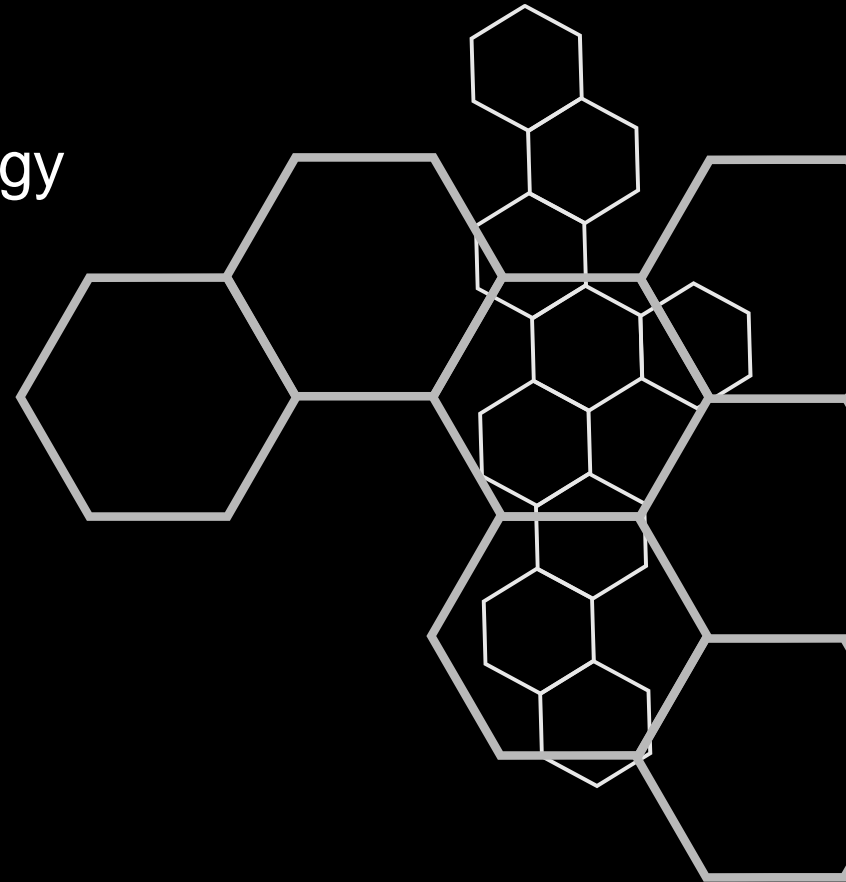




Overview of NB-IRDT presented to Community Health and Epidemiology

Dr. Ted McDonald
Director, NB-IRDT

October 30, 2019



OUTLINE

- Overview of NB-IRDT
- Legislative pathway to establishing NB-IRDT
- Multi-jurisdictional data holdings
- Using the data
- CHIP
- Relationship with GNB – governance and research agreements



NB-IRDT FUNCTIONS

- Conduct objective, rigorous and evidence-based **research and program evaluation** to support GNB planning and policy development
- Host and provide access to person-level deidentified program **data** in a highly secure research network (Fredericton, Moncton, Saint John sites) as a **data custodian**
- Receive, link, host and analyze user-provided personal information from clinical trials, observational studies, devices etc.
- Anchors MSSU-NB

DATA ACCESS

- Access to confidential data for approved projects must be on-site within the secure NB-IRDT facility's closed network
- Main lab is at UNB Fredericton with satellite sites at Université de Moncton and at UNB Saint John, via dedicated FibreOP lines
- Dual-purpose facilities in UNB SJ and UdeM – NB-IRDT and Statistics Canada Research Data Centre
- Data matching is undertaken by NB Department of Health through a crosswalk matching process
- As a custodian NB-IRDT has the authority to hold and grant access to its data holdings

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 it as a data custodian
- 2015 – *PHIPAA* allows Medicare health insurance number to be used for data matching for research purposes
- 2015 – NB-IRDT officially launched by UNB and the Premier of NB
- 2015 – First dataset 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 further data transfers were halted
- Ex:
 - Medicare Act – physician billing
 - Right to Information and Protection of Privacy Act (RTIPPA) – all personal information, including physician characteristics
 - Family Services Act and Nursing Home Act – long term care

AN ACT RESPECTING RESEARCH

- Modifies a list of other legislation to provide authority for NB-IRDT to receive and use research-relevant data from the provincial government and public bodies in a deidentified but linkable form
- Also 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
- 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

