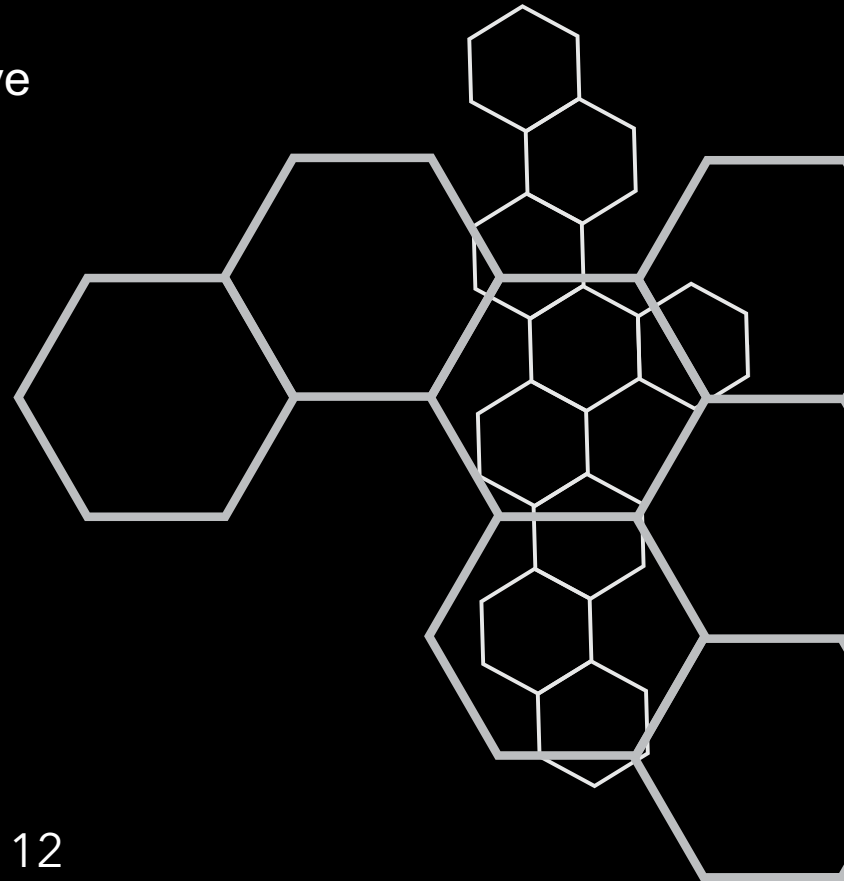


# The Health Data Landscape in Canada: a Brave New(ish) World for Researchers

**Dr. Ted McDonald**  
**Director, NB-IRDT**  
**University of New Brunswick**

Seminar for CCHE - University of Toronto Feb 12  
2021



# OUTLINE

- The Canadian Constitution
- Implications for data access
- Progress
  - At the federal level
  - At the inter-provincial level
  - At the intra-provincial level - NB-IRDT
  - At the federal-provincial level
- Towards an integrated data landscape
- What now?

# PREAMBLE

- Administrative data are data routinely collected through the provision of government services or other interactions with government – health records, school records, tax records, birth records, court records, motor vehicle registration records, vaccination records, etc
- Such data are fundamentally important for understanding and evaluating the impacts of policy and practice

