

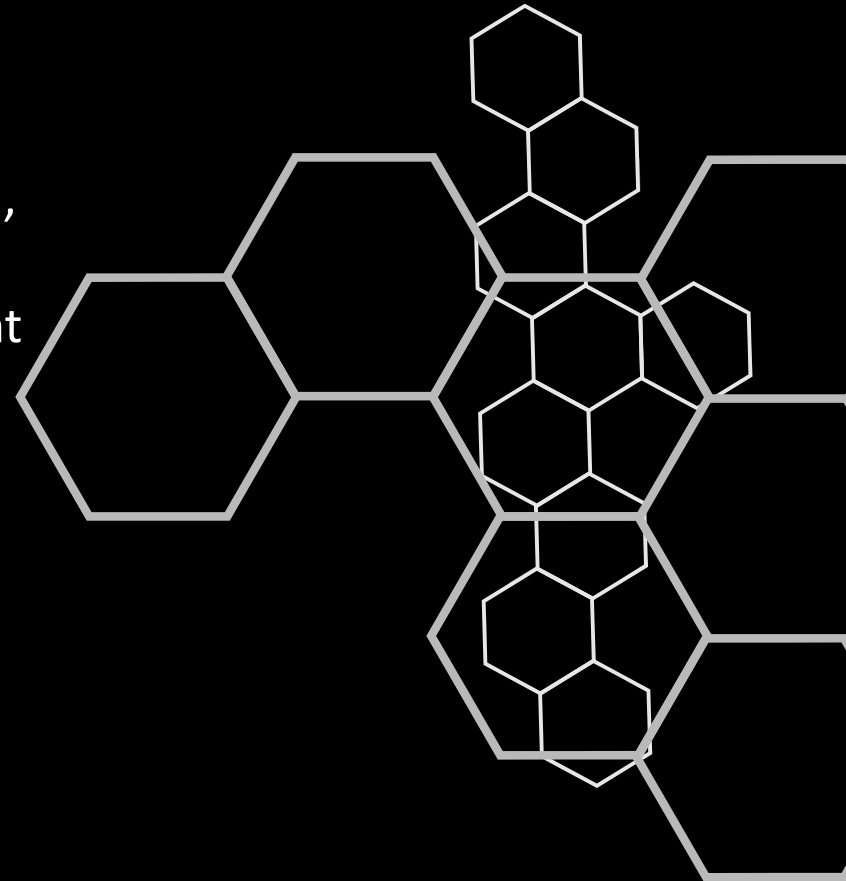


NEW BRUNSWICK INSTITUTE FOR RESEARCH,
DATA AND TRAINING:
A Ten-year Partnership Between Government
And Academia

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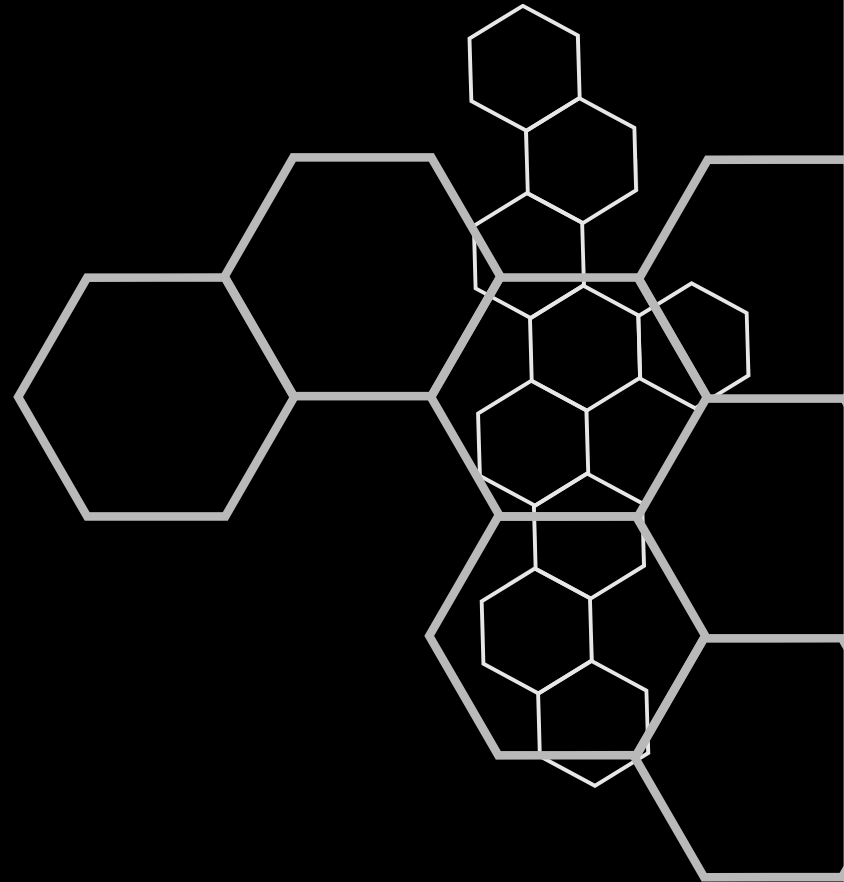


OUTLINE

- Overview of NB-IRDT
- Legislative pathway to establishing NB-IRDT
 - The process of amending legislation & developing new legislation
- The Five Safes
 - Practicing privacy
- Relationship with GNB
 - Governance and research agreements
- Enablers of success (so far)



Overview of NB-IRDT



WHAT NB-IRDT DOES

- Operates as a provincial research data centre and **data custodian** as defined in NB legislation
- Hosts and provides access to person-level deidentified but linkable program **data** in a highly secure research network (Fredericton, Moncton, Saint John sites)
- Conducts objective, rigorous and evidence-based **research and program evaluation** to support GNB planning and policy development
- Receives, links, hosts and analyzes **user-provided** personal information from clinical trials, observational studies, devices etc.

