

Surveillance Advances
Progrès dans le domaine de la surveillance

First Nations Data Governance and Public Health Surveillance in Canada: Insights, Lessons, and Future Direction

Gouvernance des données et surveillance de la santé publique pour les communautés des Premières Nations au Canada : Connaissances, enseignements et orientation future

September 24, 2024 12:00 – 1:00pm CT / 1:00 – 2:00pm ET

Speakers

- | | |
|---------------------------|--|
| Erin Corston | Director and Executive Lead, First Nations Information Governance Centre (FNIGC) |
| Gonzague Guéranger | Special Advisor and Implementation Lead, The First Nations Data Governance Strategy (FNDGS), FNIGC |
| Maria Santos | Senior Manager of Public Health Data Initiatives and First Nations Data Centre, FNIGC |



National Collaborating Centre
for Infectious Diseases
Centre de collaboration nationale
des maladies infectieuses



Public Health
Agency of Canada Agence de la santé
publique du Canada



Land Acknowledgment: NCCID



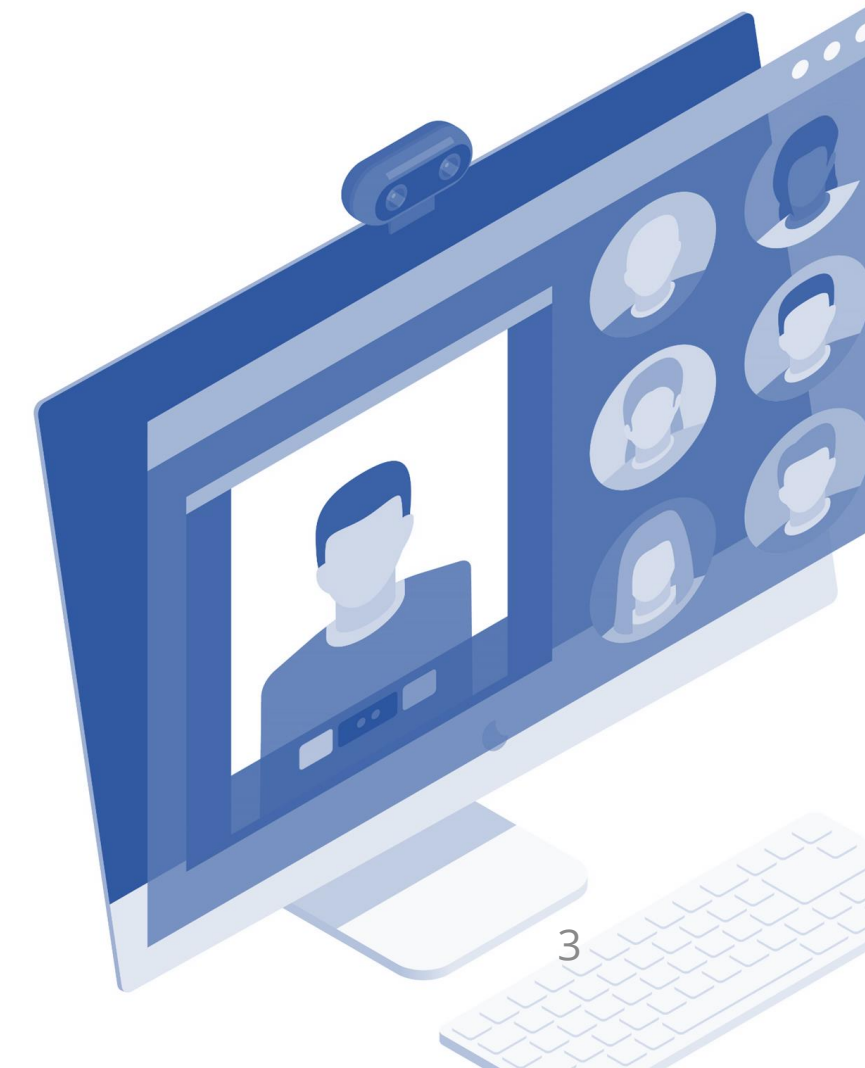
The National Collaborating Centre for Infectious Diseases is hosted by the University of Manitoba. Both the University of Manitoba and I are situated on Treaty 1 Territory, the original lands of the Anishinaabe, Cree, Oji-Cree, Dakota, and Dene peoples, and homeland of the Métis Nation. I am thankful for these lands that I live and work upon as a descendant of settlers with European ancestry and with inherited responsibilities for the lands' protection.

