Health Aging Data Inventory Project

Aging Research Exchange Group
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Outline of Presentation

- NLCHI/Research and Evaluation Department
- Definition of Aging
- Rationale/Current Knowledge
- Purpose/Objective
- Relevance to Health Aging Policy Framework
- Ethics
- Methods
- Example Data Sources
- Discussion

NL Centre for Health Information (NLCHI)

- Established in 1997 to implement the provincial EHR

- **Mandate**

  *Assist individuals, communities, health service providers and policy makers at federal, provincial and regional levels in **making informed decisions to enhance the health and well-being** of persons in the province*
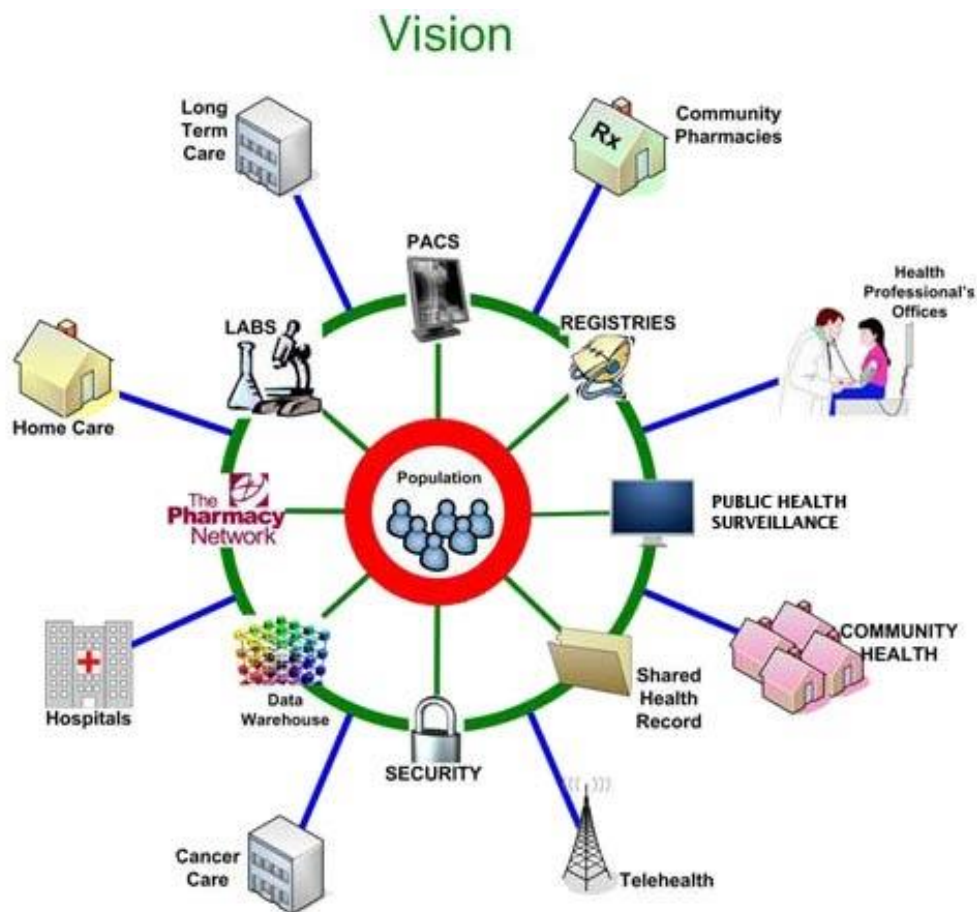
Electronic health records (EHRs) are digital records of patients' medical history, stored and shared across healthcare systems.

