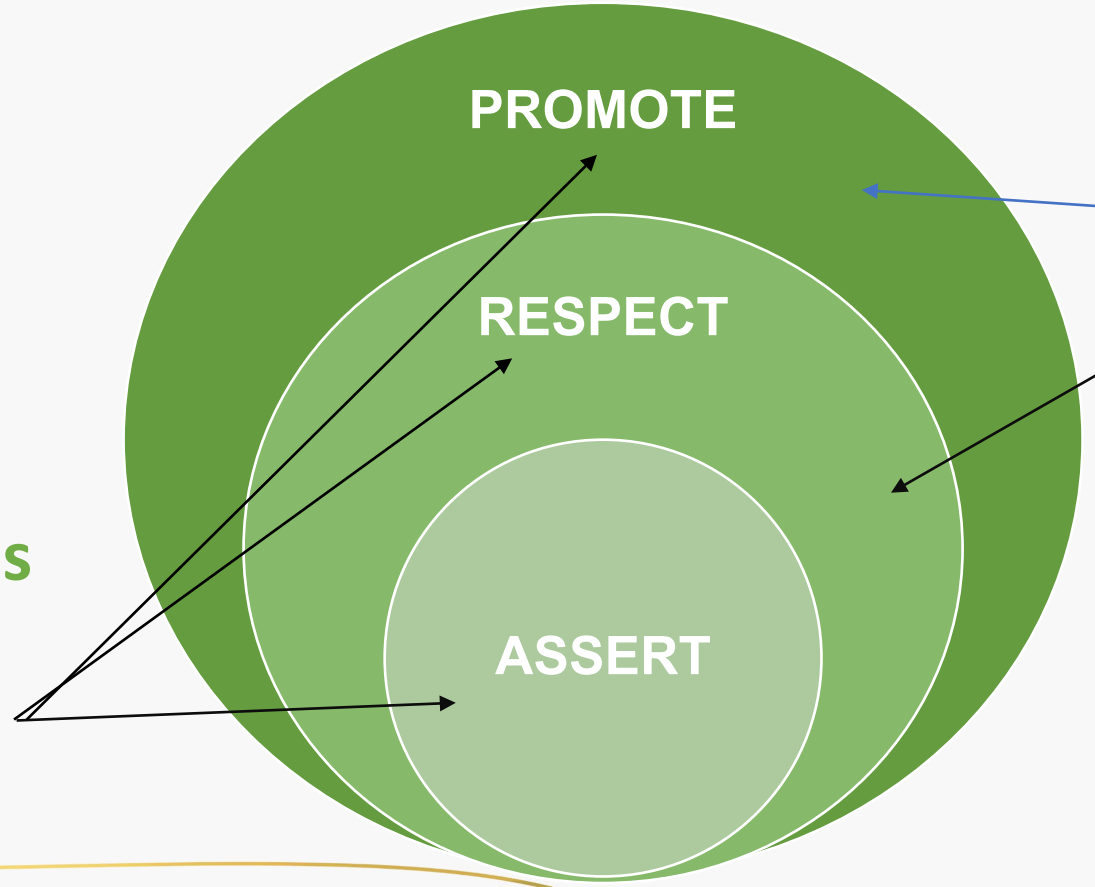
Commits to:

1. **recognition of inherent rights** to self-determination, self-government, land, territories, and resources, and to respect and promote Treaty rights, (Preamble paragraphs 11, 12 & 20)
2. **a distinctions-based approach** (Preamble paragraph 18).



Federal government UNDA action plan due June 2023

Distinct and Collective Rights

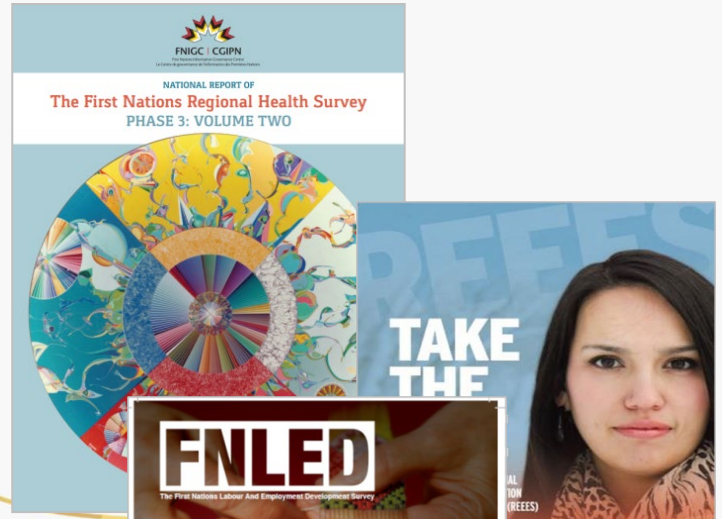


Canadian and other individuals, organizations, governments

First Nations holding collective rights

First Nations Data Centre

Data Sources



FNIGC data online

And onsite

Request review and approval

- Requestor background
- OCAP Training for all researchers
- Research purpose and analysis method
- Who will have access to the tables or data?
- Support of, and benefits and risks to, First Nations communities
- Dissemination of findings

The First Nations Data Governance Strategy (FNDGS) : A First Nations-led Solution Mandated by Rights Holders

AFN Resolution #57/2016

Funding for Regional Information Governance Centres

Coordination of First Nations regions, data governance champions and national partners to establish a national First Nations data governance strategy.