As an organization, NCCID recognizes the systemic inequities and treaties that have been implemented as part of the process of colonization intended to benefit some while harming others. We are committed to working with our partners towards reconciliation and we strive to honour the lands and their original caretakers in our work.

Housekeeping



- Seminar recording and presentation slides will be available shortly after the seminar at the NCCID website: <https://nccid.ca/>
- If you have technical problems with Zoom, please email us at nccid@umanitoba.ca
- The chat box for participants has been disabled for this session. We will use the chat box to share additional information.
- Please use the Q&A tab to submit your questions for our speakers. You can “like” other people’s questions to push them up in priority



Accreditation



Surveillance Advances is a self-approved group learning activity (Section 1) as defined by the Maintenance of Certification Program of the **Royal College of Physicians and Surgeons of Canada**.

The seminar series is also approved by the Council of Professional Experience for professional development hours for members of the **Canadian Institute of Public Health Inspectors**.

If you would like a letter of participation, please complete the survey which will be shared after the seminar.



Land Acknowledgment: PHAC



I would like to take this time to acknowledge the land where I live and work. Situated upon the traditional territories of the Erie, Neutral, Huron-Wendat, Haudenosaunee and Mississauga Peoples, this land is covered by the Dish With One Spoon Wampum Belt Covenant, an agreement between the Haudenosaunee and Anishinaabek to share and care for the resources around the Great Lakes.

Today, Dundas and the City of Hamilton are home to many Indigenous people from across the Turtle Island. We honour the Indigenous peoples who have lived on and cared for these lands for generations, and I am grateful for the opportunity to share and call this place home.

Today's speakers



Erin Corston

Director and Executive Lead, FNIGC



Gonzague Guéranger

Special Advisor and
Implementation Lead, The First
Nations Data Governance
Strategy (FNDGS), FNIGC



Maria Santos

Senior Manager of Public
Health Data Initiatives and the
First Nations Data Centre,
FNIGC

FIRST NATIONS INFORMATION
GOVERNANCE CENTRE
(FNIGC)



FIRST NATIONS DATA GOVERNANCE
STRATEGY
(FNDGS)



FIRST NATIONS DATA GOVERNANCE
AND PUBLIC HEALTH SURVEILLANCE IN
CANADA: INSIGHTS, LESSONS AND
FUTURE DIRECTION

A PRESENTATION FOR THE NCCID:
SURVEILLANCE ADVANCES SEMINAR

- *ERIN CORSTON, DIRECTOR AND TEAM LEAD*
- *GONZAGUE GUÉRANGER, SPECIAL ADVISOR AND TEAM LEAD*
- *MARIA SANTOS, SR. MANAGER, PUBLIC HEALTH DATA INITIATIVES AND THE FIRST NATIONS DATA CENTRE*

LEARNING OBJECTIVES

1. To develop a general understanding of First Nations data sovereignty and its relevance to Canada's health information and statistical systems.
2. To better understand First Nations' priorities as it relates to public health surveillance.
3. To support the vision of the First Nations Data Governance Strategy.

Conflict of interest

None to declare



FNIGC | CGIPN

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

ABOUT FNIGC

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

ORIGINATED IN THE MID-1990's

INDEPENDENT, APOLITICAL, EXPERT-BASED NON-PROFIT

GOVERNED BY REGIONAL AUTHORITIES

GROUNDING IN COMMUNITY-BASED PRINCIPLES

**CORE
ACTIVITIES**

- **NATIONAL SURVEY PROGRAM**
- **RESEARCH AND KNOWLEDGE TRANSLATION**
- **EDUCATION AND TRAINING IN OCAP®**
- **FIRST NATIONS DATA GOVERNANCE STRATEGY****
- **Data Sovereignty Research Collaborative**