(*Canada Health Infoway 2010)*

Typically includes:

- *Basic Demographics*
- *Patient History*
- *Drug, Lab and Diagnostic Imaging information*

Newfoundland & Labrador Health Information Landscape Pre and Post Electronic Health Record

*Supported through collaborative partnerships between Government of Newfoundland and Labrador, Regional Health Authorities, health care providers and the Centre for Health Information

Research and Evaluation Department

- **Mandate**
  - to support the provincial Department of Health and Community Services and Regional Health Authorities by providing knowledge development that will support programs and inform policy
  - to support and collaborate with researchers within the academic and private sectors

- **Data Assets and Expertise**
  - Custodian/holder of a variety of administrative and survey data sources (e.g. hospital abstracts, physician claims, mortality, CCHS)
  - Expertise in research methods, data linkage and secondary data analysis

Research and Evaluation Department

- **27 staff**
  - Epidemiologists
  - Statisticians
  - Research Analysts
  - Data/database analysts
  - Administration

- **Lines of Business**
  - Information Services
  - Applied Health Research
  - Evaluation

"Aging is a lifelong process of optimizing opportunities for improving and preserving health and physical, social and mental wellness, independence, quality of life and enhancing successful life course transitions"
   (Health Canada, 2002)

Rationale/Current Knowledge

- In Canada, the proportion of the population over the age of 65 is growing and is expected to increase

- A demographic shift is occurring in every province in Canada.

- However, the shift appears to be occurring at a faster rate in Newfoundland and Labrador

- NL had highest mean age in Canada in 2011 census (43.8 years)

- Expected to increases to 49 by 2021 (Department of Finance, 2006)

Population 65 years and over, by region, 2011 and projected 2036 (percent)
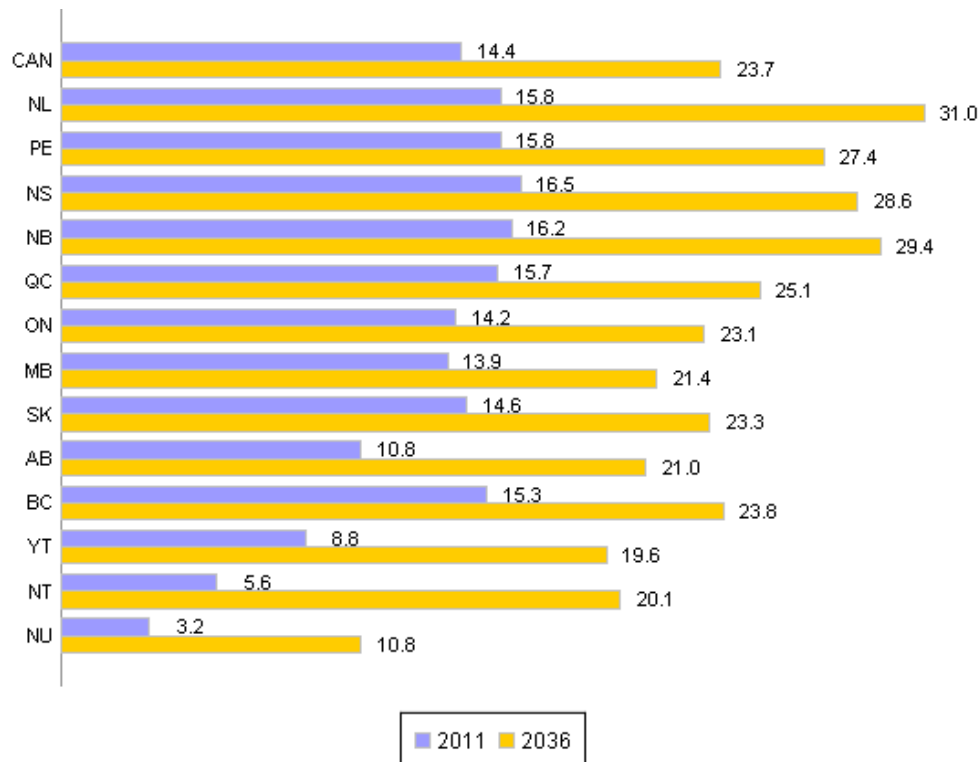
•By 2036 it is expected that the Newfoundland and Labrador will have the highest proportion of seniors.