WHAT NB-IRDT DOESN'T DO

- Does not get 'real-time' data; is not integrated into Health information systems
- Does not provide guidance on treatment or practice for specific individuals
- Does not replace regular reporting by health authorities or agencies



DATA SHARING AGREEMENTS

- Master data sharing agreements (MDSA) define NB-IRDT as the data custodian for any data transferred and enable their access for research purposes
- MDSAs in place with:
 - NB Department of Health
 - Horizon and Vitalité Health Authorities
 - NB Department Education and Early Childhood Development
 - NB Department of Post-Secondary Education, Training and Labour
 - NB Department of Social Development
 - WorksafeNB
- MDSAs in development with MPHEC, Departments of Justice and Public Safety
- Data sharing agreement signed with Immigration, Refugee and Citizenship Canada

LINKABLE LONGITUDINAL DATASETS AT NB-IRDT

Department of Health Administrative Data

- Citizen Database (Medicare)
- Hospital Discharge Abstracts
- Provincial drug plans
- Physician billing
- Provider registry
- Vital Statistics death data
- NB Insulin pump program
- Cancer and Breast Cancer screening registries
- Chronic disease indicators for diabetes, MS, COPD, hypertension, etc.
- National Rehabilitation Database
- Healthy Toddler Assessment
- Management Information System

LINKABLE LONGITUDINAL DATASETS AT NB-IRDT

Department of Health EHR and Regional Health Authority data

- Clinical ALS patient data
- NB Trauma registry
- HB-A1C
- Pulmonary function test lab data
- Diagnostic imaging database (LBP)
- IV administered chemotherapy (Vitalite HN)
- COVID-19 test results

PENDING

- Drug Information System data
- ER encounters
- IV administered chemotherapy (Horizon HN)
- CTAR radiation therapy
- Memory clinic data

LINKABLE LONGITUDINAL DATASETS AT NB-IRDT

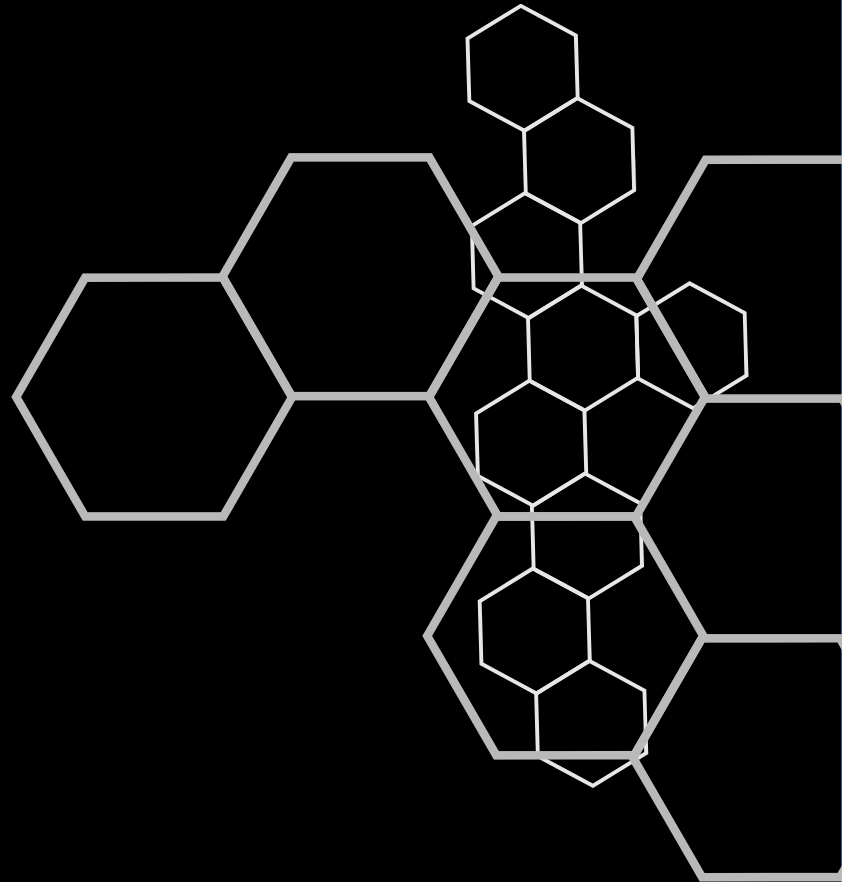
Other government data

- NB *Powerschool* K-12 student grades and attendance
- Provincial assessment scores
- Early Years Evaluation
- Adult education and training program participation
- Immigration landing records
- Long term care
- Suicide Registry
- University and community college enrollment
- Worksafe NB claims

PENDING

- Apprenticeship data
- Social support program participation
- RAI-LTCF Nursing home data
- Motor vehicle accidents
- Court appearances
- Quarry and industrial site data

Legislative Pathways to Establishing NB-IRDT



LEGISLATIVE PATHWAY FOR NB-IRDT



- 2012 – changes to the NB *Personal Health Information Privacy and Access Act (PHIPAA)* to define a research data centre and designate as a data custodian
- 2015 – *PHIPAA* allows Medicare health insurance number to be used for data matching to conduct research
- 2015 – NB-IRDT officially launched as UNB institute by UNB and the Premier of NB
- 2015 – first dataset is delivered (Discharge Abstracts Database)
- 2016 – review/approval of originating agreement, operating agreement, foundational PIA and TRA, and data sharing agreement templates by multiple agencies