**THE OCAP® PRINCIPLES ARE THE BUILDING BLOCKS TO
FIRST NATIONS DATA SOVEREIGNTY**

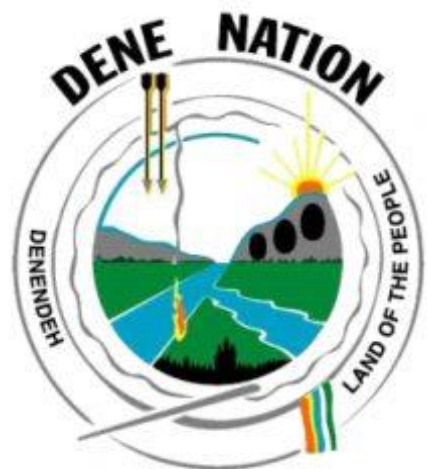
FNIGC REGIONAL PARTNERS



First Nations
Health Council



FSIN



Surveillance through the lens of COVID-19

- RHS statistics for shaping a response to COVID-19 in First Nations communities
- Collaborating on a position paper that examines challenges / limitations of First Nations COVID-19 data
 - Regional contexts in relation to First Nations COVID-19 data and data governance
 - Potential role of the First Nations Data Governance Strategy (FNDGS) to alleviate these challenges
- Data Sharing Agreement with ISC to access COVID-19 data

Data Quality Challenges



- Data quality issues regarding counts of First Nations people
 - First Nations identifiers: Self-reporting (census or case reports) vs. Indian Registry
 - Exclusion of First Nations based on place of residence or the *Indian Act*
 - Exclusion of First Nations population living in urban settings, especially vulnerable populations such as the homeless and/or mobile populations are undercounted
- Data collected does not reflect community priorities and realities (of limited utility)

Data Quality Challenges (cont'd)

- Impacts
 - Invisible to health statistics –missed opportunity for evidence-based response to the pandemic
 - Misclassification bias mostly results in underestimated rates and reduced differences
 - Cannot examine intersection with different population groups within First Nations (e.g. people living with disabilities, gender identity) to see if there are disproportionate effects





Data Integration Challenges

- Jurisdictional and complex relationships
- Data flow in the jurisdictions vary and limitations are not transparent or well-documented
- Aggregation of disparate information into two separate datasets
 - ISC dataset excludes First Nations without status or living off-reserve, First Nations in some self-governing communities and potentially those who live on-reserve but seek care outside the community
 - PHAC dataset exclude First Nations who do not self-identify or First Nations that live in provinces / territories that do not report on First Nations identity

Data Integration Challenges (cont'd)

- Impacts of non-integrated information health systems (between federal and provincial health services)
 - challenges with contact tracing and follow-up treatment
 - a fragmented and incomplete picture of the realities of First Nations

Data-Sharing Challenges



- First Nations face barriers for accessing data because the data is often under the control of provincial or federal government and subject to privacy legislation.
- Data sharing agreements and partnerships to access data require significant effort and collaboration, as well as capacity, resulting in significant delays during a pandemic.
- Relationship between provincial / territorial governments and First Nations become key for how COVID-19 data is shared.

Data-Sharing Challenges (cont'd)

- Need federal / provincial / territorial / First Nations governance structures that support the flow of data and information and the ability to work across jurisdictions
- Lack of information for small communities / regions – due to measures for protecting individual privacy
 - Involve First Nations in how data is clustered so that it can be meaningful



Infrastructure and Capacity Challenges

- Lack of technological capacity to collect and use data
- Limited internet access; poor connectivity
- Lack of digital medical records
- Need for enhanced data literacy so that First Nations can access and use data in a way that supports communities
- Need human resources or expertise
- Attrition of staff or high turnover during the pandemic
- Competing priorities:
 - e.g. wildfires, floods

Link to FNDGS [video](#)

BREAK: FOR THE FNDGS EXPLAINER VIDEO



The First Nations Data Governance Strategy (FNDGS) Background

AFN Resolution #57/2016

Calling on the government of Canada to fund a national network of Regional Information Governance Centres



Federal Budget 2018

\$2.5 million to FNIGC and its partners to:

- A. Design a National Data Governance Strategy
- B. Coordinate the establishment of Regional Information Governance Centres (RIGC)

March 2020 – Tabling the Strategy

FNIGC and its partners delivered the comprehensive First Nations Data Governance Strategy articulating key outcomes and benefits for First Nations and Canada



Federal Budget 2021

\$51.5 million to FNIGC and its partners to continue the development and implementation of a First Nations Data Governance Strategy