Source: HRSDC calculations based on Statistics Canada. *Estimates of population, by age group and sex for July 1, Canada, provinces and territories, annual* (CANSIM Table 051-0001); and Statistics Canada. *Projected population, by projection scenario, sex and age group as of July 1, Canada, provinces and territories, annual* (CANSIM table 052-0005). Ottawa: Statistics Canada, 2011. http://www4.hrsdc.gc.ca/.3ndic.1t.4r@-eng.jsp?iid=33

Rationale/Current Knowledge

- According to the World Health Organization, a major strategy towards better health policy is to enable open access to both published and unpublished health information (WHO, 2004).

- Through research and development initiatives secondary data sources can be used to monitor population change and needs

- Health information should be easily accessible so that policy-makers can make well-informed decisions (WHO, 2004).

Rationale/Current Knowledge

- Knowledge translation and uptake of research by policy makers continues to be a challenge across Canada

- Kiefer et al. (2005) conducted a literature review and interviews to identify priority areas for policy makers in population and public health research and knowledge transfer. Some noteworthy recommendations were:
  - Researchers and end users should be better connected
  - There is a need for more involvement of policy-makers in knowledge generation
  - There should be some agreement around a standard of evidence and methodologies
  - Better connection to potential research data sources

Rationale/Current Knowledge

- Secondary data holdings contain a vast amount of information and are a valuable resource for health care planning, policy development, and applied health research needed to understand healthy aging

- However, a lack of knowledge about the data can impede their use

- Therefore, developing an inventory of aging related data sources and the assessment of quality of such data holdings, as well as the transfer of this knowledge to potential users is important

- The experience of the Newfoundland and Labrador Centre for Health Information (NLCHI) in working with administrative datasets combined with its connection to many relevant stakeholders in the health and social sectors, provides the research team with an excellent knowledge base regarding potential data holdings

Purpose/Objectives

- The purpose of the project is to conduct an inventory of data related to healthy aging in Newfoundland and Labrador (NL)

- The specific objectives of the project are to:

1. identify the data needs of stakeholders
2. identify available data holdings
3. systematically assess/report on quality of the identified data holdings
4. identify gaps and limitations in identified data holdings
5. identify potential strategies to acquire missing information
6. produce a data inventory report and make it available to stakeholders

Ethics

- Given that the project will involve collection of information on data holdings and related organizational information rather than acquisition/use of actual data, and that interviewed individuals will not be the direct focus of the research, ethical issues are expected to be minimal.

- Thus, the project did not require ethics review

Methods

- There are six steps required to complete this project:

    1. Identification of stakeholder needs

    2. Identification of data holdings

    3. Systematic assessment of the quality of the identified data holdings

    4. Identification of information gaps and limitations in the identified data holdings

    5. Suggest strategies to acquire missing information

    6. Produce a data inventory report

1. Identification of Stakeholder needs

In order to identify the data needs of stakeholders with respect to healthy aging information in the province, we will consult:

1. Research Community
2. Department of Health and Community Services Government of NL
   - Aging and Seniors
   - Policy Development
   - Planning and Evaluation Divisions
3. Regional Health Authorities
4. Recent survey of regional health authorities' health data needs
5. Annual stakeholder reports and strategic planning documents related to healthy aging
6. Other stakeholders as identified

Relevance to Healthy Aging Policy Framework

- The Provincial Healthy Aging Policy Framework provides goals to help meet Government of NL policy directions:

  1) Recognition of Older Persons

  2) Celebrating Diversity

  3) Supportive Communities

  4) Financial Well-Being

  5) Health and Well-Being

  6) Employment, Education and Research

- It is intended that the inventory will assist program planners, policy makers and researchers to identify data holdings and help fill gaps in data sources that could be utilized to gain a greater understanding of these and other areas of healthy aging