# SERVICE PROVISION IN CANADA - JURISDICTIONS

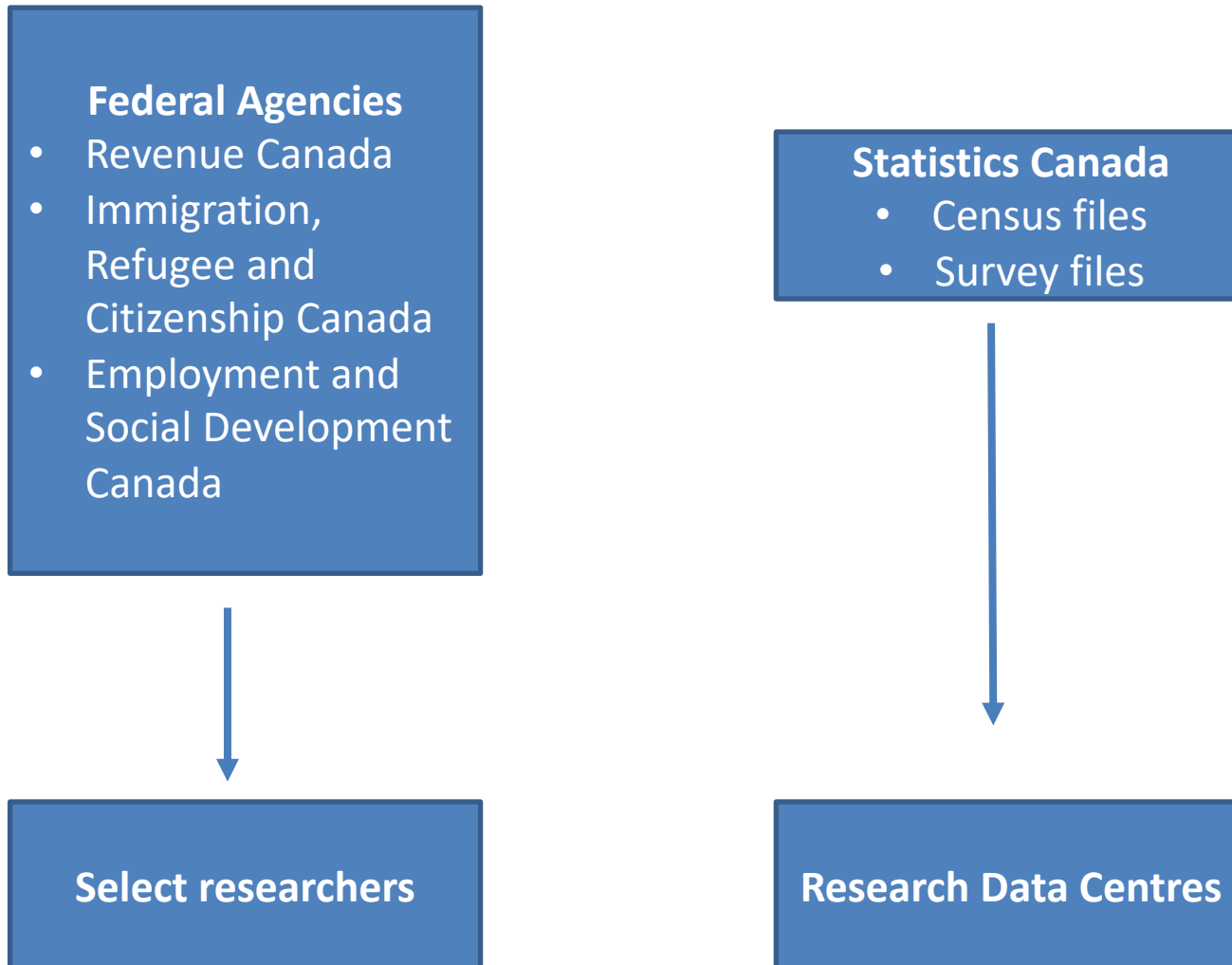
- Federal - trade, immigration, employment insurance, aboriginal and indigenous affairs, federal taxation, public pensions, census, military
- Provincial - health, education including higher education, direct taxation, social assistance/income support
- Both - justice and public safety