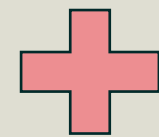
FEDERAL CONTEXT: A UNIQUE OPPORTUNITY

The Transformational Approach to Indigenous Data (TAID)

The TAID is a federal umbrella initiative stemming from Budget 2021 setting aside **\$81.5M**

\$59.5M
for Indigenous-led Data Strategies

- **\$51.5M to First Nations (FNDGS)**
- **\$4.0M to Inuit**
- **\$4.0M to Métis**



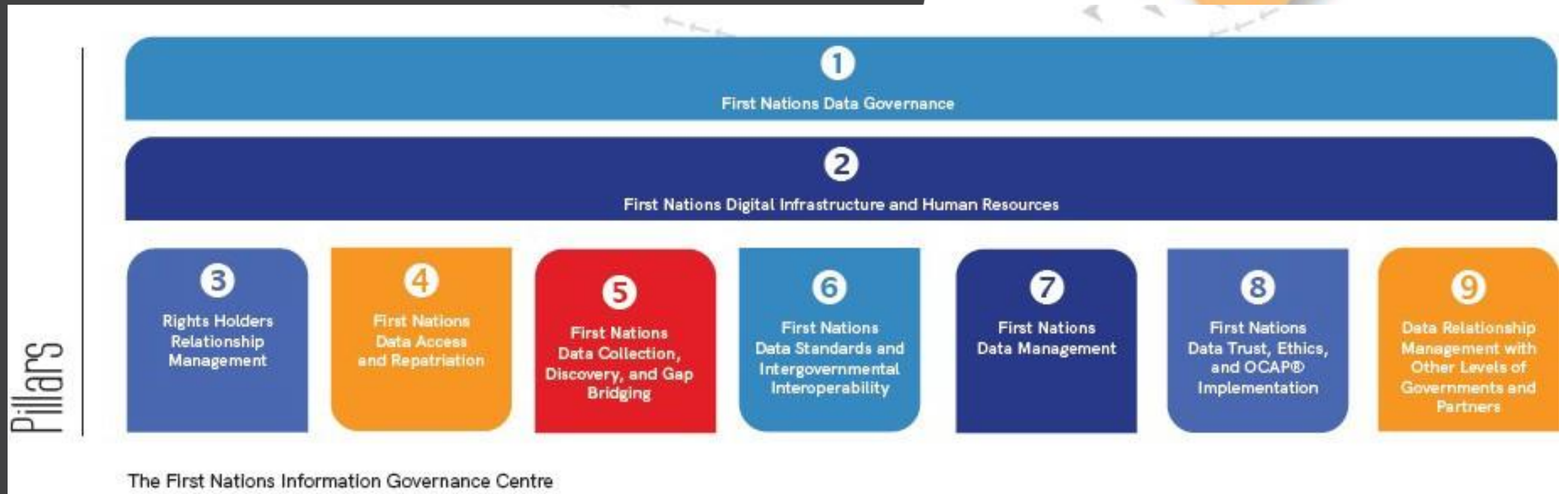
\$22.0M
for ISC and Statistics Canada

- **\$9.5M to ISC: Readying Data Access and Transition**
- **\$13.0M to Statistics Canada: Supporting Indigenous Data Capacity**

FNDGS - BACKGROUND

Anchored in a robust strategic framework with:

- A clear vision and path for achieving **data sovereignty**
- **9 strategic pillars** where capacities must be built
- A set of First Nations **guiding principles**



FULLY FUNCTIONAL INFORMATION GOVERNANCE CENTRES – A GENERIC MODEL

The Strategy Visions:

A national network of First Nations-led of **fully functional data and statistical centers** that will provide **shared services** to **communities, their governments, and their service delivery organizations.**

For data and statistical services at all levels:

- NATIONAL
- REGIONAL
- LOCAL

Regional Governance Body of RIGC
(e.g., Board of Directors)

Executive Team

Corporate functions
(Data Policies, Planning, IM/IT, HR, Finance etc.)