Provincial Healthy Aging
Policy Framework

Newfoundland
Labrador
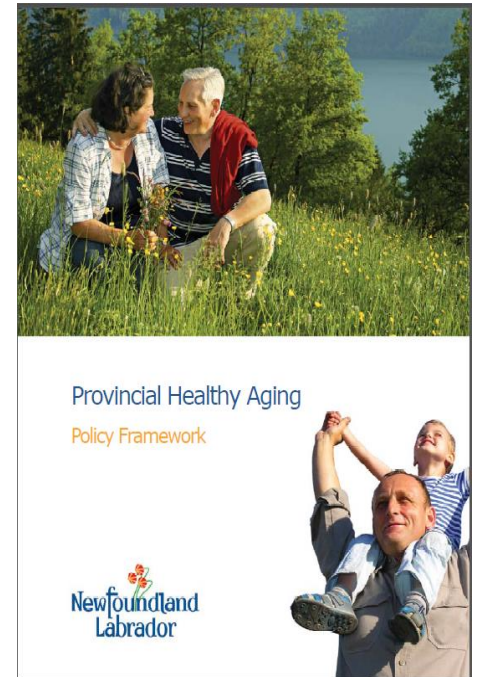
2. Identification of Data Holdings
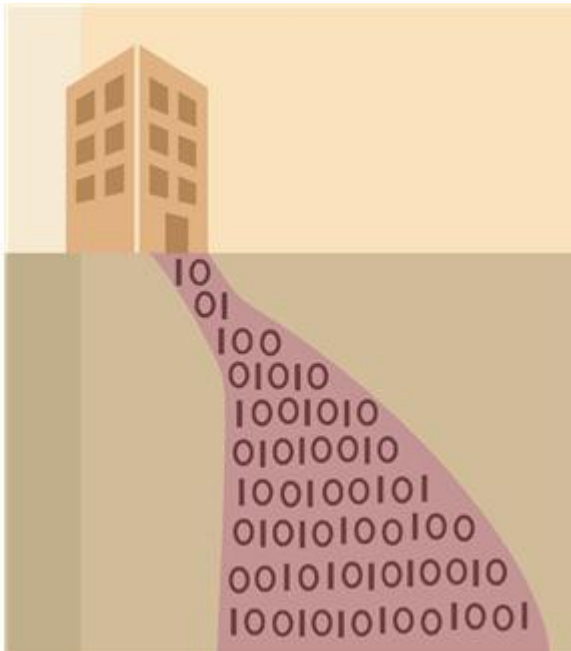
- Data custodians or representatives of these organizations will be contacted and consulted to confirm and supplement information obtained from websites, as well to identify other appropriate data holdings.

Datasheet for each data source

DATA SOURCE NAME
Brief description of data source:
Database availability and accessibility:
Start date:
Release date:
Frequency of data collection:
Type of data collection:
Selected data elements applicable to healthy aging:
Relevance to healthy aging:
Description of overall strengths and/or weakness of the database based on the assessment:
Degree to which age categories can be stratified:
Important Notes:
Link to data custodians' website:

3. Systematic assessment of the quality of the identified data holdings

Initial screening of data sources will be based on the following inclusion criteria:

- Contains data for the Newfoundland and Labrador population
- Relevance to Health Canada's definition of healthy aging
- Relates to one or more of the six priority directions of the NL Provincial Healthy Aging Policy Framework: 1) Recognition of Older Persons, 2) Celebrating Diversity, 3) Supportive Communities, 4) Financial Well-Being, 5) Health and Well-Being, 6) Employment, Education and Research

•Databases that meet initial criteria will be further assessed using a pre-developed data assessment tool.

3. Systematic assessment of the quality of the identified data holdings (cont'd)

The assessment will be based on:

1. Documents and metadata available to support the data source such as data dictionaries, data quality reports & articles
2. Consultations with database managers or other appropriate persons responsible for the databases.

CIHI/NLCHI Data Quality Framework

- **Accuracy** – data reflects the objective for what is was designed to measure

- **Timeliness** – The data is available to the user when required. It also refers to how current or up to date the data is during time of release

- **Reliability/Comparability** – The data is consistent over time and across all sources of transactions (e.g. edits, updates, data linkage processes)

- **Usability** – The data must be understandable, accessible, and easy to use

- **Appropriateness/Relevance** – The degree to which the data reflects the current and future needs of the end-users. The data should contain only what is needed; irrelevant, redundant, and inappropriate information should be removed

4. Identification of information gaps and limitations in the identified data holdings

- Once the databases have been identified and evaluated, information gaps in available data based on the provincial Healthy Aging Policy Framework priority directions will be documented, and the results of the systematic assessment of identified databases compiled.