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 signed 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
- MDSAs in negotiation with Public Safety, Justice and WorksafeNB
- 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
- Cancer and Breast Cancer screening registries
- Chronic disease indicators for diabetes, MS, COPD, hypertension, etc.
- National Rehabilitation Database
- Healthy Toddler Assessment

LINKABLE LONGITUDINAL DATASETS AT NB-IRDT

Department of Health EHR, RHA data

- Clinical ALS patient data
- NB Trauma registry
- HB-A1C
- Pulmonary function test lab data

PENDING

- Drug Information System data
- ER encounters
- Diagnostic imaging database
- IV administered chemotherapy

LINKABLE LONGITUDINAL DATASETS AT NB-IRDT

Other provincial government data

- NB *Powerschool* k-12 student records
- Standardized testing
- Early Years Evaluation
- Adult education and training program participation
- Provincial Nominee Program immigrant data
- Long term care
- Suicide Registry

PENDING

- Community college enrollment data
- Apprenticeship data
- Income support program participation
- Motor vehicle accidents
- Unexpected death data
- Court appearances
- Quarry and industrial site operations data

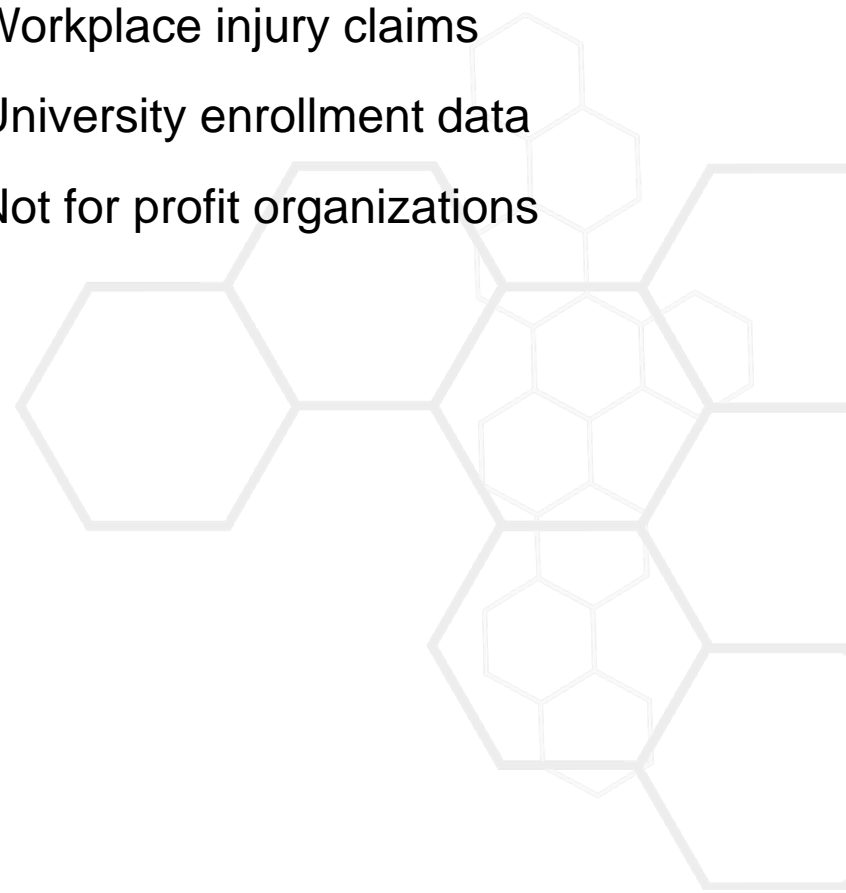
LINKABLE LONGITUDINAL DATASETS AT NB-IRDT

Other agency data

- RAI-MDS nursing home data
- Immigration, Refugee and Citizenship Canada landing records

PENDING

- Workplace injury claims
- University enrollment data
- Not for profit organizations



ACCESSING DATA AT NB-IRDT



PROJECTS USING NB-IRDRT PLATFORM DATA

- Feasibility review - 5
- Application review - 4
- Approved and underway - 19
- Completed - 8