1 - Statistical Production Services

DATA COLLECTION

DATA ANALYTICS & RESEARCH

DATA DISSEMINATION

2 - Data Stewardship Services

DATA HOLDING & META DATA

DATA PROTECTION AND QUALITY

ACCESS TO DATA HUB SERVICES

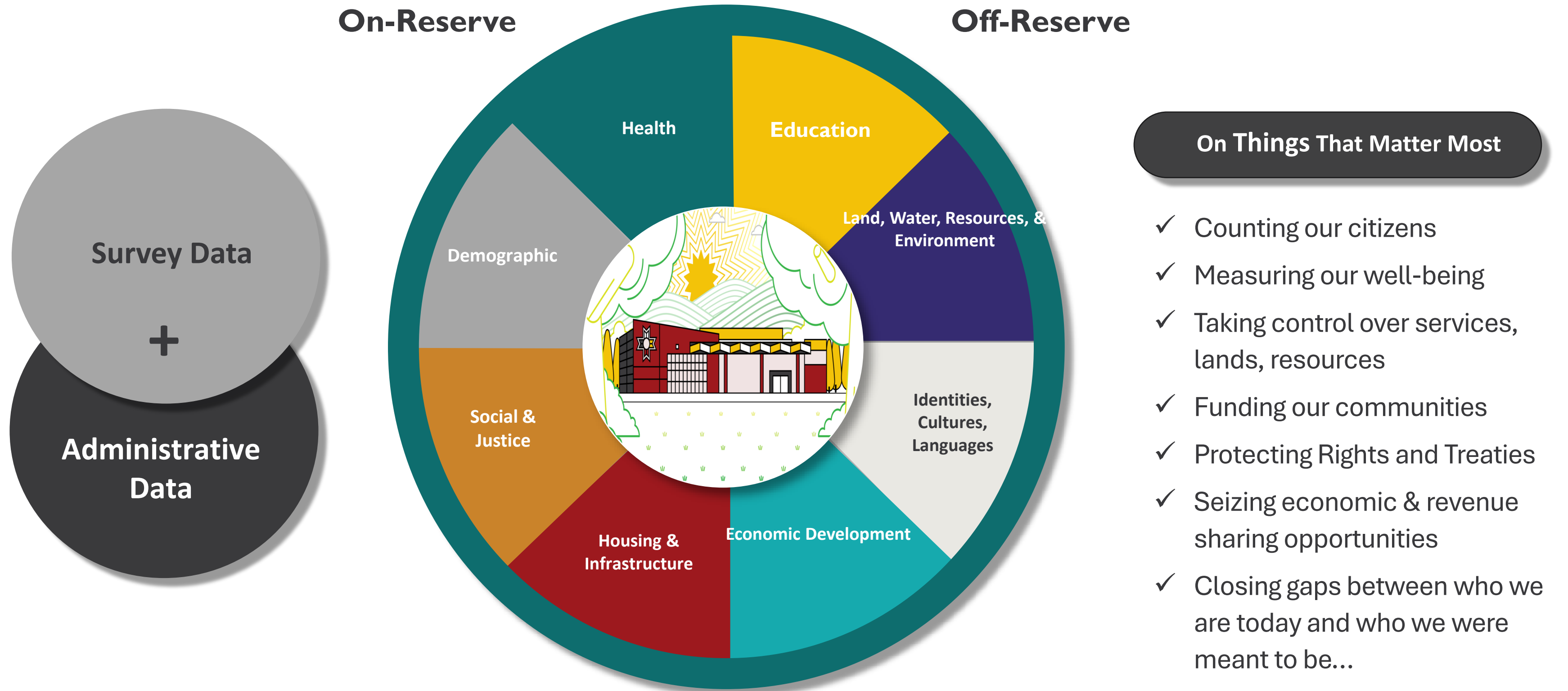
3 - Local Data Capacity Development Services