5. Provide strategies to acquire missing information

- An environmental scan, consultation with stakeholders, and discussion of gaps in aging-related data holdings will be used to make recommendations on methods to alleviate gaps in information identified.

6. Produce a data inventory report

The report will include:

- An overview of the proposed information in a worksheet format for each data source;

- A brief commentary of the databases' strengths and weaknesses based on the assessment;

- Gaps in available data holdings;

- Inventory limitations and gaps in information

- An appendix with complete assessment using the assessment tool for each data holding

- Function as a data catalogue

Datasheet for each data source

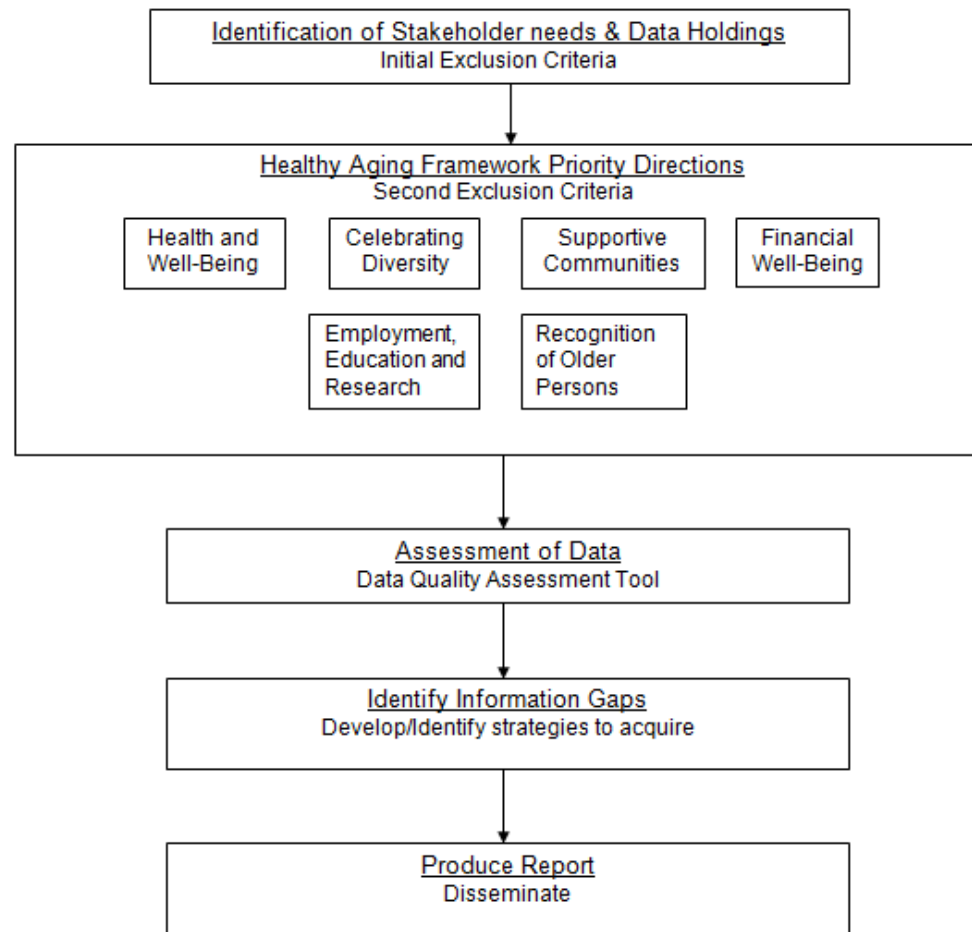| DATA SOURCE NAME |
|---|
| **Brief description of data source:** |
| **Database availability and accessibility:** |
| **Start date:** |
| **Release date:** |
| **Frequency of data collection:** |
| **Type of data collection:** |
| **Selected data elements applicable to healthy aging:** |
| **Relevance to healthy aging:** |
| **Description of overall strengths and/or weakness of the database based on the assessment:** |
| **Degree to which age categories can be stratified:** |
| **Important Notes:** |
| **Link to data custodians' website:** |

Dissemination

The final report will be disseminated electronically to custodians of identified data holdings and other relevant stakeholders.