Budget 2018

$2.5 million to design a National Data Governance Strategy and coordinate the establishment of Regional Information Governance Centres

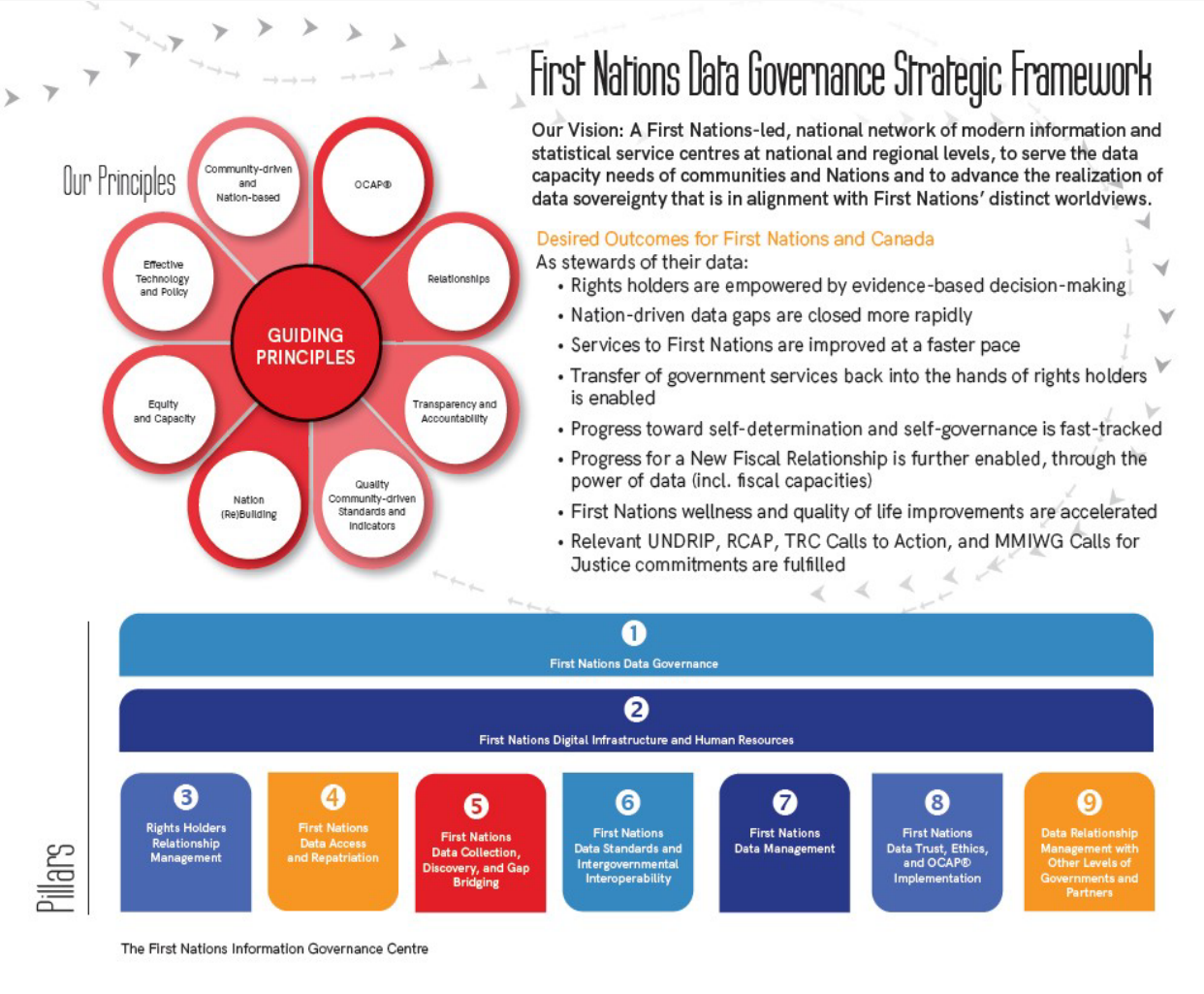
March 2020 – Tabling of Strategy

FNIGC and its partners delivered the comprehensive report entitled **A First Nations Data Governance Strategy** articulating key outcomes and benefits for First Nations and Canada with strong linkages with Canada's priorities and commitments.

Budget 2021

$73.5 million to continue work towards the development and implementation of a First Nations Data Governance Strategy

First Nations Data Governance Strategy



The FNDGS framework outlines:

- a vision for achieving broad outcomes;
- a set of eight high-level guiding principles;
- nine strategic pillars;
  - two horizontal enabling pillars; and
  - seven functional, data stewardship pillars.
- Strategy for development of Regional First Nations Information Governance Centres

What does it look like? Principles, practice, and partners

First Nations asserting OCAP®

- Tui'kn Partnership (Unamak'i)
- Chiefs of Ontario – ICES Agreement
- First Nations Data Centre
- FNHSSM - Health Information Research Governance Committee (HIRGC)
- Atlantic and Alberta Chiefs resolutions

Non-First Nations respecting OCAP®

- University of Saskatchewan Learning Charter
- ACA *Guidelines for a Graduate Program in Archival Studies*
- HelpSeeker Technologies
- Common Approach standards

OCAP® after Twenty Five Years

OCAP® education and training:

- Online course success (200+ learners/mo.); course relaunch March 2023
- Increasing workshops
- Federal commitment to OCAP® education for civil service in Open Government Action Plan

Applied Research:

- Intellectual Property
- Privacy Legislation
- UNDA and data sovereignty
- Next?: progressive data science

Sustainable First Nations led services:

- Survey design and delivery
- First Nations Data Centre – data stewardship and access
- First Nations Data Governance Strategy

Much thanks, love, and kindness to everyone

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