DATA NEEDS ASSESSEMENT

DATA LITERACY & TRAINING

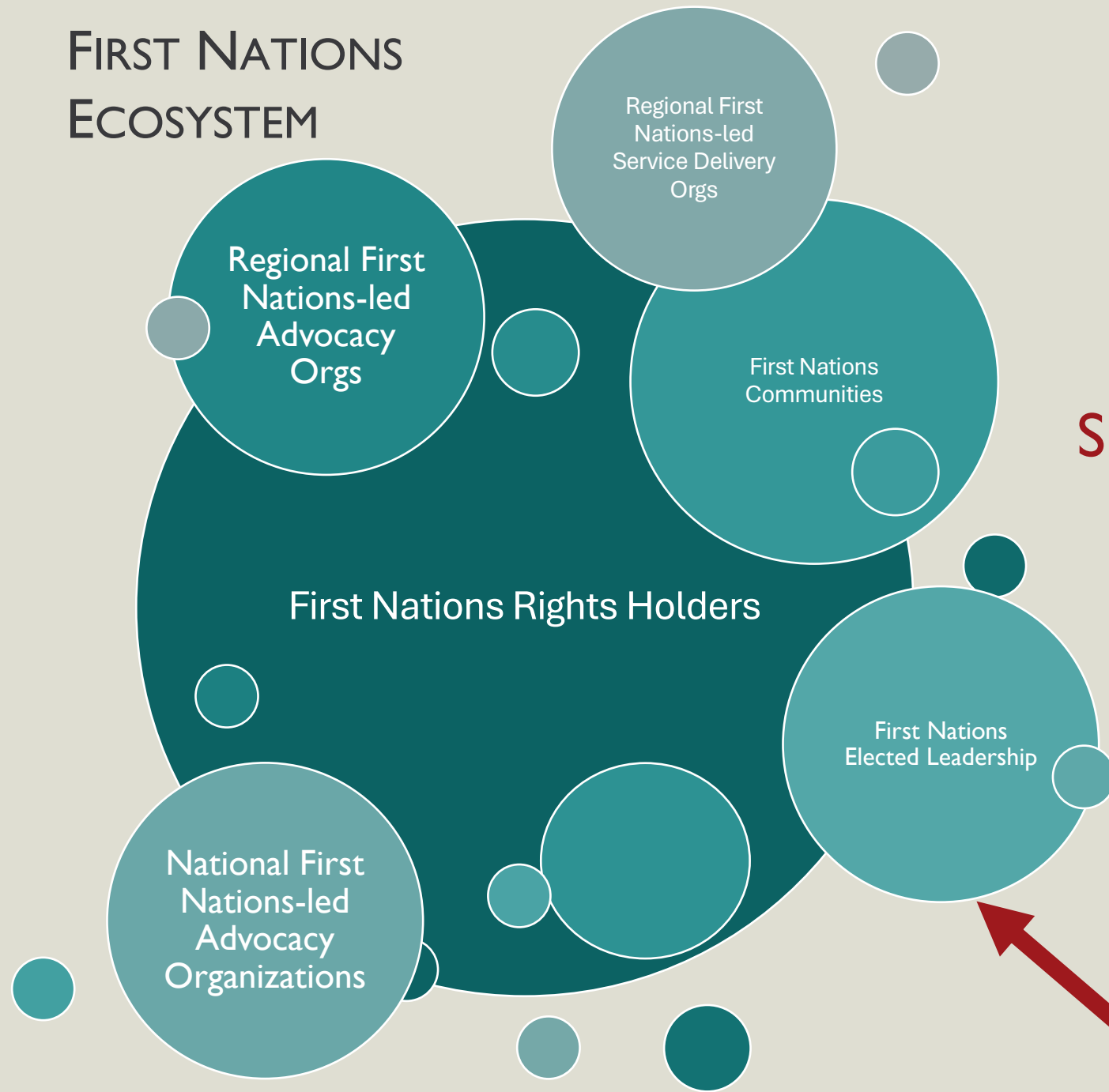
CUSTOMED CAPACITY BUILDING

FIRST NATIONS' DATA SOURCES



DATA USERS LANDSCAPE

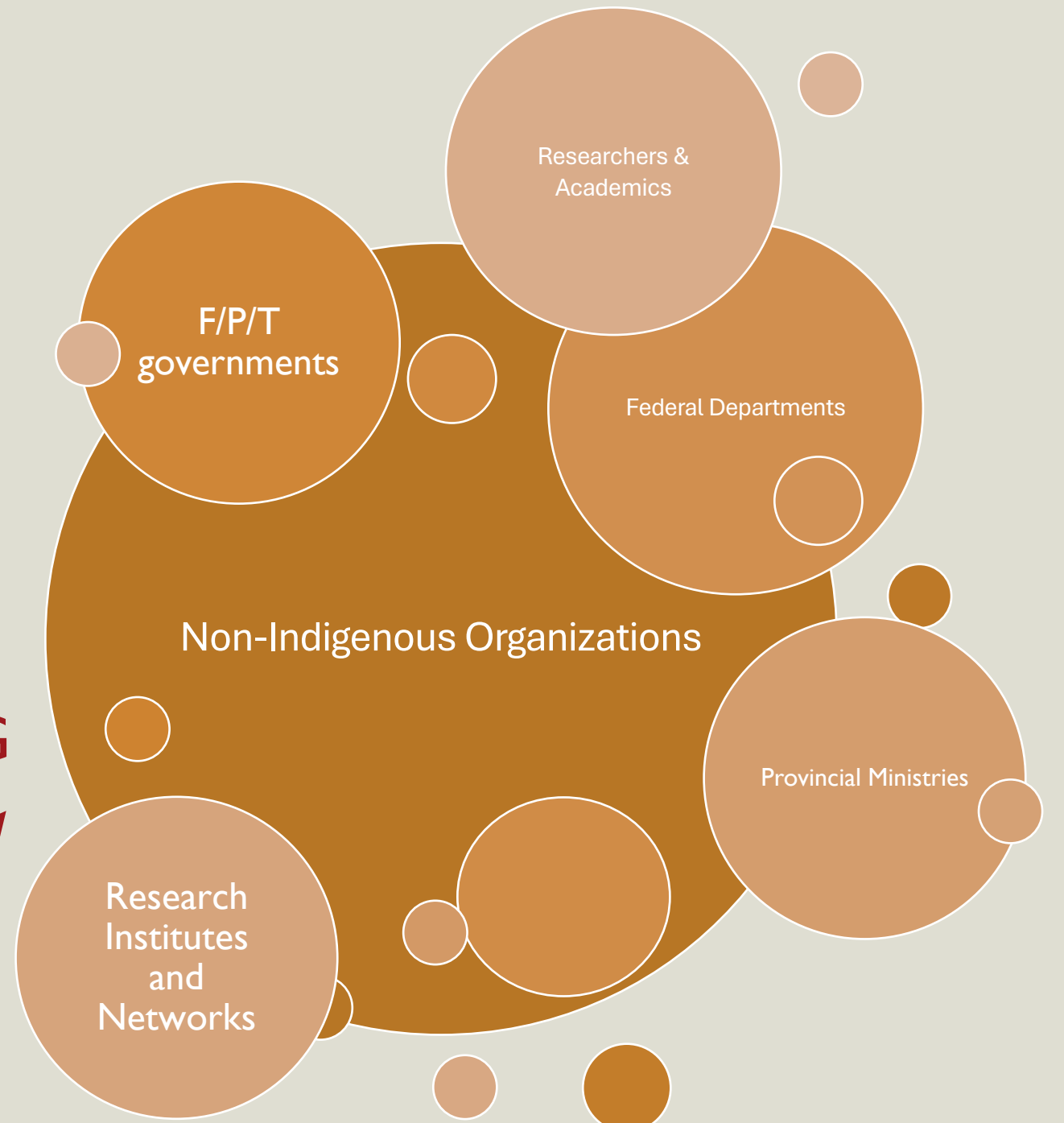
FIRST NATIONS ECOSYSTEM



SERVING FIRST NATIONS' DATA & STATISTICAL NEEDS

SERVING

ENGAGING



CONTRIBUTING TO AND BENEFITING FROM MORE INCLUSIVE CANADIAN STATISTICAL SYSTEMS

(Access to datasets; collaboration on shared objectives; and participation at key technical F/P/T data tables)

