DEVELOPING A DATA REPOSITORY WHILE PROTECTING PRIVACY:

The experience and impact of legislative change in New Brunswick

October 15, 2020
OUTLINE

• Overview of NB-IRDT

• Legislative pathway to establishing NB-IRDT
  - the process of amending legislation & developing new legislation

• Establishing reassurance
  - 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 de-identified 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.

• Anchors the NB Maritime SPOR SUPPORT Unit
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
STAFF AND BUDGET

- 2 Research associates
- 6 Database analysts
- 2 Research assistants
- 1 Affiliated postdoctoral fellow
- 8 Operations staff
- 2 Seconded GNB employees
- 4 Program evaluators (Healthy Seniors Pilot Project)
- $2.7m in grant and contract revenue in 2019
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 (PHIPPA) 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
THE SOLUTION

• An Act Respecting Research
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 de-identified 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
HOW DID WE (NB) MAKE THIS HAPPEN?

• Executive Council Office, Deputy Clerk led the process – late 2016
• ‘Green lighted’ by the Premier of NB as a priority
• Coordination by a senior policy advisor assigned to the role
• Engagement with Deputy Ministers
• Early engagement with the Office of the Attorney General
• Follow-up by each Department with OAG
  • “please help draft text that will achieve the objectives”
• Consultations: The Official Opposition, The Privacy Commissioner, many stakeholder groups
Obstacles to the transfer of administrative data were narrowed to operational issues

- Drafting agreements
- Identifying and mobilizing available resources
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
Establishing Reassurance
- Practicing Privacy
DATA LIFE CYCLE

Collect

Access

Use

Share

Dispose
WORKING WITHIN THE LAW

Policy

• Legislative guidance
• Research specific requirements
• Safeguards
  • Administrative
  • Physical
  • Technical
PRIVACY PRINCIPLES

Principles

• Accountability
• Identifying Purpose
• Limiting Collection
• Limiting Use, Disclosure and Retention
• Safeguards
PRIVACY PRINCIPLES

Principles

• Consent
• Accuracy
• Openness
• Individual access to ones own data
• Challenge compliance
Planning

- Proactive not reactive; Preventive not remedial
- Privacy as the default setting
- Privacy embedded into design
- Full functionality – Positive sum not zero sum
- End-to-End security – Full life cycle protection
- Visibility and Transparency
- Respect for User Privacy
FIVE SAFES FRAMEWORK

Procedures

- Safe People
- Safe Projects
- Safe Settings
- Safe Data
- Safe Outputs
POLICY + PRINCIPLES + PLANNING + PROCEDURES

Legislation

Privacy Principles

Privacy by Design

Five Safes

Frameworks
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
- Work stations 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

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
MEMORANDUM OF UNDERSTANDING

Signed by President of UNB and GNB Clerk Feb 2018

Commits both GNB and UNB to:

• Long term sustainability of NB-IRDT
• Annual Research Plan
• Annual Training Plan
• NB-IRDT as “researcher of choice” for GNB

Reaffirms participation in GNB / NB-IRDT governance committees
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
PETL PRIORITY PROJECT – STUDENT RETENTION

• How well does NB do in retaining post-secondary graduates of NB institutions after graduation?

• Using:
  • K-12 school data
  • Post-secondary enrollment and graduation data for all 4 public universities and 3 community college systems
  • Medicare registration data

• How do retention rates vary by:
  • Home province or country
  • Field of study, location of study
  • Personal characteristics

• How do our results compare to MPHEC survey results?
RESEARCH AGREEMENT WITH THE COUNCIL OF ATLANTIC MINISTERS OF EDUCATION AND TRAINING (CAMET)

• Analysis of postsecondary education outcomes for residents of Atlantic Canada using linked administrative data

• Using:
  • K-12 school data
  • Post-secondary enrollment and graduation data
  • Tax filer data (via the Statistics Canada Research Data Centre)

• To study:
  • The choice to enter postsecondary education
  • Geographic mobility following graduation
  • Labour market outcomes following graduation
OTHER RESEARCH WITH GNB UNDERWAY / IN DEVELOPMENT

• **Public Safety and the Chief Coroner** – Suicide prevention and infrastructure

• **Environment and Local Government** – Health effects of industrial activity

• **Social Development** – Non-profit organization data development and program evaluation

• **Departments of Health and Social Development** – pathways from home care to hospital *alternative level of care* to nursing home care
COVID-RELATED RESEARCH

• Seven rapid reviews and forecast reports

• Measuring vulnerability and resiliency in NB communities

• Socioeconomic status and the take-up of COVID testing

• Analysis of COVID exposure using serology testing
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
WHY HAS IT WORKED

• Shared vision and commitment to supporting evidence-based policy and program development

• Clearly defining the mandate to meet demand while avoiding duplication – complementary capacity

• Champions within ECO, line departments and public bodies

• Sustained infrastructure funding through MSSU-NB but leveraging MSSU funds wherever possible

• Long term relationships built on mutual trust and communication
WHERE TO NOW?

• More structured relationship with GNB – priority setting, resource allocation, inter-departmental collaboration, evaluating longer term program effects

• More federal-provincial data linkages through Statistics Canada
  • Interprovincial comparisons
  • Longitudinal analysis
  • Income tax and Census linkages

• More joint problem-solving
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