# IMPLICATIONS FOR PROGRAM DATA

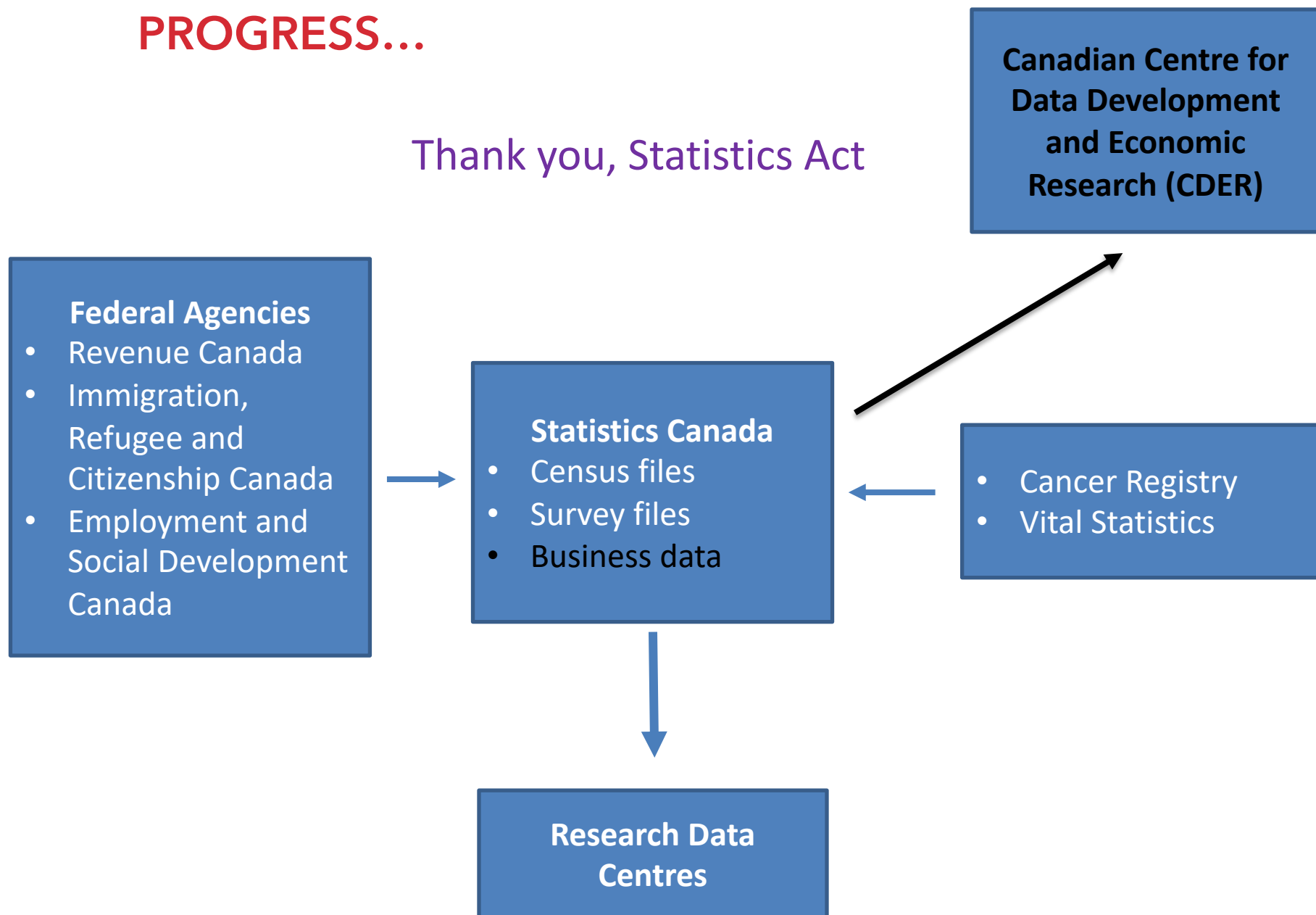


# ACCESS TO FEDERAL DATA - not that long ago

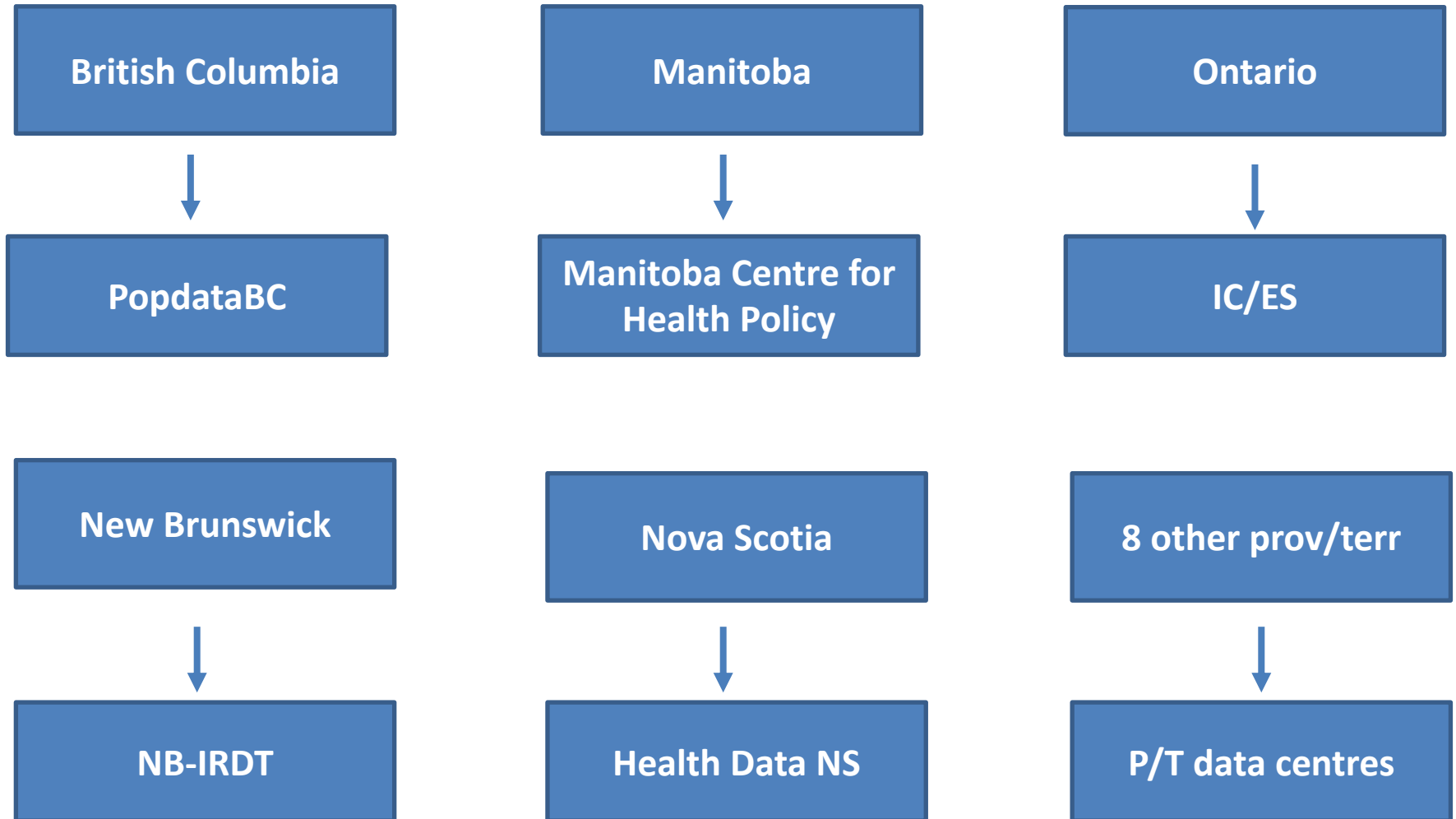


# PROGRESS...

Thank you, Statistics Act



# ACCESS TO PROVINCIAL DATA



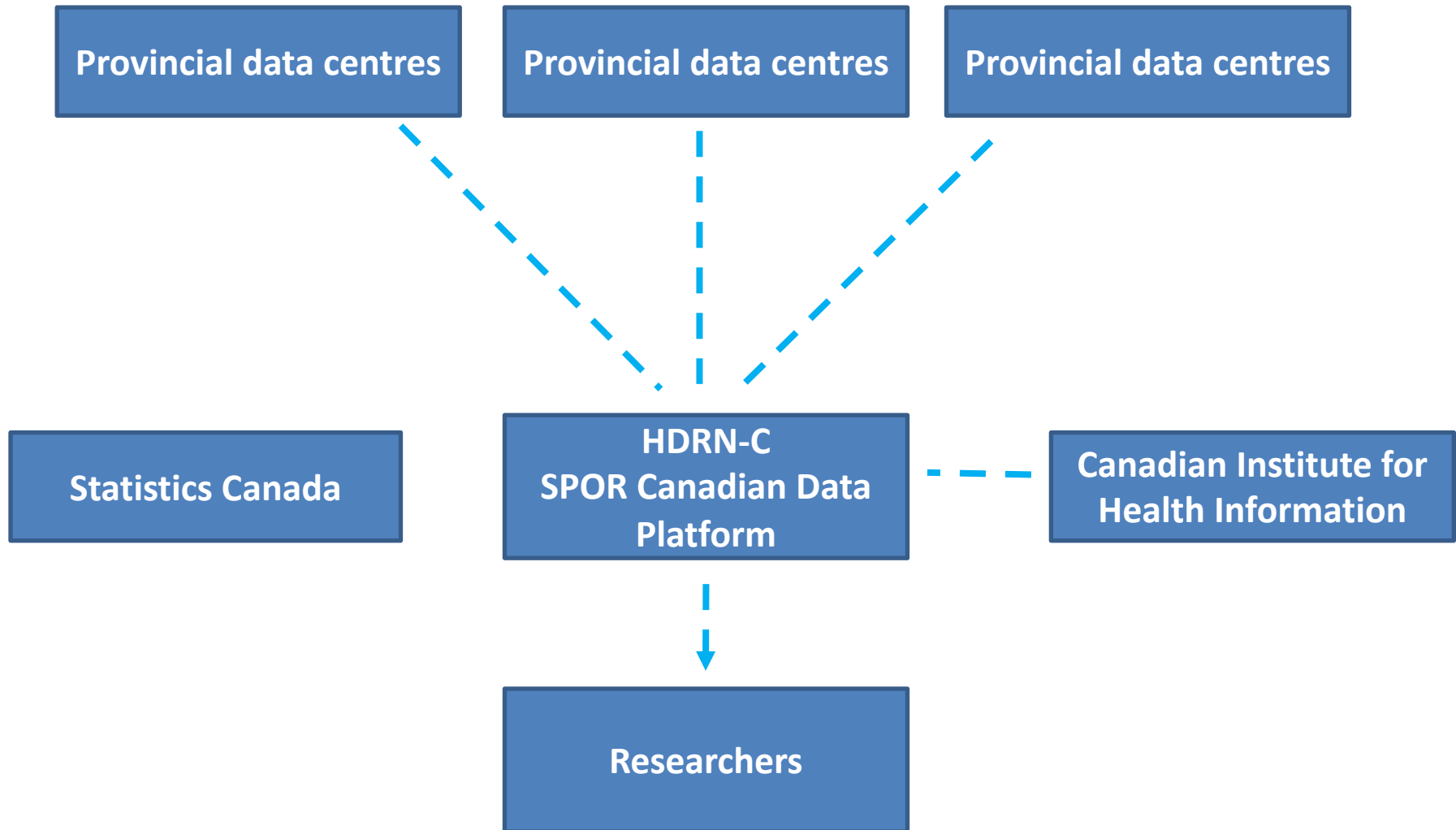


# PROVINCIAL ADMINISTRATIVE DATA CENTRES

- All\* have linkable health records (hospital, physician, drug data)
- Some datasets are consistently defined across provinces (CIHI)
- Many have clinical data
- No sharing of data between provincial data centres
- A few have some education data, income support data, justice data
- None has income tax data



## PROGRESS...



# Key Data Holdings at HDRN Canada Organizations

Last updated June 2020

	BC	AB	SK	MB	ON	QC	NB	NS	NL	CIHI	STC
<b>COVID-19 TEST RESULTS DATA</b>											
<b>HEALTH ADMINISTRATIVE DATA</b>											
Acute care hospitalizations											
