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

Chronic Disease Research Exchange Group
April 17, 20013

Kayla D. Collins

Newfoundland & Labrador
Centre for
Health Information

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 reasonable 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
- 1991, 1996, 2001, 2006, 2011

Population Estimates (1991 to 2012)

- – 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

Longitudinal Research/Surveillance Data

- 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

Request comes into the Centre

Information Request Coordinator

Preliminary Inquiry

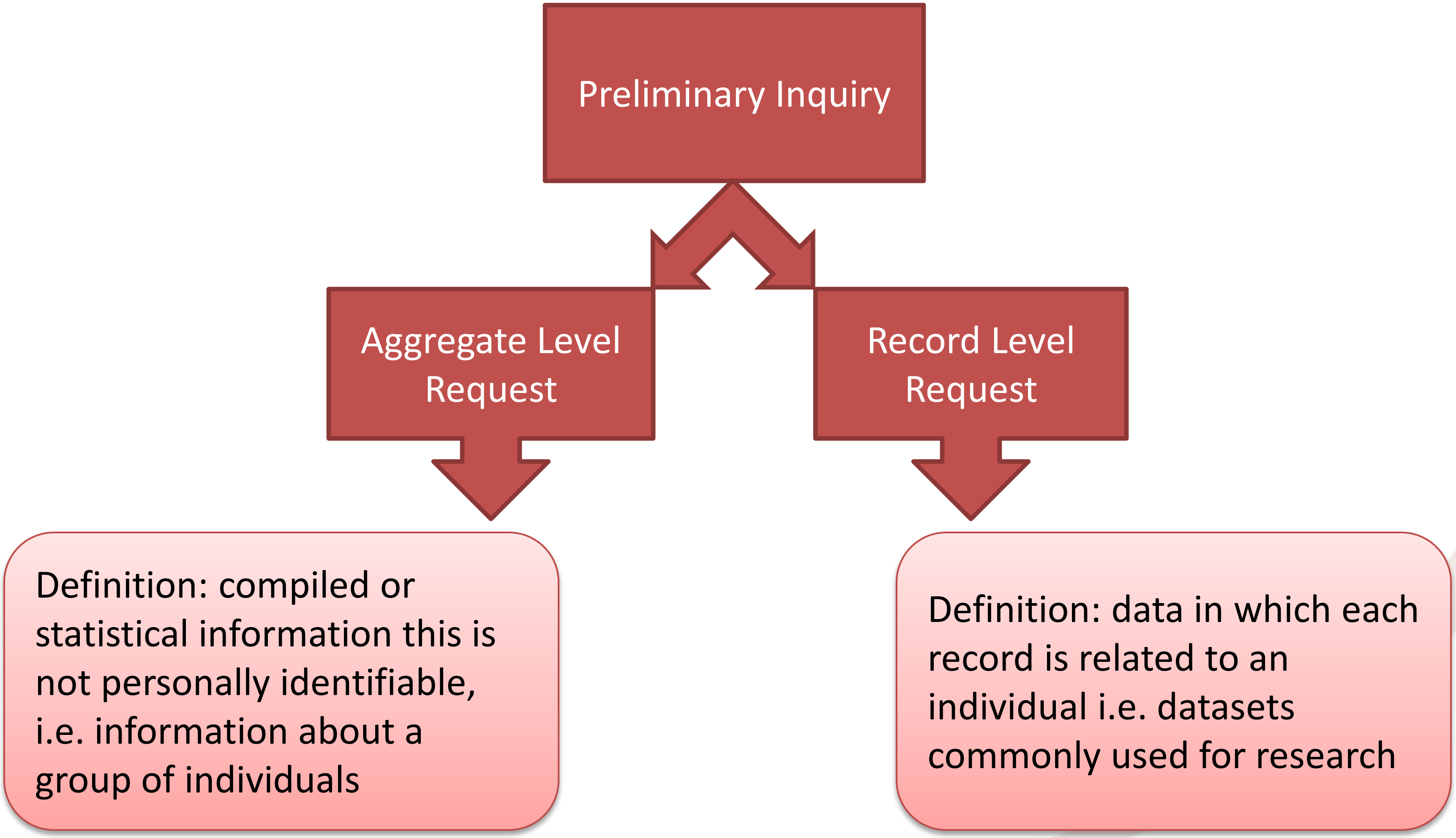
Intake – Preliminary Inquiry

- 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

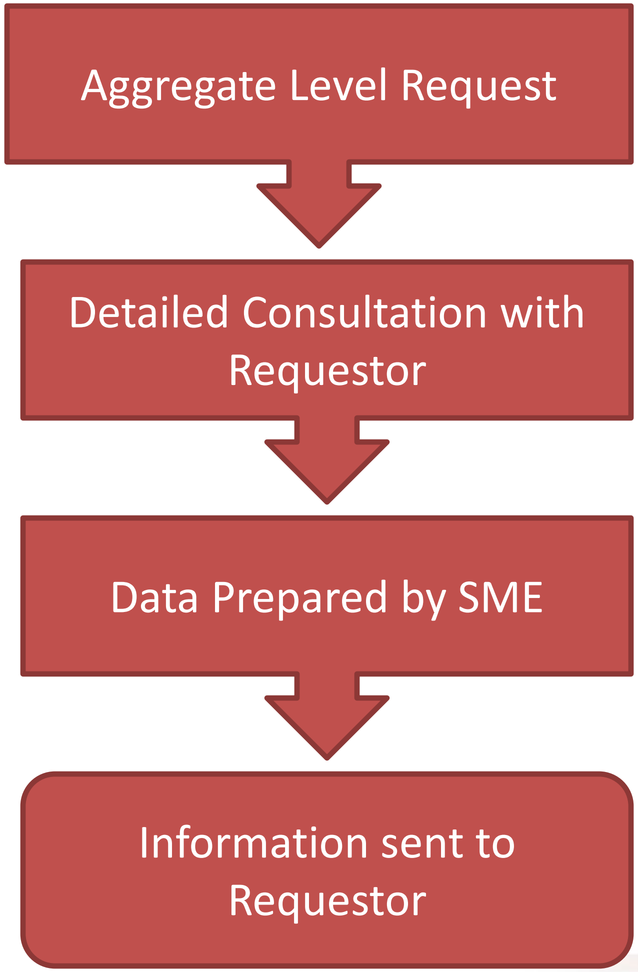
Aggregate Level Request

Record Level Request

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

Definition: data in which each record is related to an individual i.e. datasets commonly used for research

Processing - Aggregate Level Request