THE KEY CHALLENGE

- Personal Health Information Protection and Access Act (PHIPAA) was modified to define NB-IRDT as a data custodian, but lack of clear legislative authority in other legislation meant that **all further data transfers were halted**
 - Medicare Act – physician billing
 - Right to Information and Protection of Privacy Act (RTIPPA) – all personal information, including Medicare provider information, education, income support, justice, training, immigration, housing
 - Family Services Act and Nursing Home Act – long term care
- Departments also could not share data with each other except for specifically prescribed reasons – so data couldn't be linked

AN ACT RESPECTING RESEARCH

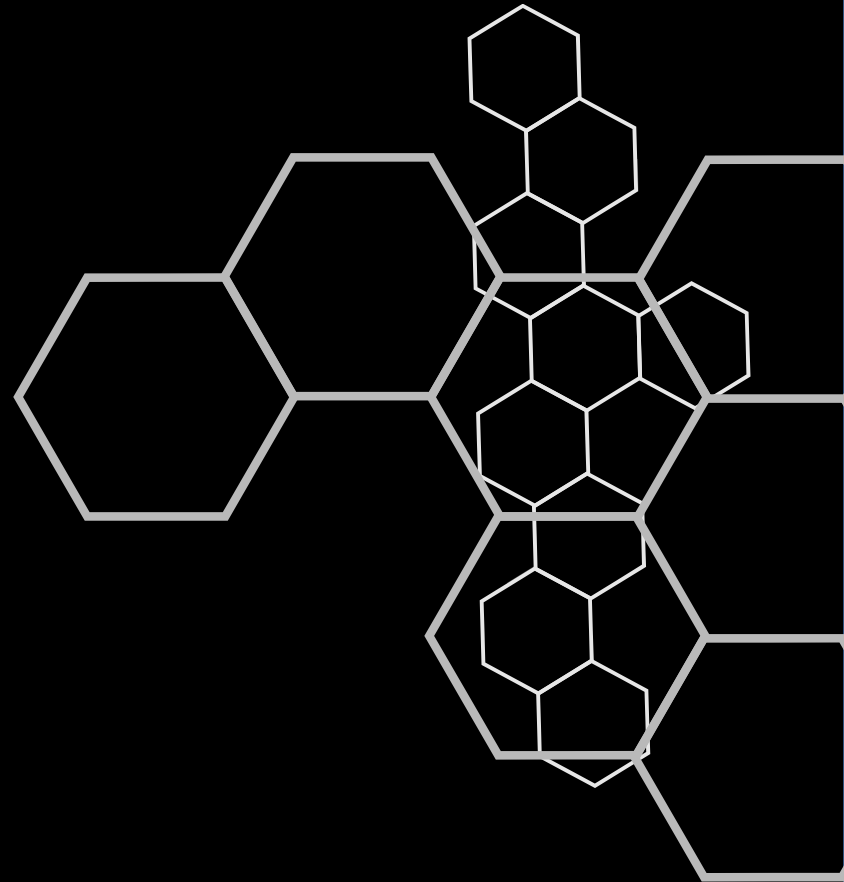
- Modifies a list of other legislation to **provide legal authority** for NB-IRDT to receive and use research-relevant data from the provincial government and public bodies in a deidentified but linkable form
- Provides authority for Departments and public bodies to share identifying information with NB Department of Health for **data matching purposes** with NB-IRDT
- Bill 57 proclaimed into law May 2017
 - 10+ pieces of legislation including RTIPPA and Medicare Act
- Bill 29 proclaimed into law June 2019
 - MPHEC Act, Education Act, Medical Services Act, Labour Market Research Act, Family Income Security Act, Family Services Act, Early Childhood Services Act, Clean Water Act

THE IMPLICATION

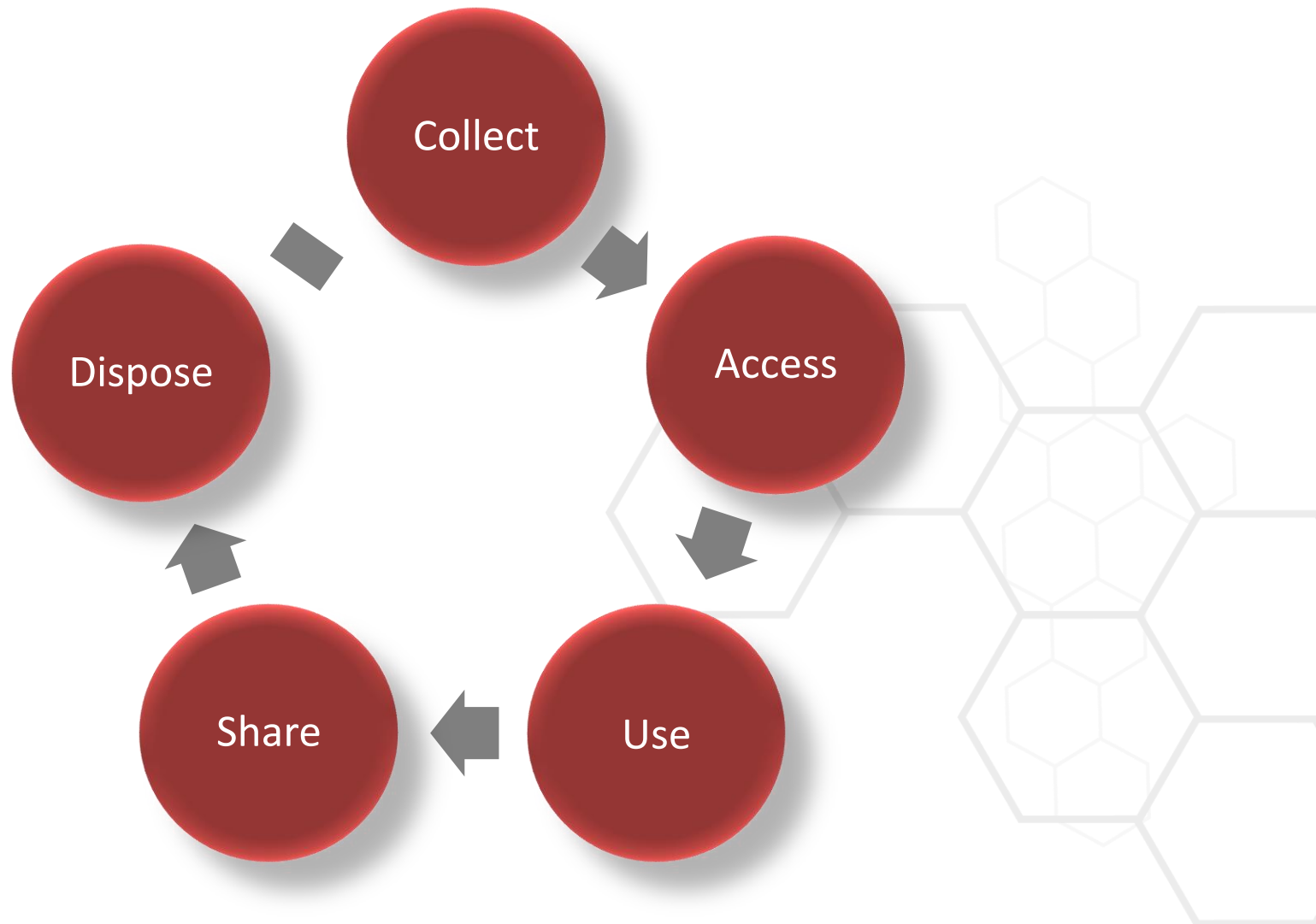
- Obstacles to the transfer of administrative data were narrowed to operational issues
 - Drafting agreements
 - Identifying and mobilizing available resources



