Lessons from the Development of a Canadian National System of Surveillance

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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

<table>
<thead>
<tr>
<th>Year</th>
<th>Initiative/Progress</th>
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<tbody>
<tr>
<td>1991</td>
<td>Feasibility of administrative data for diabetes surveillance¹</td>
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<tr>
<td>1996</td>
<td>Diabetes surveillance system in Manitoba²</td>
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<td>1999/2000</td>
<td>Canadian Diabetes Strategy</td>
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<td>2003</td>
<td>First report from the National Diabetes Surveillance System (NDSS)</td>
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<td>2004</td>
<td>Public Health Agency of Canada forms</td>
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<td>2005</td>
<td>Integrated Strategy on Healthy Living and Chronic Disease - Hypertension surveillance feasibility work begins</td>
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<tr>
<td>2006/07</td>
<td>Feasibility studies in 5 provinces for arthritis, asthma, COPD and mental illness</td>
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<tr>
<td>2007/2008</td>
<td>Funding for validation studies (heart disease, stroke, osteoporosis and neurological diseases)</td>
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<tr>
<td>2009/2010</td>
<td>Hypertension added to Canadian Chronic Disease Surveillance System (CCDSS)</td>
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<tr>
<td>~2011/2012</td>
<td>Stroke, ischemic heart disease, myocardial infarction, heart failure to be added to CCDSS</td>
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<tr>
<td>~2012/2013</td>
<td>Arthritis, bowel disease, renal disease and neurological diseases to be added to CCDSS*</td>
</tr>
</tbody>
</table>

*Neurological Disease Surveillance Advisory Committee (formed Dec 2009) and CCDSS Neurological Diseases Working Group (formed Jan 2011)
Similar data are generated on incidence, multi-morbidity, health services utilization and mortality.
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 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
<table>
<thead>
<tr>
<th>Data Source</th>
<th>Target Population</th>
<th>Advantages &amp; Disadvantages</th>
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<tbody>
<tr>
<td>Administrative Data (e.g. CCDSS)</td>
<td>• Everyone in Canada who seeks medical care</td>
<td>• Population-based, cost effective</td>
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<td></td>
<td></td>
<td>• Can follow patients longitudinally</td>
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<tr>
<td></td>
<td></td>
<td>• Can link to other data sources (labs, drug data)</td>
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<tr>
<td>Hospitalizations</td>
<td></td>
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<tr>
<td>Physician visits</td>
<td></td>
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<tr>
<td>National Health Surveys</td>
<td>• Age 12 and older*</td>
<td>• Population-based</td>
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<tr>
<td>• e.g. Canadian Community Health Survey</td>
<td></td>
<td>• Costly</td>
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<td></td>
<td></td>
<td>• Cross sectional (prevalence only)</td>
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<td></td>
<td></td>
<td>• Self report</td>
</tr>
<tr>
<td>Electronic Medical Records</td>
<td>• All age groups</td>
<td>• Population based in some areas</td>
</tr>
<tr>
<td>• Canadian Primary Care Sentinel Surveillance System Network (CPCSSN)</td>
<td>• Patients seen in primary care</td>
<td>• Can follow patients longitudinally</td>
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<td></td>
<td>• &gt;200,000 currently</td>
<td>• Includes medications, lab data</td>
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<td></td>
<td>• Up to 1 million by 2015</td>
<td>• Clinical diagnoses</td>
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<td></td>
<td>• # of EMR vendors high</td>
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<td>interRAI</td>
<td>• Patients in complex continuing care facilities, nursing homes, mental health institutions, those receiving home care services</td>
<td>• Population-based in some provinces</td>
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<td></td>
<td></td>
<td>• Rich clinical data (not admin data)</td>
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<tr>
<td></td>
<td></td>
<td>• Clinical diagnoses</td>
</tr>
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<td></td>
<td></td>
<td>• Validated scales</td>
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<td>Canadian Longitudinal Study of Aging</td>
<td>• Ages 45-85</td>
<td>• Population based (excl. territories)</td>
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<tr>
<td></td>
<td>• 50,000</td>
<td>• Costly but rich longitudinal data</td>
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<td>• Full clinical assessments in 30,000</td>
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<td></td>
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<td>• Long follow up (20 years +)</td>
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*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”