Access to Data for Chronic Disease Research at the NL Centre for Health Information

Chronic Disease Research Exchange Group
April 17, 2013

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Overview

- The Centre’s role
- Data assets
- Request/Data access process
- Contacts
Centre for Health Information

• A comprehensive health information centre
• Crown corporation governed by the Centre for Health Information Act
• Improve health through quality health information
The Centre’s Role

• Develop, implement and operate a provincial EHR
• Maintain key health databases
• Data quality and standards
• Prepare and distribute health reports
• Carry out and support applied health research and benefits evaluations
• Provide information to health professionals, the public, researchers and health system decision-makers
Legislative Framework

• Personal Health Information Act
• Centre for Health Information Act
• Health Research Ethics Authority Act
• Management of Information Act
• Access to Information and Protection of Privacy Act
Acts enable the Centre to provide information...

• Where consent has been given
• For research approved by the HREA
  – Only that which is minimally necessary
• That is de-identified
  – Format such that an individual cannot reasonably be identified
Analytic Services

• Prepare aggregate level numbers and statistics
  – Statistics can be used in reports, paper introductions etc.
• Prepare datasets to be used for research
• Link datasets together so that they can be used for research
  – Link internal datasets
  – Link internal datasets with external datasets
• Navigate information system
  – Statistics Canada, CIHI, other government agencies
• Collaborate on research
Data Assets

• Categories of data
  – Administrative data
  – Population data
  – National surveys
  – Longitudinal research/surveillance data
  – EHR data
Data Assets

• Provincial administrative data

  – Births
  – Mortality
  – Hospital data
  – Physician claims
Live Birth System (1991-2011)

– Live Birth Notification (LBN) forms
– Vital Statistics
– Clinical and Demographic data
– Resident and non-resident births
Stillbirth Database (1991-2011)

- Vital Statistics
- Resident and Non-Resident stillbirths
- Conditions surrounding each stillbirth, but no implication of cause
NLCHI Mortality System (1991-2011)

– Provincial death notifications
– Vital Statistics
– Resident and non-Resident deaths
– Conditions surrounding each death (ICD 9/10 codes)
– Not used for underlying cause of death
Annual Mortality Files (1975-2009)

- Statistics Canada
- Vital Statistics
- Resident deaths only
- Occurred anywhere in Canada
- Underlying cause of death (ICD 9/10 code)
Clinical Database Management System (CDMS) (1995/06-2011/12)

- Hospitalizations in Provincial acute care facilities
- Acute care and surgical day care discharges
- Patients and providers
- Administrative and clinical data on hospitalization (e.g. LOS, Diagnoses, Case-mix Group, Resource Intensity Weighting, ELOS)
- Diagnoses (ICD-9/10) and procedures (CCP/CCI)
Medical Care Plan (MCP) (1995-2011)

• At the discretion of the Minister

Physician Claims
– Fee-For-Service Physician Billings
– Diagnosis (3 digit ICD-9), service provided (fee code), patient and physician

Health Insurance Registry
– Individuals eligible for provincial health care insurance
– MCP #, name, dob, postal code of residence
– Often used to determine age and place of residence
Census of Population

– Statistics Canada
– Conducted every 5 years
– All residents complete short form (basic demographics)
– 20% sample completed long form

– Statistics Canada
– Between Census years
– Population by sex and single year ages
– Based on Census, trends in births, deaths, immigration, emigration
National Health Surveys

• Statistics Canada/Health Canada

• National Population Health Survey (NPHS)
• Canadian Community Health Survey (CCHS)
• Canadian Tobacco Use Monitoring Survey (CTUMS)

• Health status, health determinants, behaviour, health system utilization

• Linkage to administrative/clinical health databases via health care insurance number (MCP number)
National Health Surveys

• Governed by data sharing agreements with federal government

• Some restrictions related to usage/linkage to other datasets

• Survey Files
  – Master File (Research Data Centres)
  – PUMF (universities/public agencies)
  – Share File (Provincial Health Depts)
  – Link File (Provincial Health Depts)
Canadian Community Health Survey (CCHS)