The 5 Safes Framework: Practicing Privacy



DATA LIFE CYCLE



ESTABLISHING A PRIVACY PROGRAM

Policy

- Legislative guidance
- Research specific requirements
- Safeguards

Principles

- Guiding set of standards
- Minimally acceptable
- Internationally recognized

Planning

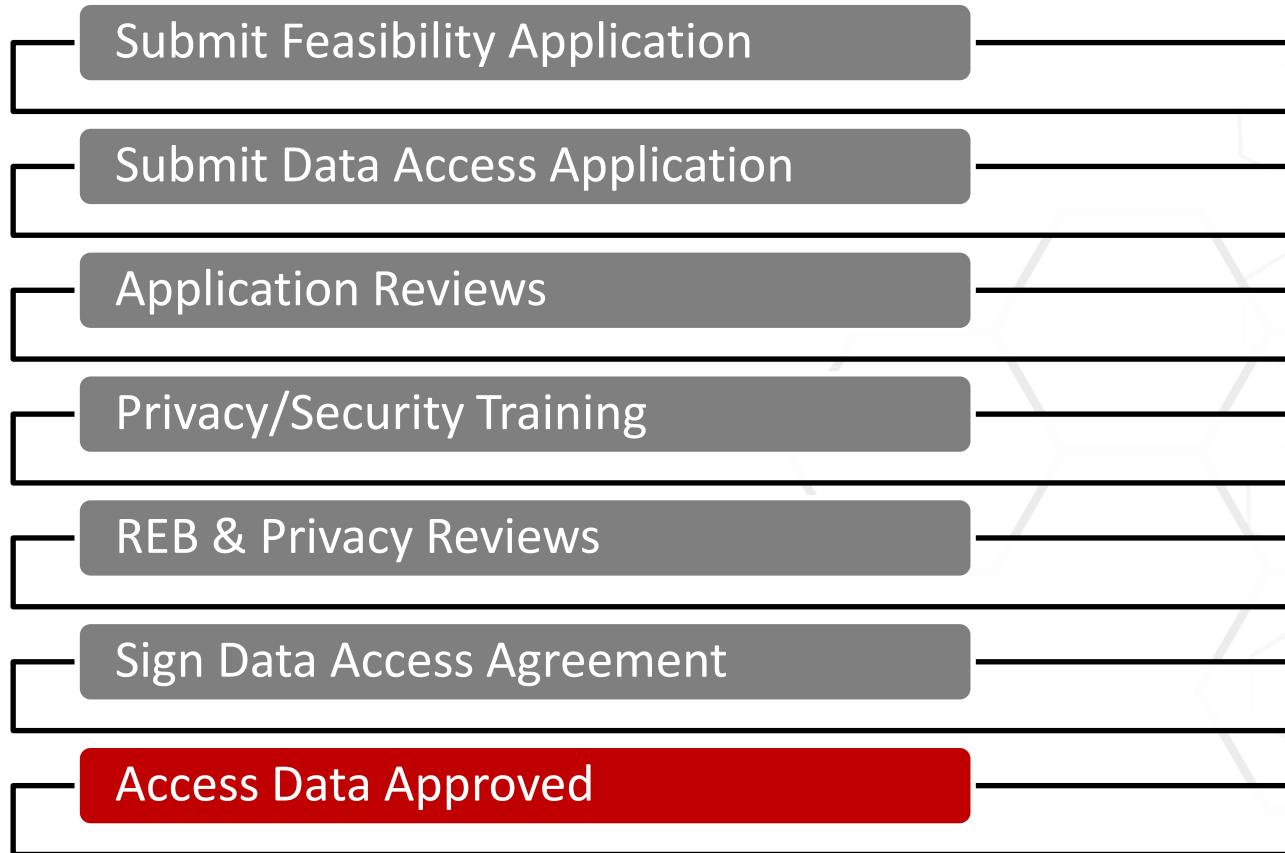
- Adopting of Privacy by Design
- Proactive and preventative
- Balance between privacy and security