Aggregate Level Request

Detailed Consultation with Requestor

Data Prepared by SME

Information sent to Requestor

- 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
  - http://www.nlchi.nl.ca/index.php/request-record-level-information
- 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...

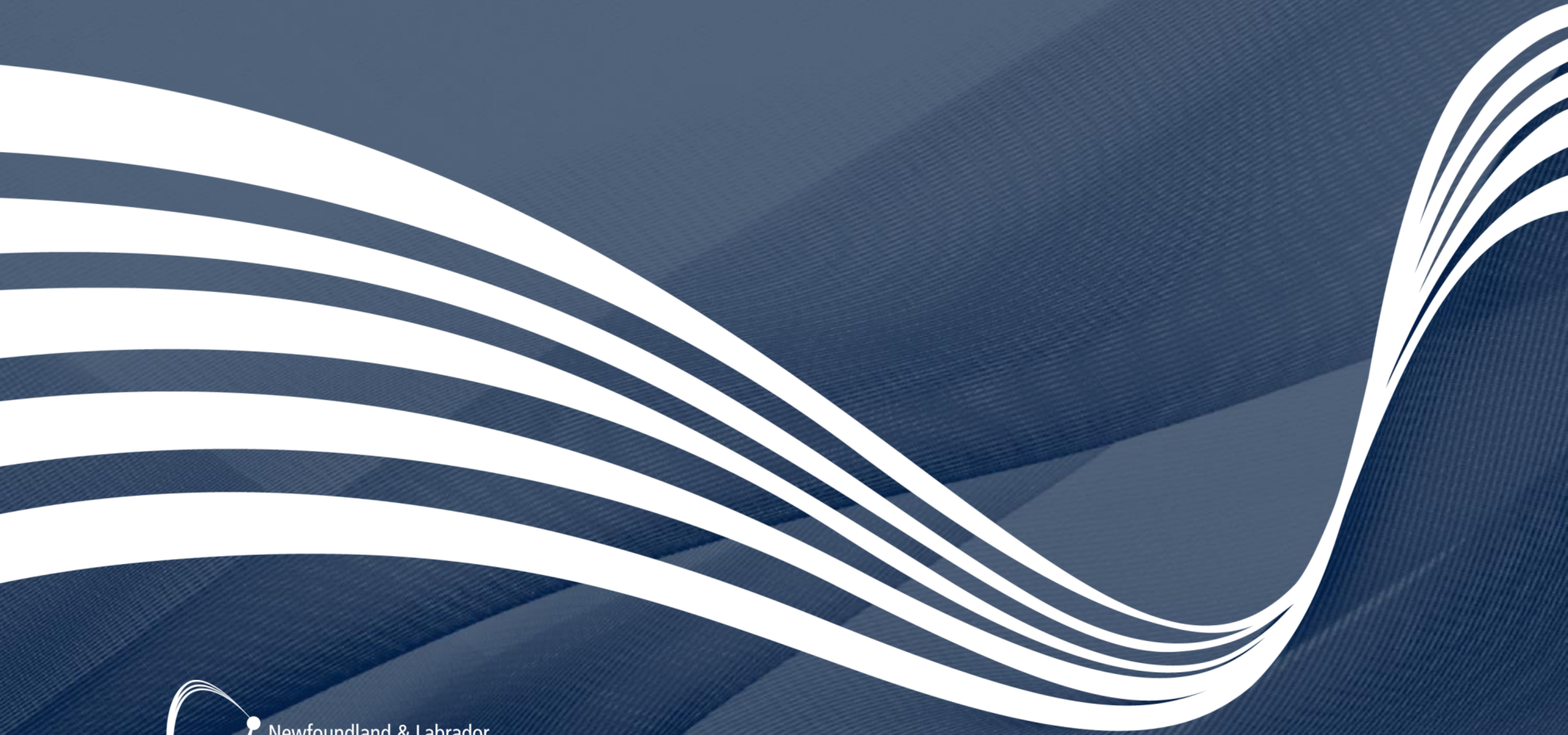
- Proof of authorization to link/disclose data to the Centre
  - e.g. Consent form, data sharing agreement
- Conditions on the approval
  - i.e. follow MUN policy, work on MUN asset
- Study proposal developed
- Different data assets/different governing models
- MUN requires data sharing agreements
-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

Contacts

Karen Purcell
Information Request Lead
inforequests@nlchi.nl.ca
752-6554

Sarah Wickham
Privacy Officer
sarah.wickham@nlchi.nl.ca
752-6072

Kayla Collins
Director, Research and Information Services
kayla.collins@nlchi.nl.ca
752-6045



Newfoundland & Labrador
Centre for
Health Information