

Lessons from the Development of a Canadian National System of Surveillance

NATHALIE JETTÉ MD, MSc, FRCPC

Assistant Professor Neurology

Hotchkiss Brain Institute

Calgary Institute of Population and Public Health

University of Calgary, Canada

Institute of Medicine

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Outline of Presentation

- Chronic Disease Surveillance in Canada (context)
 - National Diabetes Surveillance System (NDSS)
 - Canadian Chronic Disease Surveillance System (CCDSS)
- National Population Health Study of Neurological Conditions
- Planning epilepsy surveillance in Canada – Lessons learned
 - Administrative health data
 - National health surveys
 - Electronic medical records
 - interRAI
 - Canadian Longitudinal Study of Aging

Canadian Chronic Disease Surveillance System

Canadian Chronic Disease Surveillance

...not an overnight process

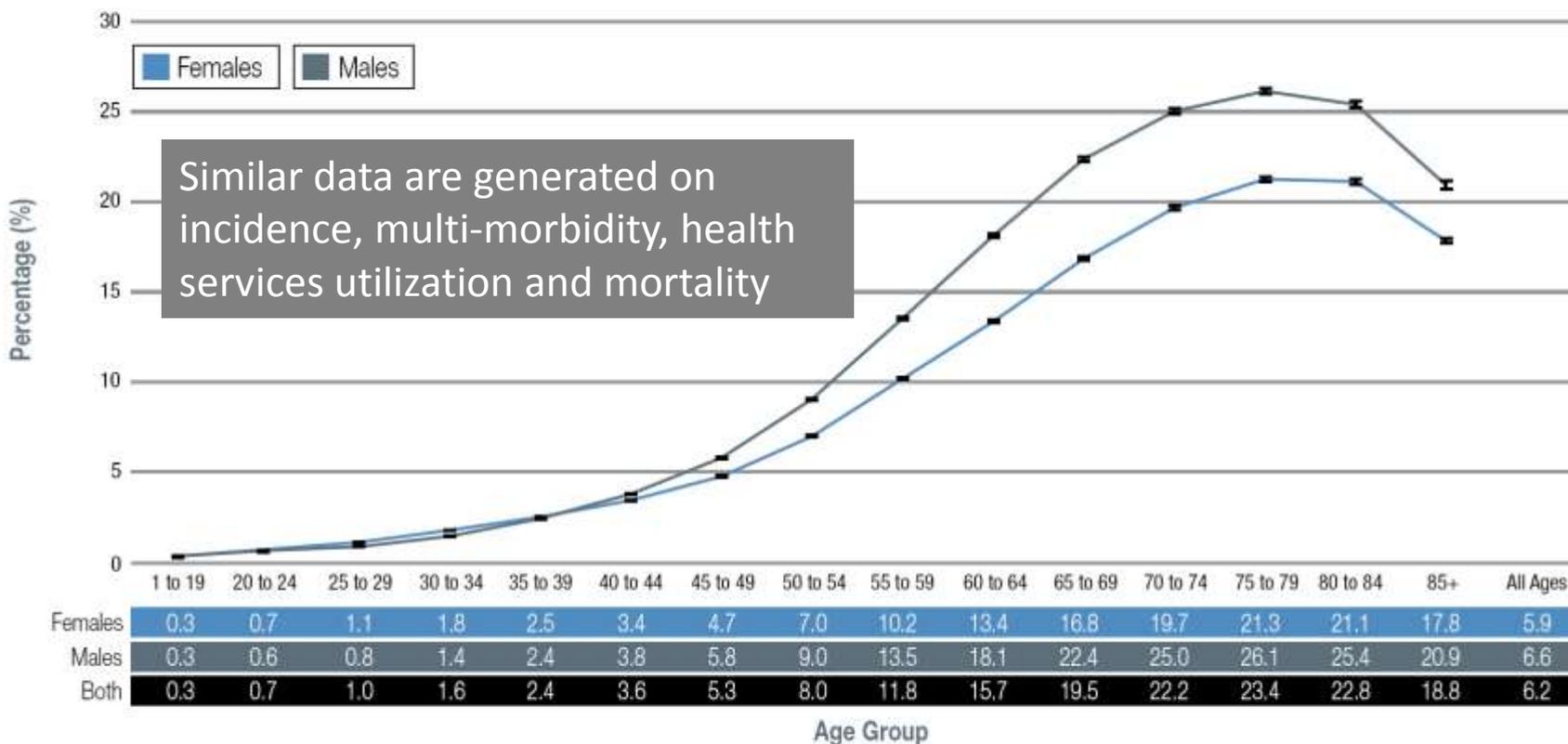
Year	Initiative/Progress
1991	Feasibility of administrative data for diabetes surveillance ¹
1996	Diabetes surveillance system in Manitoba ²
1999/2000	Canadian Diabetes Strategy
2003	First report from the National Diabetes Surveillance System (NDSS)
2004	Public Health Agency of Canada forms
2005	Integrated Strategy on Healthy Living and Chronic Disease - Hypertension surveillance feasibility work begins
2006/07	Feasibility studies in 5 provinces for arthritis, asthma, COPD and mental illness
2007/2008	Funding for validation studies (heart disease, stroke, osteoporosis and neurological diseases)
2009/2010	Hypertension added to Canadian Chronic Disease Surveillance System (CCDSS)
~2011/2012	Stroke, ischemic heart disease, myocardial infarction, heart failure to be added to CCDSS
~2012/2013	Arthritis, bowel disease, renal disease and neurological diseases to be added to CCDSS*

¹K. Young et al. CMAJ 1991; 144(3):318-24. ²J. Blanchard et al. Diabetes Care 1996;19:807-11.

*Neurological Disease Surveillance Advisory Committee (formed Dec 2009) and CCDSS Neurological Diseases Working Group (formed Jan 2011)

NDSS Report – Sample Data (Prevalence)

Figure 1. Prevalence Percentages of Diagnosed Diabetes among People Aged 1 Year and Older by Age Group and Sex, Canada,¹ 2006-07



Source: Public Health Agency of Canada, using NDSS data files contributed by provinces and territories, as of April 2009

¹ Data for Nunavut were unavailable.

‡ The 95% Confidence Interval shows an estimated range of values which is likely to include the true prevalence rate 19 times out of 20.

**National Population Health Study
of Neurological Conditions
(NPSNC)**

National Population Health Study of Neurological Conditions (NPSNC)

- Purpose of Study (2010-2013):
 - To develop a better understanding of the epidemiology and impact of 14 neurological conditions* by addressing the following areas:
 1. Incidence, prevalence
 2. Multi-morbidities
 3. Impact to individuals, families and societies
 4. Health systems services
 5. Risk factors for the development of conditions and poor health outcomes

*Alzheimer's disease and related dementia, amyotrophic lateral sclerosis, brain tumours, cerebral palsy, dystonia, **epilepsy**, Huntington's disease, hydrocephalus, multiple sclerosis, muscular dystrophy, Parkinson's disease, Tourette Syndrome, traumatic brain injury, spina bifida, spinal cord injury

The NPSNC → Integrated Knowledge Translation from A to Z

Federal Government Agencies

- Ministry of Health, Statistics Canada
- Public Health Agency of Canada (PHAC)
- Canadian Institutes for Health Research (CIHR)
- Canadian Institute of Health Information (CIHI)

Neurological Health Charities of Canada (NHCC)

- Established 2006
- Responsible for obtaining funding for NPSNC from government by lobbying
- Now consists of > 25 neurological charities

Researchers

- Clinicians
- Researchers
- Research Associates
- Students

Other Stakeholders

- Provincial health ministry managers (Alberta Health and Wellness, etc)
- Patients
- Miscellaneous other stakeholders

National Population Health Study of Neurological Conditions

National Population Study of Neurological Conditions – example of data sources

Incidence Prevalence Comorbidity

- Administrative data
- Canadian Community Health Survey (CCHS)
- Canadian Primary Care System Surveillance Network (CPCSSN)
- Clinical Registries
- interRAI

Impact of Neurological Conditions

- Follow up impact survey to CCHS
- Experience of people with neurological conditions, their families and caregivers (Aboriginal survey, national survey)
- interRAI

Health Systems Services

- Administrative data
- Canadian Community Health Survey
- Canadian Primary Care System Surveillance Network
- interRAI
- Other data sources through funded projects

Planning Epilepsy Surveillance in Canada

Data Source	Target Population	Advantages & Disadvantages
Administrative Data (e.g. CCDSS) <ul style="list-style-type: none"> •Hospitalizations •Physician visits 	<ul style="list-style-type: none"> •Everyone in Canada who seeks medical care 	<ul style="list-style-type: none"> •Population-based, cost effective •Can follow patients longitudinally •Can link to other data sources (labs, drug data)
National Health Surveys <ul style="list-style-type: none"> •e.g. Canadian Community Health Survey 	<ul style="list-style-type: none"> •Age 12 and older* •Some exclusions† •130,000 every 2 years 	<ul style="list-style-type: none"> •Population-based •Costly •Cross sectional (prevalence only) •Self report
Electronic Medical Records <ul style="list-style-type: none"> •Canadian Primary Care Sentinel Surveillance System Network (CPCSSN) 	<ul style="list-style-type: none"> •All age groups •Patients seen in primary care •>200,000 currently •Up to 1 million by 2015 	<ul style="list-style-type: none"> •Population based in some areas •Can follow patients longitudinally •Includes medications, lab data •Clinical diagnoses •# of EMR vendors high
interRAI	<ul style="list-style-type: none"> •Patients in complex continuing care facilities, nursing homes, mental health institutions, those receiving home care services 	<ul style="list-style-type: none"> •Population-based in some provinces •Rich clinical data (not admin data) •Clinical diagnoses •Validated scales
Canadian Longitudinal Study of Aging	<ul style="list-style-type: none"> •Ages 45-85 •50,000 	<ul style="list-style-type: none"> •Population based (excl. territories) •Costly but rich longitudinal data •Full clinical assessments in 30,000 •Long follow up (20 years +)

*for 2010-2012 CCHS< neurological conditions are being captured for every household members

†exclusions: population on Indian Reserves, living in remote areas, living in long term care institutions, Canadian Force Bases.

Administrative Health Data

- First step is validating condition of interest, then develop best “case definition” algorithm
- ***Lessons Learned in Canada:***
 - Easy to validate hospitalization and emergency room visit data
 - data are very good*, accessible, affordable, etc.
 - Tougher to validate epilepsy coding in primary care → if a large portion of epilepsy care is provided by general practitioners, need to validate epilepsy coding from that source
 - More challenging to validate GP coding
 - Need to collaborate with physicians who are part of a primary care network, national surveillance system, etc to increase likelihood of success.
 - Can be used as a sampling frame for more in-depth studies

*Jetté et al. *Epilepsia* 2010

National Health Surveys

- CCHS – cross sectional but q2 years (130,000 people)
 - ~80% response rate
 - Do provide rich health related data including data on comorbidities, health related behavior, access to care, etc.
- ***Lessons Learned in Canada***
 - If based on self report of epilepsy, important to ask respondents if they have epilepsy **or** if they have a seizure disorder
 - Can be used as sampling frame but very costly
 - E.g. follow-up impact survey currently underway for every CCHS respondent who answered “yes” to having a neurological condition

Electronic Medical Records - CPCSSN

- Network of sentinel family physicians attached to primary care research networks across Canada which collects data from their electronic medical records at regular intervals to develop a longitudinal database for the purposes of epidemiological surveillance and research.
- Initial focus: COPD, diabetes, hypertension, osteoarthritis and depression
- ***New focus: epilepsy***, Parkinson's disease, and dementia
 - data on prevalence, incidence, multi-morbidities, risk factors, medications, health services, procedures, etc



Electronic Medical Records - CPCSSN

- ***Lessons Learned in Canada:***
 - Critical to ensure primary care physicians are engaged, and see this as “value-add”
 - Physicians appreciate getting reports back on their patient population
 - Performance measurement
 - What % of their patients with diabetes have HbA1C in the target range?
 - What % of their patients with hypertension have adequate blood pressure measurements?
 - It is possible to do this with a variety of EMR vendors.
 - Primary care physicians are very interested in this initiative.

interRAI

- Enables care providers to assess the following factors in patients who are receiving home care, who are living in institutions etc:
 - Function, health, social support, service use, quality of life
 - Data complete in settings where it is being collected
- **Lessons Learned:**
 - Important to validate diagnosis*
 - Mandated in some provinces, not in others thus not consistently collected → best in provinces where mandated
 - Assessments done annually (always done) and quarterly if changes in clinical status (not always done)
 - Important to fill gaps around transition of care by linking to other data sources (e.g. hospitalization data)

*Hardie et al. *Epilepsy Res* 2007 → The validity of epilepsy or seizure documentation in nursing homes (>92% agreement between neurologists review of nursing home records and minimum data set documentation).

Canadian Longitudinal Study of Aging

- Enrolling 50,000 Canadians ages 45-85
- Plan for 20+ years follow up
- Extensive clinical, biological, physical data being collected on 30,000 (in-depth assessments)
- Questionnaires and database linkages planned for all 50,000 over 20+ years
- ***Lessons learned:***
 - Very costly
 - Challenging to link to other data sources nationally
 - But an excellent and rich source of clinical, biological and physical data



Recommendations

1. Build on existing infrastructure and methodology to increase likelihood of feasibility.
 - Collaborate with individuals involved in other surveillance systems (e.g. ongoing CDC surveillance initiatives)
2. Several data sources may be necessary to address complete population
 - Administrative data to capture all those who access medical services
 - National health surveys will also capture those who may not currently be seeking medical care
 - interRAI data will capture those in nursing homes, those receiving home care, etc.

Recommendations

3. Consider using administrative data as sampling frames for surveys
 - Although administrative data may not address epilepsy severity or impact on QOL, consider using them as sampling frames for more detailed surveys.

4. Consider electronic medical records for surveillance
 - Feasible, cost effective once in place, as long as participating sentinel physicians are engaged and see it as “value added”