Procedures

- Safe Projects
- Safe People
- Safe Settings
- Safe Data
- Safe Outputs

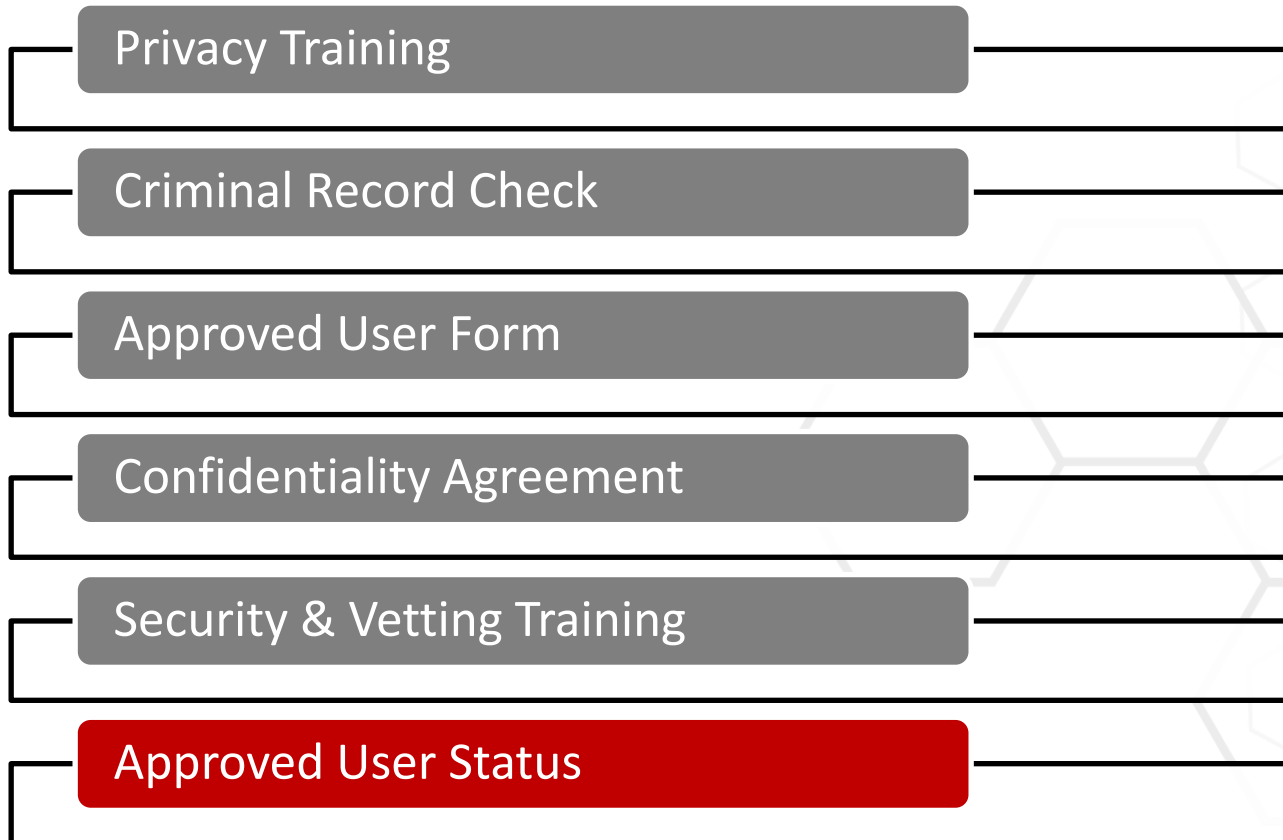
SAFE PROJECTS

Evaluating data analysis projects for appropriateness



SAFE PEOPLE

Evaluating researchers who see data



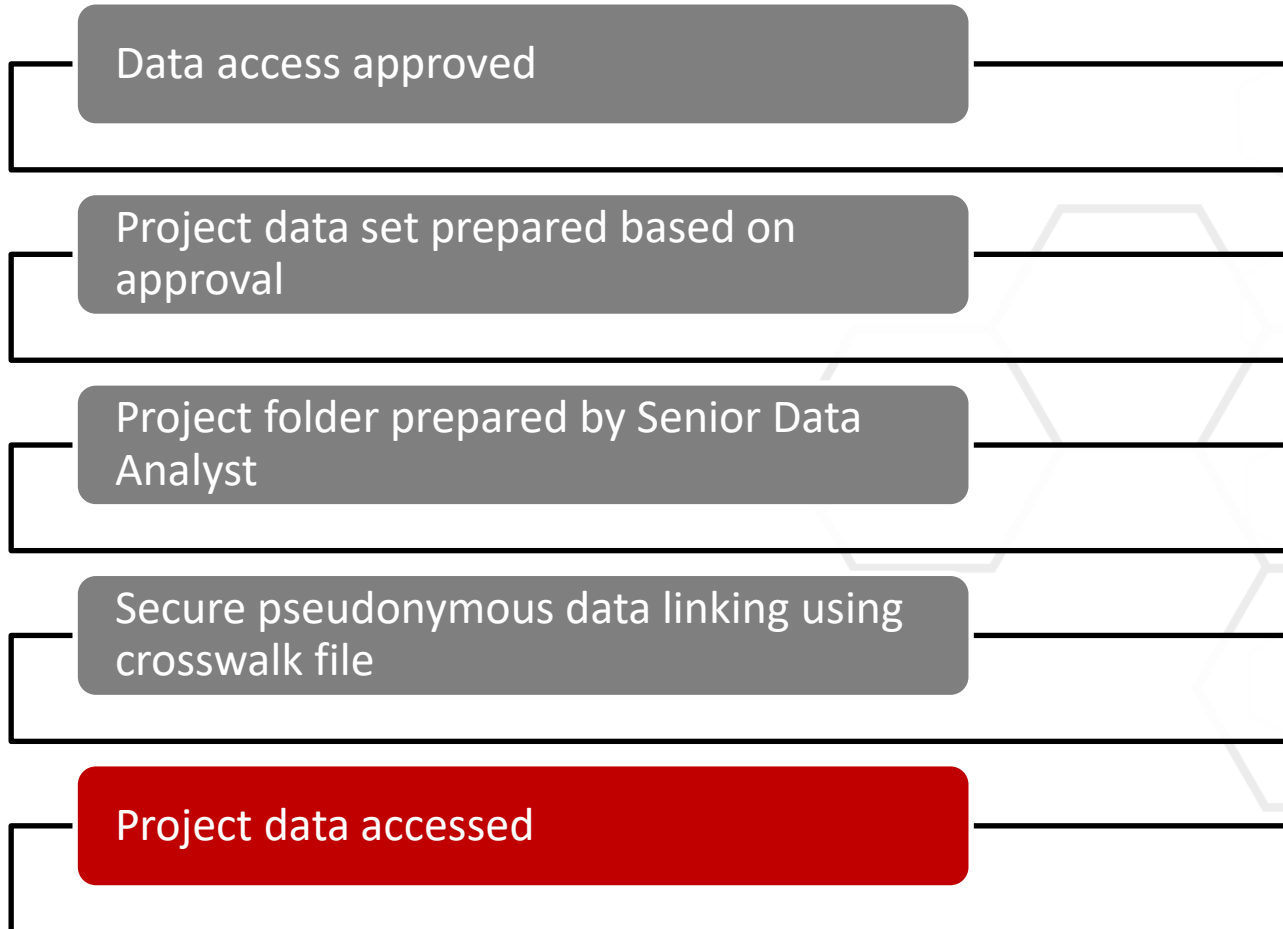
SAFE SETTINGS

Data access

- Two factor authentication to enter
- Unique User Names & Passwords
- Workstations disabled
- Worked saved on local server
- Network air gapped
- Satellite sites – zero-clients