- It will also be made available publicly on the NLCHI website, communicated to the Department of Health and Community Services through the Evidence to Policy Liaison Committee, and an article in the NLCHI's newsletter that is widely distributed to stakeholders within the health system.

A summary of the findings of the project will also be presented to other stakeholders and at a scientific/health conferences

Project Flow Diagram

Sample Data Sources

Administrative Data

Clinical Database Management System (CDMS)

NLCHI Live Birth System

NLCHI Stillbirth System

NLCHI Mortality System

Statistics Canada Annual Mortality Data Files

Statistics Canada Annual Stillbirth Data Files

Provincial Rehabilitation System

Telehealth Utilization Data

MCP Data

Provider Registry

Beneficiary Registration Database

Physician Claims Database

National Surveys

National Population Health Survey

Canadian Community Health Survey

National Longitudinal Survey of Children and Youth

Canadian Tobacco Use Monitoring Survey

Youth Smoking Survey

Population Data

Census

Population Estimates

NL Electronic Health Record

Client Registry

Provider Registry

Pharmacy Network

Sample Data Sources

Surveillance/Research Data

Newfoundland and Labrador Chronic Disease Surveillance System

Cervical Cancer Surveillance System

Suicide Database

Longitudinal Paediatric Research Database

Cancer and Chronic Disease Research Database

Research Studies or Special Projects:

First Nation Administrative Health Database

ER/PR Patient Listing and Communications Database

NewLab Psoriasis Clinical Database

Total Joint Replacement Wait List Dataset

Childhood Leukemia Dataset

Illegal Drug Use Pharmacist Survey Dataset

Adverse Drug Events (ADEs) in Paediatric Patients Dataset

Adverse Drug Events (ADEs) in Adult Patients Dataset

Seniors Medication Use Dataset

Newfoundland and Labrador Prescription Drug Program (NLPDP) Dataset

Emergency Room Triage Dataset

References

Canadian Institute for Health Information. (2009). *The CIHI data quality framework*. Ottawa: CIHI

Department of Finance, Government of Newfoundland and Labrador. (2006). *Demographic Change: Issues & Implications*.
Retrieved from: http://www.economics.gov.nl.ca/pdf2006/demographyupdate.pdf

Health Canada (2002). Division of Aging and Seniors. Dare to Age Well: Workshop on Healthy Aging. Part 1: Aging and Health
Practices. Ottawa: Government of Canada.

Heng, D., Pong, R. W., Pitblado, J. R., Lagace, C., & Desmeules, M. (2005). Sources of data for rural health research: Development
of an inventory of Canadian databases. *Journal of Agricultural Safety and Health, 11*(2), 219-227.

Kiefer, L., Frank, J., Di Ruggiero, E., Dobbins, M., Manuel, D., Gully, P. R., et al. (2005). Fostering evidence-based decision-making in
Canada: Examining the need for a Canadian population and public health evidence centre and research network. *Canadian
Journal of Public Health*, 96(3), I1-40.

Newfoundland and Labrador Centre for Health Information. (2009). *Data quality framework*. Newfoundland and Labrador: NLCHI.

Ontario Ministry of Health and Long-Term Care. (2012). *Health Analyst's Toolkit.* Health Analytics Branch

Statistics Canada. (2011). *Canada's population estimates: Age and sex*. Retrieved from: http://www.statcan.gc.ca/daily-
quotidien/110928/dq110928a-eng.htm

World Health Organization. (2004). *World Report on Knowledge for Better Health.*

THANK YOU

Questions?

Discussion

- Data Needs

- Other Data Holdings

- Perceived Gaps in Available Data