EXAMPLES OF RECENT AND ONGOING WORK USING ADMIN DATA

- Hospital volume, surgical experience and adverse events for hip and knee replacement, Caesarean section, and colorectal surgery
- The effects on hospitalization rates and patient outcomes of hospital service rationalization
- Trauma patients and in-hospital and post-discharge mortality
- Validating algorithms identifying non-traumatic spinal cord injury
- Breast cancer screening and stage at diagnosis of breast cancer
- Environmental air pollution in MS risk and hospitalization

EXAMPLES OF UPCOMING WORK USING ADMIN DATA

- Characterizing prevalence of frailty among community dwelling seniors and in those at the time of admission to long-term care facilities in NB
- Primary and secondary physician service use among patients experiencing MS-related hospitalizations
- ‘Zoomers on the go’: evaluating the potential health benefits of participating in peer-led exercise groups for older NBers
- Impact of socioeconomic and geographic factors on long-term outcomes after cardiac surgery
- Trends in the primary care management and health service use of the dementia population in NB

OTHER HEALTH COLLABORATIONS

- RECAP-COAST

Cost effectiveness evaluation of Hep-C treatment and support services using health, social and justice data (Funding: Merck and NBHRF; PI: Dan Smyth)

- CanREVALUE

National collaboration on real world evidence evaluation of oncology drugs (Funding: CIHR, PI: Kelvin Chan)

- CIHR – Canadian Data Platform (Funding: CIHR; PI: Kim McGrail)

COPD HEALTH INFORMATION PLATFORM (CHIP)

- A database of pulmonary function test data linked with patient records, administrative data and socioeconomic and demographic information (Funding: AstraZeneca and NBHRF; PI: Ted McDonald)
- All clinical data transferred including referrals for Asthma
- Support advancement in the management of COPD at the system planning, research, clinical practice and patient levels
- Undertake predictive modeling of incidence and outcomes

PROGRESS TO DATE

- Full clinical records from Horizon Health PFT clinics (~ 70k tests, 11 yrs) extracted, transferred and linked to administrative data
- Full clinical records from Vitalité Health PFT clinics (~50k tests, 11 yrs) extracted, transferred and linked to administrative data
- Data include spirometry results from all PF tests, smoking status, measured height/weight/BMI, demographics
- Research working group formed with clinicians, health services, Dept of Health, academics and patients

INITIAL RESEARCH QUESTIONS

- How do rates and trends of COPD in New Brunswick differ depending on the method of case identification: self-reported, PHAC algorithms on diagnostic codes, clinical testing?
- How does the method of case identification impact observed trends across a range of personal characteristics?
- What percentage of patients diagnosed with COPD have never had spirometry testing? What percentage of patients with clinical confirmation of COPD are not receiving appropriate treatment?
- Do differing demographic environmental exposures and individual behaviours/characteristics lead to different patterns of re-hospitalization and exacerbations?

	CCHS (RDC)	CCHS-DAD (RDC)	CCDSS (NB-IRDT)	NB-CHIP (NB-IRDT)	Full IRDT platform
Demographics	√	√	√*	√*	√*
Health behaviours	√	√	X	√	X
Clinical/medical characteristics	X	X	√	√	√
Service use	√*	√*	√	√	√
Geographic information	√	√	√	√	√
Environmental info	√	√	√	√	√
Quality of life information	√	√	X	X	X
Drug information	X	X	X*	√	√

√ denotes available; X denotes not available; * denotes caveat

MEMORANDUM OF UNDERSTANDING WITH GNB

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

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, Director NB-IRDT, representatives from each agency from which data is sought

RESEARCH AGREEMENTS WITH GNB

- Research Agreement with **Postsecondary Education, Training and Labour (PETL)**
 - labour market program evaluation, immigrant retention and outcomes, postsecondary graduate retention and outcomes, and labour market information
- Two Research Agreements with **Education and Early Childhood Development**
 - Evaluation of Early Childhood Centres (daycare subsidy program)
 - Evaluation of research initiative on hours of instruction increase for kindergarten through grade 2
- Research agreement with **Department of Social Development**
 - Supporting data collection, data curation and program evaluation by nonprofit organizations in Saint John

OTHER COLLABORATIONS WITH GNB UNDERWAY / IN DEVELOPMENT

- **Transportation and Infrastructure** – Motor vehicle collisions and infrastructure improvement
- **Public Safety and the Chief Coroner** – Suicide prevention and infrastructure
- **Environment and Local Government** – Health effects of industrial activity
- **Treasury Board** – Analysis of results from the GNB Workplace Wellness Survey

CONTACT INFORMATION

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