- No mobile devices
- Secure Research Environment**

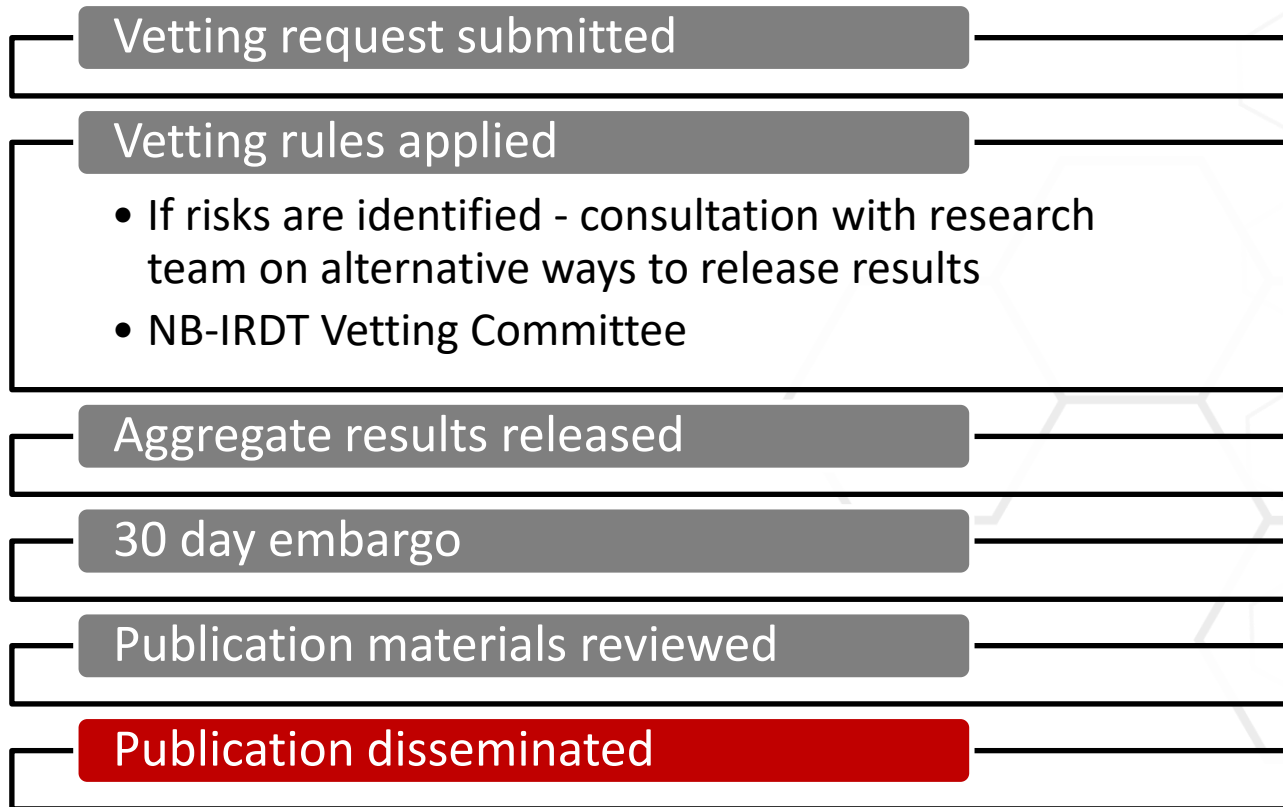
SAFE DATA

Verifying and Mitigating Disclosure Risk in the Data



SAFE OUTPUTS

Verifying and Mitigating Disclosure Risk in Statistical Analysis Results and Tabulations



TRANSFERRING DATA TO NB-IRDT

Confirm appropriate agreement

Identify data set

NB-IRDT data transfer documentation

- Data Sharing Agreement
- Individual Disclosure Schedule
- Privacy Impact Assessment

