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
Cancer and Breast Cancer screening registries
Chronic disease indicators for diabetes, MS, COPD, hypertension, etc.
National Rehabilitation Database
Healthy Toddler Assessment
Management Information System

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
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
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

Collect -> Access

Use -> Dispose

Share -> Use
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

- Submit Feasibility Application
- Submit Data Access Application
- Application Reviews
- Privacy/Security Training
- REB & Privacy Reviews
- Sign Data Access Agreement
- Access Data Approved
SAFE PEOPLE

Evaluating researchers who see data

- Privacy Training
- Criminal Record Check
- Approved User Form
- Confidentiality Agreement
- Security & Vetting Training
- Approved User Status
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

- Data access approved
- Project data set prepared based on approval
- Project folder prepared by Senior Data Analyst
- Secure pseudonymous data linking using crosswalk file

Project data accessed
SAFE OUTPUTS

Verifying and Mitigating Disclosure Risk in Statistical Analysis Results and Tabulations

- Vetting request submitted
- Vetting rules applied
  - If risks are identified - consultation with research team on alternative ways to release results
  - NB-IRDT Vetting Committee
- Aggregate results released
- 30 day embargo
- Publication materials reviewed
- Publication disseminated
TRANSFERRING DATA TO NB-IRDT

1. Confirm appropriate agreement
2. Identify data set
3. NB-IRDT data transfer documentation
   - Data Sharing Agreement
   - Individual Disclosure Schedule
   - Privacy Impact Assessment
4. DH data transfer documentation
   - Data Sharing Agreement
   - Crosswalk File application
5. Data preparation
6. 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
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

Federal government

Provincial governments

Provincial data centres

Statistics Canada

SPOR Canadian Data Platform

Research Data Centres

Researchers

Other data custodians: CLSA, Atlantic Path, CPCSSN, biobanks...
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