- Statistics Canada
- Cross-Sectional Household Survey
- General Surveys
  - ~130,000 CA, ~4,000 NL
  - RHA level
- Focus Content Survey
  - Mental Health, Nutrition, Health Measures, Healthy Aging
  - ~30,000 CA, ~1,500 NL
  - Provincial Analysis
Linkage of multiple datasets

- Canadian Chronic Disease Surveillance System (NL component)
- First Nation Administrative Health Database
- Longitudinal Pediatric Research Database
- Cancer and Chronic Disease Research Database
- Cervical Cancer Surveillance System
- Suicide Database
Canadian Chronic Disease Surveillance System (CCDSS)

- Collaborative network of P/T systems supported by PHAC
- Health insurance registry, physician claims, hospital data, mortality data
- Diabetes, Hypertension, Asthma/COPD, Mental Illness
  - Pilot: IHD/AMI/Heart Failure and Arthritis/Osteoporosis
  - Feasibility: Stroke, Neurological Conditions and Injury
- Case definitions based on validation studies
- Incidence, prevalence, mortality, HSU and co-morbidities
- Record level data for case/non-case for each condition
Cancer and Chronic Disease Research Database (CCDRD)

- Individuals in the CCDSS with diabetes linked to provincial Oncology Patient Information System (OPIS)
- Flags individuals with a diabetes and/or cancer diagnosis between April 1, 1995 and March 31, 2009
- Originally developed to study the association between diabetes and cancer
- Future expansion:
  - Ongoing updates with most recent years of data
  - Incorporate additional health conditions
Longitudinal Pediatric Research Database

- Linkage of birth, hospital, physician claims, mortality
- Originally developed to study association between birth weight and health service utilization
- May be used for other perinatal and paediatric health
- Currently 1996 to 2010, planned expansion
EHR Data

• EHR development/implementation in progress

• Major components relevant to research
  – Client Registry
  – Pharmacy Network
  – Laboratory data

• Drug Information System (DIS) of the Pharmacy Network currently operational
  – Information related to prescriptions filled within NL
  – 84 pharmacies connected
  – 240,350 unique patients
  – 6,008,232 dispenses
Request Process - Intake

1. Request comes into the Centre
2. Information Request Coordinator
3. Preliminary Inquiry
Intake – Preliminary Inquiry

• Should the request be directed to another organization?
• Does the Centre have the information requested?
• Is the Centre permitted to provide the information requested?
• Is ethics approval required?
Intake – Preliminary Inquiry

• Is a data linkage needed?
• Is there an associated fee?
• What documentation will be required from requestor?
  – Consent forms, letter of support, authority to link/disclose
• Is there a pre-existing data sharing agreement with the requestor?
Request Process - Processing

Preliminary Inquiry

Aggregate Level Request
Definition: compiled or statistical information this is not personally identifiable, i.e. information about a group of individuals

Record Level Request
Definition: data in which each record is related to an individual i.e. datasets commonly used for research
Processing - Aggregate Level Request

- Less sensitive
- Generally in the form of counts and percentages
- Statistical analysis can be provided
- Generally do not release cell counts less than 5
Processing - Record Level Requests

- Record Level Request
- Detailed Consultation with Requestor
- Secondary Uses Committee (SUC)
- Chief Information Officer (CIO)
- Data Prepared by SME
- Information sent to Requestor
Secondary Uses Committee

• Knowledge areas represented
  – Data quality and standards, data availability, data extraction, privacy, legislation, research, request coordination, secondary use best practices, and information security

• Assess request based on privacy principles and SU best practices

• Ethical assessment is outside the scope of the Committee
Processing

• Application collects information to inform the SUC recommendation
• If the request is for research HREA approval must be granted
• Applications are found on the web
• Submitted to IRC
  – im@nlchi.nl.ca
Processing

• Applications must be submitted two weeks prior to SUC meeting date

• SUC meets first Wednesday of each month

• Preliminary inquiry well in advance
What to expect...

• Proof of authorization to link/disclose data to the Centre
  – e.g. Consent form, data sharing agreement
• Conditions on the approval
  – i.e. follow MUN policy, work on MUN asset
• Study proposal developed
• Different data assets/different governing models
• MUN requires data sharing agreements
• Time lapse
  – ~2-3 months if proposal is developed
Contacts

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