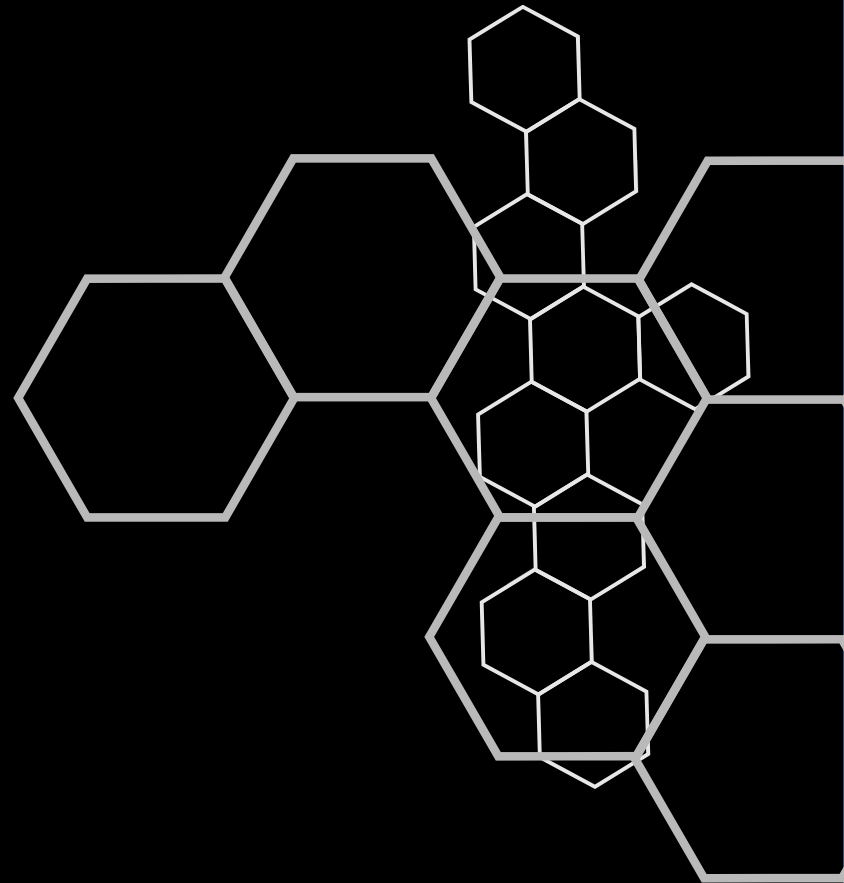
DH data transfer documentation

- Data Sharing Agreement
- Crosswalk File application

Data preparation

Data transfer

Relationship with the Government of New Brunswick



GOVERNANCE

Partnership Coordination Committee

- Provides high-level guidance and direction on sustainability
- Membership: UNB VP-Research (Chair), Clerk of Executive Council Office, three Deputy Ministers, VP Research of both Regional Health Authorities

Data and Research Committee

- Reviews all applications submitted to access NB-IRDT data; reviews all publication/presentation material prior to public release
- Membership: Deputy Secretary to Cabinet, Director of Health Analytics, GNB Chief Privacy Officer, representatives from each agency from which data is sought, NB-IRDT's Director and Privacy Officer

RESEARCH AGREEMENTS WITH GNB

5-year Research Agreement with Postsecondary Education, Training and Labour (PETL)

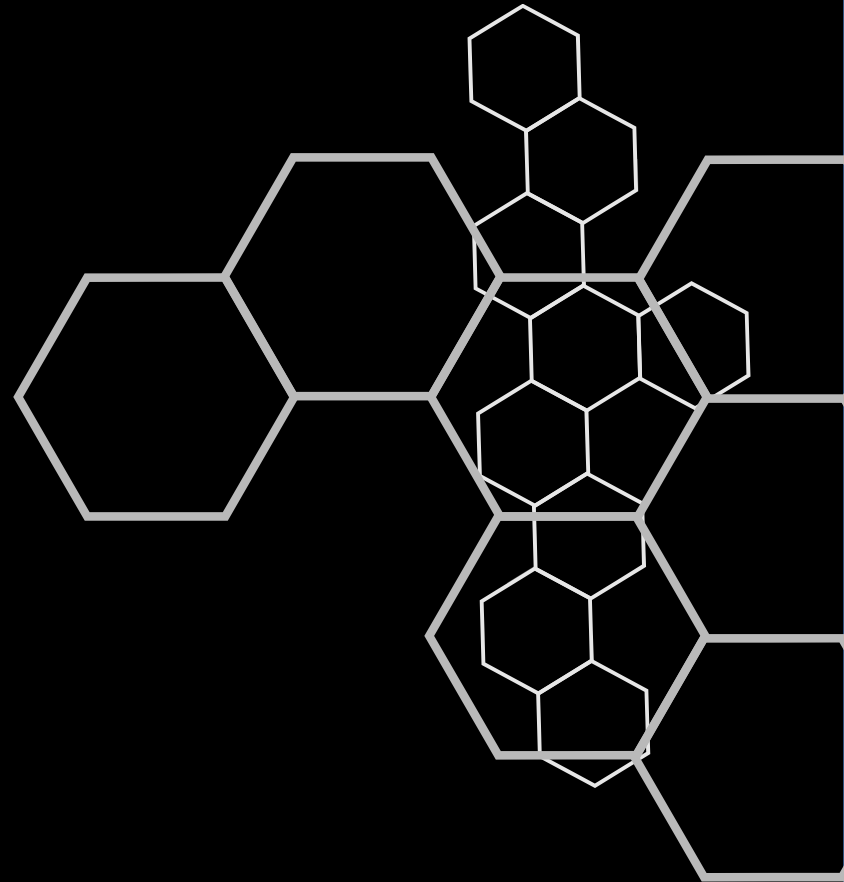
- Research related to labour market program evaluation, immigrant retention and outcomes, postsecondary graduate retention and outcomes, and labour market information projects
- Governance board sets priority areas each year and monitors progress quarterly
- Includes PETL Deputy Minister and assistant Deputy Ministers as well as assistant Deputy Minister from Executive Council Office

RESEARCH AGREEMENTS WITH GNB

2 Research Agreements with Education and Early Childhood Development

- Evaluation of Early Childhood Centres (daycare subsidy program) - **health, education and social impacts** on children and parents in the short, medium and longer terms
- Evaluation of research initiative on hours of instruction increase for kindergarten through grade 2 – effects on children, parents, teachers, school support staff in the short, medium and longer terms

Enablers of Success
(so far)



FEATURES OF THE NB APPROACH

- NB-IRDT is a data custodian with a clearly defined research mandate
- Central role played by the GNB Executive Council Office in integration, sustainability and oversight
- Corporate role played by GNB Department of Health for data matching
- No UNB affiliation is required to access data
- No restriction on who can request to access data but the purpose must be legitimate research
- Standard templates for data sharing agreements and privacy impact assessments for data transfer to both NB-IRDT and GNB DH
- Politically neutral

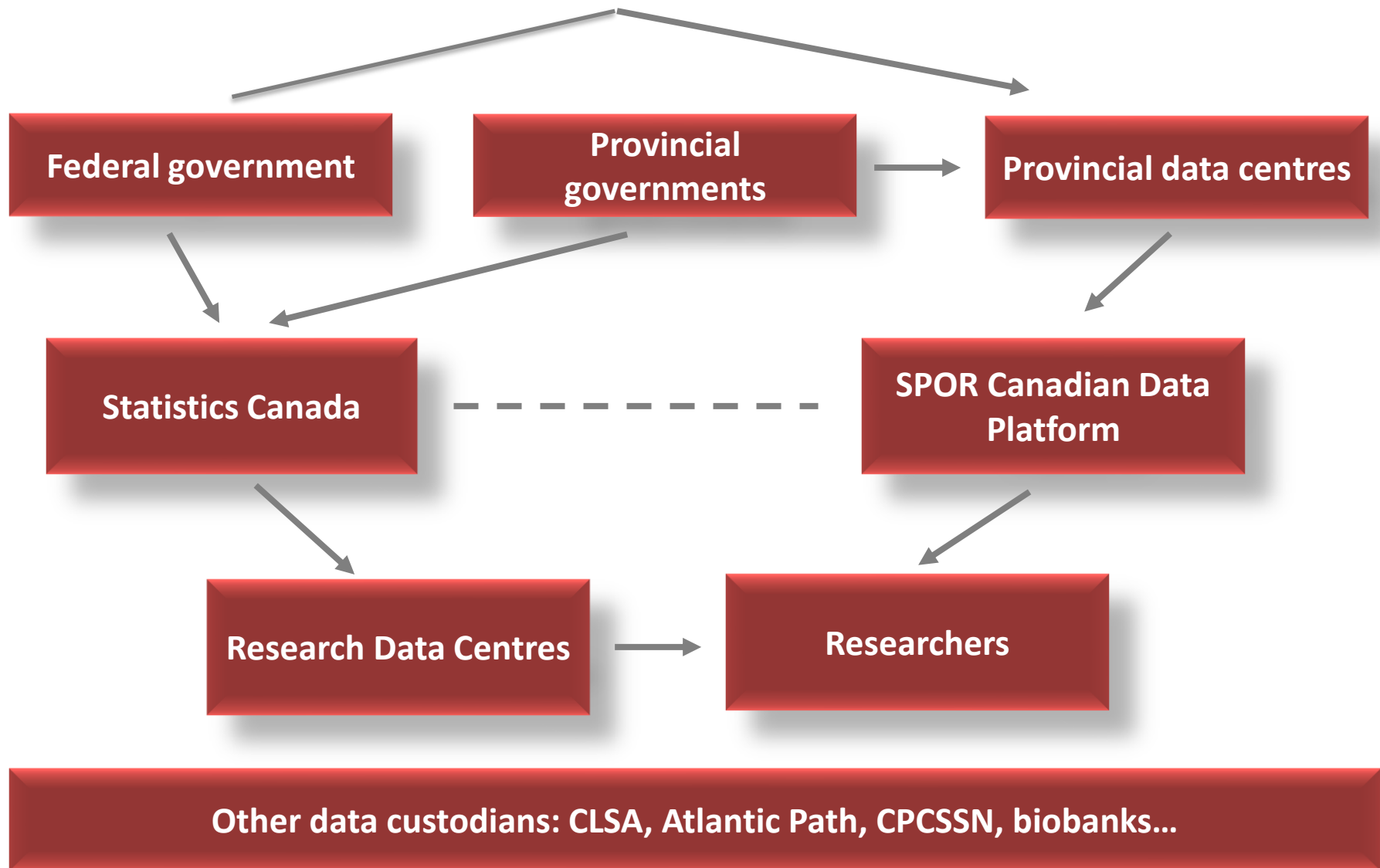
NB-IRDT AND THE DATA LANDSCAPE IN CANADA

- Canadian Federation of 13 provinces and 3 territories
 - Federal – trade, immigration, employment insurance, aboriginal and indigenous affairs, federal taxation, public pensions, census, military
 - Provincial – health, education including higher education, direct taxation, social assistance/income support
 - Both – justice and public safety

HEALTH DATA RESEARCH NETWORK CANADA (HDRN)

- Connects provincial data centres, Statistics Canada and the Canadian Institutes of Health Information
- Common algorithm development, common metadata, unified negotiation on data sharing agreements with partners
- Privacy working group
- Common intake form (Data Access Support Hub) for multi-jurisdictional research

A UNIFIED ADMINISTRATIVE DATA ACCESS MODEL FOR CANADA



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