Ambulatory clinic visits											
ED visits											
Physician claims											
Prescribed medications											
Home care							plan		plan		
Continuing care											
<b>OTHER HEALTH DATA</b>											
Vital statistics											
Primary care EMR											
Cancer registry											
PREMs and PROMs											
Genomics						plan			plan		
Lab and imaging						plan		plan			
<b>SOCIAL DATA</b>											
Education											
Immigration											
Workers compensation											
Early childhood development					plan						
	BC	AB	SK	MB	ON	QC	NB	NS	NL	CIHI	STC

## LEGEND AND NOTES:

	Population-wide coverage
	Less than population-wide coverage
plan	Linkage and integration planned not yet implemented



# NEW BRUNSWICK'S ADMINISTRATIVE DATA CENTER

## NB-IRDT

- Provincial research data centre and data custodian
- Secure data sites at UNB-Fredericton, UNB-Saint John and U de Moncton
- Anchors NB Maritime SPOR SUPPORT Unit (MSSU)
- Launched 2015



# AN ACT RESPECTING RESEARCH

- Bill 57 proclaimed into law May 2017 defined a legal authority for NB-IRDT to receive and use research-relevant data from provincial government departments and public bodies in a deidentified but linkable form
- Bill 29 proclaimed into law June 2019 modified additional pieces of provincial legislation to include this legal authority
  - 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

## BILL 57

### An Act Respecting Research

Her Majesty, by and with the advice and consent of the Legislative Assembly of New Brunswick, enacts as follows:

#### *Personal Health Information Privacy and Access Act*

1(1) *Section 1 of the Personal Health Information Privacy and Access Act, chapter P-7.05 of the Acts of New Brunswick, 2009, is amended by repealing the definition “research data centre” and substituting the following:*

“research data centre” means a public body that compiles and links personal information or personal health information for the purposes of research, analysis or evidence-based decision-making. (*centre de données de recherche*)

# DATA SHARING AGREEMENTS

- Master data sharing agreements (MDSA) define NB-IRDT as the data custodian for any data transferred and enable access for research purposes
- MDSAs signed with:
  - NB Department of Health
  - Horizon and Vitalité Health Networks
  - NB Department Education and Early Childhood Development
  - NB Department of Post-Secondary Education, Training and Labour
  - NB Department of Social Development
  - Worksafe New Brunswick
  - Immigration, Refugee and Citizenship Canada

# LINKABLE LONGITUDINAL DATASETS AT NB-IRDT

## Health Administrative and Clinical Data

- Citizen Database (Medicare)
- Hospital Discharge Abstracts
- Provincial drug plans
- Physician billing
- Provider registry
- Vital Statistics death data
- Clinical ALS patient data
- NB Trauma registry
- HB-A1C
- Pulmonary function test lab data
- Cancer and Breast Cancer screening registries
- Chronic disease indicators for diabetes, MS, COPD, hypertension, etc.
- National Rehabilitation Database
- Healthy Toddler Assessment
- Diagnostic imaging database (LBP)
- IV administered chemotherapy (Vitalite HN)
- COVID-19 test results

# LINKABLE LONGITUDINAL DATASETS AT NB-IRDT

## PENDING

- Drug Information System data
- ER encounters
- IV administered chemotherapy (Horizon HN)
- CTAR radiation therapy
- Memory clinic data
- Parent-child assistance program 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
- IRCC Immigration landing records
- Long term care
- Suicide Registry
- Worksafe NB claims
- Apprenticeship data
- Social support program participation
- RAI-MDS Nursing home data
- CANUE environmental data
- Quarry and industrial site data
- University and community college enrollment, program and graduation

# USING THE DATA - EXAMPLE 1

## Evaluating the short and longer term impacts of the NB Early Learning Centre program

- Program: Subsidizing daycare costs for kids in low income families to participate in pre-K regulated ELCs
- Objectives: better outcomes for kids, more educational attainment and labour market experience for parents
- Linked datasets required
  - ELC program participation, ELC facility characteristics
  - Receipt of income support or other means tested programming
  - Early years assessments
  - Births data
  - Enrollment in postsecondary education (community colleges and universities)
  - K-5 (and beyond) school performance, attendance
  - Mental and emotional health measures of children and parents
  - Medicare Registry

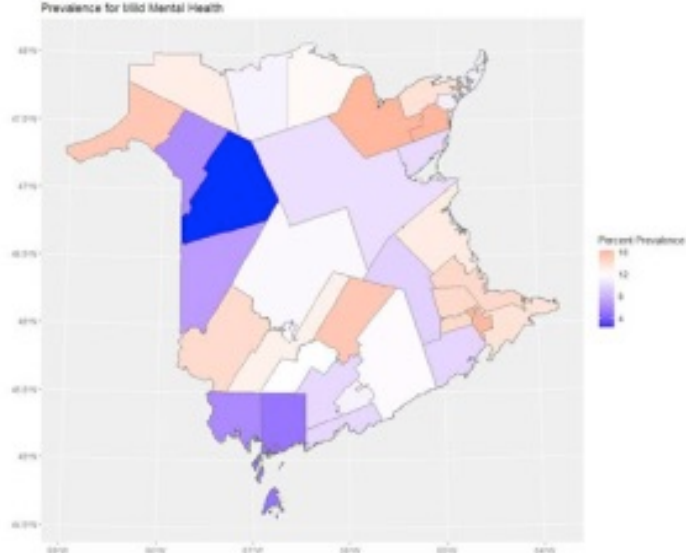
## USING THE DATA - EXAMPLE 2

### Covid community vulnerability

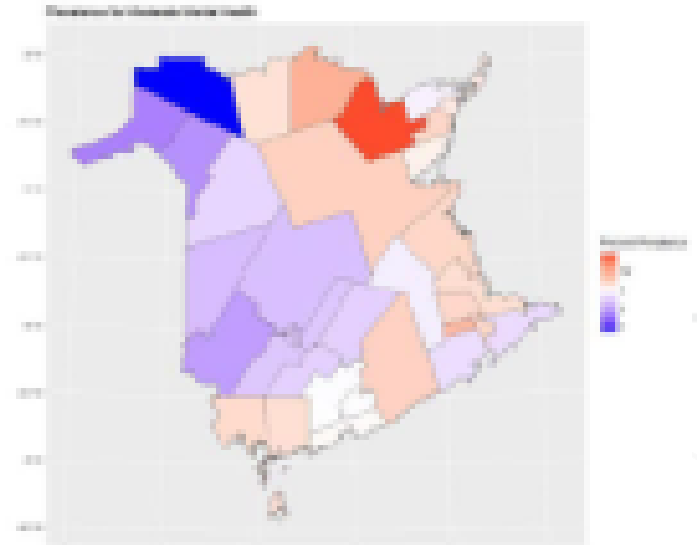
- Key question: What communities in NB are most vulnerable to the direct (infection, hospitalization, ICU, mortality) and indirect (isolation, economic slowdown, delayed testing and procedures) of COVID-19?
- Datasets used
  - Medicare Registry - location of residence, household composition
  - CCDSS Mental Health, COPD, Diabetes
  - Social support programs
  - K-12 school report cards and provincial assessments
- Indicators (phase 1)
  - Prevalence of Multimorbidity with Relevant Physical Condition
  - Prevalence of Households with Children and Older Adults (65+)
  - Prevalence of Mental Illness (Possible, Diagnosed, and Acute)
  - Prevalence of Households with Older Adults Living Alone
  - Prevalence of Households with Single Parents
  - Demographic Dependency Ratio

# Prevalence of mental health issues

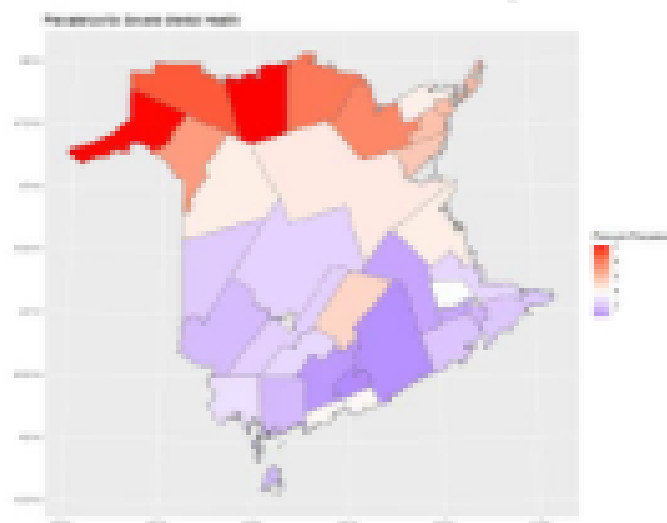
1



2



3



1. Sought help
2. Diagnosed
3. Hospitalized

## PROVINCIAL SHARING



## FEDERAL (STATCAN/RDC) DATA

- CanCHEC-DAD-NACRS: Census, vital statistics, cancer registry, tax records, hospital admissions and ambulatory care
- ELMLP: Post-secondary education, apprenticeships and tax records (to come: Census and employment insurance)
- CCHS-CVSD-DAD-NACRS-OMHRS: Canadian Community Health Surveys, vital statistics, hospital admissions, ambulatory care and the Ontario mental health reporting system
- Hospitalization records linked to Income tax records (100% sample)
- K-12 school, post-secondary education, tax records for British Columbia
- K-12 school data from the Atlantic Provinces (in progress)

## FEDERAL/NATIONAL

## PROVINCIAL DATA SHARING

- Immigration, Refugee and Citizenship Canada (IRCC) has data sharing agreements with
  - IC/ES
  - PopdataBC
  - Manitoba Centre for Health Policy
  - NB-IRDT
- CanPATH, CLSA are working with HDRN to extend data sharing agreements to all provincial administrative data centres

# THE DATA LANDSCAPE IN SWEDEN

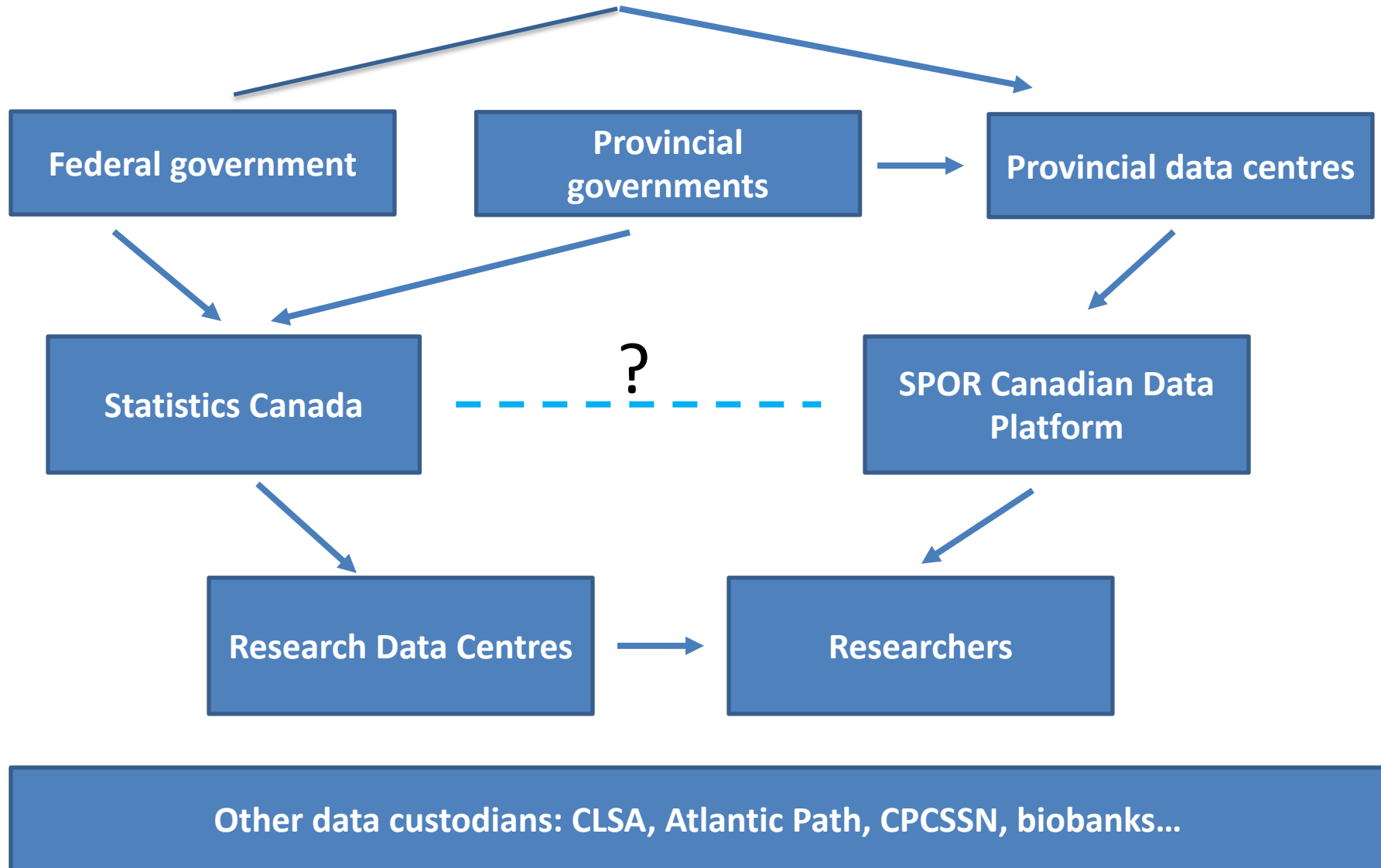
- Central population register based on a unique national identifier, linking:

Dwelling register  
Taxation registers  
Income and wealth  
Wages and salaries  
Labour market registers  
Unemployment, labour market training  
Register on educational attainment  
Student registers  
Social security registers  
Criminal registers  
90 Health-based registers (I-M)

Inflammatory Bowel Disease  
Inguinal Hernia Surgery  
Intensive Care  
Kidney Cancer  
Knee Arthroplasty  
Leukaemia  
Liver Cancer  
Lung Cancer  
Macula  
Mammography Screening  
Neuromuscular Diseases



# A UNIFIED ADMINISTRATIVE DATA ACCESS MODEL FOR CANADA?





# NOW WHAT?

- Consistent data documentation and data standards
- A variety of access models
- Enabling legislation
- Modernized data collection - EHR, EMR
- Linking to (really) big data
- AI/machine learning for administrative data
- **Coordination and communication**



# CONTACT INFORMATION

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