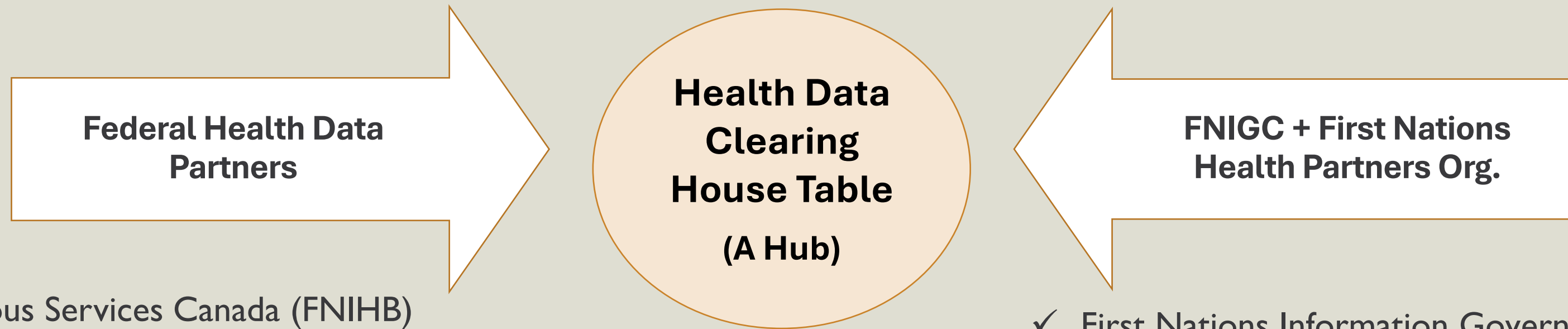
An example of a health data transforming initiative flowing from the FNDGS: **The First Nations Health Data clearing House Table**

Context

- ❑ Budgets 2023/2024 allocated \$200B over 10 years to modernize healthcare and health info systems.
- ❑ Multiple F/P/T committees and working groups have been set up.
- ❑ First Nations lack the capacity to engage in modernization, including to govern their health information.
- ❑ The FNDGS can be instrumental in bridging gaps by building First Nations' data capacity.
 - A **First Nations Health Data Clearing House** created under the FNDGS.
 - A MOU was signed in Feb 2024 by ISC Deputy Minister and FNIGC.

A First Nations Health Data Clearing House Table

An example of a health transforming initiative flowing from the FNDGS



- ✓ Indigenous Services Canada (FNIHB)
- ✓ Health Canada
- ✓ Public Health Agency of Canada
- ✓ Canada Institute of Health Information
- ✓ Canada Health Infoway
- ✓ Health Workforce Canada
- ✓ Statistics Canada
- ✓ ...

- ✓ First Nations Information Governance Center
- ✓ Assembly of First Nations
- ✓ First Nations Health Manager Association First Peoples Wellness Circle (TBC)
- ✓ National Collaborating Center for Indigenous Health (TBC)
- ✓ Thunderbird House (TBC)

INTEGRATING

MAPPING GAPS

CLOSING GAPS

TOWARDS INCLUSIVE HEALTH INFORMATION SYSTEMS

QUESTIONS for your CONSIDERATION

To Inspire a Cultural Shift Towards Greater Diversity and Inclusion

For Indigenous
Organizations...

Data Gaps: What do you believe are the most critical health data gaps faced by First Nations and impacts ?

For public health
practitioners...

Data for Decision Making: What are the main issues with Canada's information and statistical systems, with respect to First Nations public health data (including with provinces and territories)?

For
researchers...

Data Collection & Analysis: What are the main challenges you experience adhering to the OCAP® principles while doing community-based research?

For health sciences
students...

Data Access: In what ways could better access to, and control of data by First Nations, help advance health and wellness outcomes?

Questions, discussion?

THANK YOU!

FNDGS inquiries: ecorston@fnigc.ca

General FNIGC inquiries: info@fnigc.ca

Media inquiries, please contact: media@fnigc.ca

OCAP® inquiries please contact: ocap@fnigc.ca



FNDGS | SGDPN



FNIGC | CGIPN

Discussion Period

Any questions?

Please use the **Q&A tab** to submit your questions for our speaker. You can “**like**” other people’s questions to push them up in priority.



Closing Remarks



Thank You!



The seminar recording and presentation slides will be posted on <https://nccid.ca/> within a few weeks.

Join us on **Tuesday, October 29, 2024 (1:00-2:00pm ET)** for the next seminar on **cancer surveillance** and **Ontario's Occupational Disease Surveillance System.**

Visit <https://nccid.ca/surveillance-advances-seminar-series/> for more information.



Your feedback is important to us!



Please complete our **post-seminar evaluation survey** by scanning its QR code. Today's post-seminar survey will also be distributed to you shortly after the seminar.

Additionally, if you attended any seminars in the 2023-2024 season, please complete the **Year-End survey** using its QR code below.

Survey for today's seminar:



2023-2024 Year-End Survey:

