The promised potential of useable data from electronic medical records: lessons from the Canadian Primary Care Sentinel Surveillance Network

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Introductions

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Objectives and disclosures:

Objectives:
- Describe CPCSSN
- Provide an update of CPCSSN activities: research and quality improvement
- Discuss lessons learned

Disclosures:
- Funded by CIHR/Michael Smith Foundation as part of SPOR PIHCIN in BC
- Funded by consortia of funders across Canada: departments of family medicine, Alberta Innovates, Universities
8 provinces using 10 EMRs

- **British Columbia**
  - BCPCReN, Wolf Medical Systems, MedAccess, Oscar

- **Alberta**
  - SaPCReN, Calgary—MedAccess
  - AFRPN, Edmonton—MedAccess, Wolf

- **Manitoba**
  - MaPCReN, Winnipeg—JanokeMed

- **Ontario**
  - DELPHI, London—Healthscreen, Purkinje
  - NORTReN, Toronto—Nightingale, xwave,
  - CSPC, Kingston—P&P, Oscar, xwave

- **Quebec**
  - Q-Net, Montréal—Da Vinci

- **Nova Scotia / New Brunswick**
  - MARNet, Halifax—Nightingale, Purkinje

- **Newfoundland**
  - APBRN, St. John’s—Wolf Medical Systems

11 Networks: >800 sentinels, >1,000,000 patients
CPCSSN Facilitates:

- Chronic disease surveillance
- Practice quality improvement
- Primary care research
Why CPCSSN?

1. Help build a resource developed by and for family physicians/primary care
2. Contribute to development of primary care population health surveillance in Canada
3. Collaborate with primary practices in neighbouring areas, other provinces and across Canada
4. Engage in practice quality improvement activities minimal time commitment
5. Receive Mainpro credits for auditing your own practice
Data extracted at quarterly intervals

Health data
- Patients assigned a unique CPCSSN identifier
- Reviewed to ensure all personal identifiers are removed
- Common chronic conditions: hypertension, diabetes, COPD, osteoarthritis, Parkinson’s, dementia, epilepsy…..
- Laboratory data (A1C, eGFR, etc)

Demographic information
- Year of birth, encounter date, ethnicity, occupation, education, language, postal code

EMR Data Linkage File (kept at the practice site/EMR provider)
- Contains only identifiers linking data to the patient (CPCSSN number, postal code, DOB, gender, PHCN)
What participation entails

http://spor-bcphcrn.ca/bc-cpcssn/

- Review and sign a consent to share patient’s health information (15 min)
- Complete a yearly practice profile (10 min)
- Meetings (with food!) with your practice colleagues to engage your practice data & to brainstorm your questions
- 3-hour reflection exercise on the data feedback report, for which 3hr Mainpro C credits will be provided (up to 15 credits yearly)
Recent Activities

- Received a privacy innovation award (2013) by the International Association of Privacy Professionals for its privacy sensitive work
- Added a network node in Northwest Territories
- Opportunity to begin working with First Nation, Inuit, Metis communities
- Validation work for other chronic conditions
- Development of tools for clinicians, researchers
- Supporting research projects
InQUIRE: Sentinel specific patient panel with adjustable date range
Relevant technical quality of care indicators can be monitored, ensuring a true overview of patients with particular chronic conditions.
Data Presentation Tool:

- **3,668 Patients Found**

**Time Since Last Visit – Months**
- Over 36: 24.5%
- 24 - 36: 5.2%
- 12 - 24: 7.7%
- 0 - 12: 62.6%

**Condition Prevalence**
- Diabetes Mellitus: 340 - 9.3%
- Depression: 3,668 - 100.0%
- Hypertension: 737 - 20.1%
- COPD: 191 - 5.2%
- Osteoarthritis: 614 - 16.7%
- Dementia: 268 - 7.3%
- Parkinson's: 42 - 1.1%
- Epilepsy: 73 - 2.2%

**Age Gender Distribution**
- Total Patients: 3,668
- Male: 1,638
- Female: 1,230
- Unknown: 800
Other CPCSSN tools

- Multimorbidity cluster analysis toolkit (A computational cluster analysis explores the distinct clinical profiles that exist within a sample of individuals living with multimorbidity)
- Medically complex algorithm
- Frailty algorithm
Examples of Research Projects

- Comparison of HbA1c versus Fasting Blood Glucose in the diagnosis of Diabetes Mellitus and Pre Diabetes in a Canadian Population

- Retrospective Cohort Study Using the Canadian Primary Care Sentinel Surveillance Network Data to Examine Depression in Patients With a Diagnosis of Parkinson’s Disease

- The relationship between strict adherence to hypertensive guidelines and cognitive decline

- Using Local and National EMR Data to Examine Paediatric and Adult Weight Trends in Primary Care

- Epidemiology of Multimorbidity: A Comparative Study between Scottish and Canadian Primary Care Populations

- Temporary hypertension in Canada and UK from the perspective of the electronic medical record (EMR)
Lessons learned
Thanks to all funders, stakeholders, partners and sentinel physicians/nurse practitioners

http://spor-bcphcrn.ca/bc-cpcssn/
Extra
Step 1: For each participating medical practice, an RDM extracts EMR data into CPCSSN practice database.

Step 2: For each CPCSSN practice database, an RDM de-identifies the EMR records and assigns a unique, meaningless CPCSSN identifier before the records leave the practice.

Step 3: For each CPCSSN practice database, an RDM uploads the CPCSSN practice database to their regional CPCSSN server.

Step 4: RDMs transform the CPCSSN practice database into a standardised CPCSSN Microsoft Access database file.

Step 5: RDMs merge multiple CPCSSN practice databases into a single CPCSSN regional database.

Step 6: RDMs perform data coding, cleansing, case detection, reporting & further de-identification on the CPCSSN regional database.

Step 7: RDMs transfer the CPCSSN regional database to a private folder on the central server.

Step 8: Senior Data Manager uploads & merges the CPCSSN regional databases into a single CPCSSN central repository database.

Step 9: Senior Data Analyst and Senior Epidemiologist perform analysis & reporting on the CPCSSN central repository database.

Step 10: Data reports & analyses are shared with members of the CPCSSN team and with CIHI.

CPCSSN Central Server

Regional Servers
At the regional network or CPCSSN server

- Data coding, cleansing and case detection performed

- Data is processed and entered on to a regional CPCSSN server located at the High Performance Computing Virtual Laboratory (HPCVL) at Queen’s University, Kingston, ON
  - Identifiers such as name, phone number, and address are removed
  - Identifying text is removed from other fields
The central repository

- The secure national server located at the High Performance Computing Virtual Laboratory HPCVL
- De-identified and processed health data is sent from each region to the central server where it is merged, for subsequent reporting and analysis
Current data sources for chronic disease

- Database of Admissions and Discharge
- Provincial Billing Databases
- Community Health Surveys
- Census Data
- CIHI Nationally
- NLCHI provincially

But where do people with chronic disease receive most of their care?

No database of activity in primary care