Improving recording of sociodemographic and risk factor data in the Canadian Primary Care Sentinel Surveillance Network (CPCSSN) database

Neil Drummond¹
Jody Boffa¹
Dave Jackson¹
Terri-Lyn Bennett²
Alan Katz³
Karim Keshavjee⁴
on behalf of CPCSSN

1 Dept of Family Medicine, University of Calgary
2 Public Health Agency of Canada
3 Dept of Family Medicine, University of Winnipeg
4 Infoclin
Background

• CPCSSN is a network of sentinel family physicians attached to primary care research networks across Canada.

• Downloads data from their electronic medical records at regular intervals to develop a longitudinal database for the purposes of epidemiological surveillance and research.

• Focus on COPD, diabetes, hypertension, osteoarthritis, depression, dementia, epilepsy and Parkinson’s disease.

• Ability to add short- or long-term surveillance on other conditions as required (subject to REB approval).

• Long-term aim is to develop an all-cause morbidity sentinel surveillance network for primary care in Canada, similar to those found in many countries.
Ten Primary Care Research Networks
Seven Provinces & Seven EMRs

- British Columbia
  - BC-CPCSSN - *Wolf*
- Alberta
  - SAPCReN Calgary – *MedAccess/Wolf*
  - AFPRN Edmonton - *MedAccess*
- Manitoba
  - MaPCReN Winnipeg - *JonokeMed*
- Ontario
  - DELPHI London – *Healthscreen*
  - NORTReN Toronto – *Nightingale*
  - CSPC Kingston – *OSCAR*
- Quebec
  - Q-net Montreal - *DaVinci*
- Nova Scotia
  - MARNet Halifax - *Nightingale*
- Newfoundland
  - APBRN St. John’s – *Wolf*
Progress to date

- 200 family physician sentinels across the country and patient sample of 20 000

- intention to increase to 1000 representative sentinels and 1 000 000 representative patients across the country by 2015

- sentinels use an EMR for clinical work and practice full scope family medicine (may exclude obstetrics)

- Currently undertaking case definition validation, developing data cleaning algorithms, improving case deidentification software
Data holdings

- Medications
- Laboratory data (only for diabetes at present)
- Encounter data
- Risk factor data
- Disease data
- Referral data
- Procedure data
- Examination data
- Patient socio-demographic
Proportions of socio-demographic variable completion

- Ethnicity 0.3%
- Gender 99.7%
- DoB 99.2%
- Occupation 3.0%
- Highest educational attainment 0.2%
- Housing status 4.6%
- FSA 39.3%
- Language 7.4%
How do other primary care surveillance systems collect sociodemographic and risk factor data?

BEACH programme (Australia)
Age, gender, aboriginal status recorded routinely by paper questionnaire. Smoking status, alcohol consumption, BMI and specific interests are investigated through a supplementary patient subsample survey.

General Practice Research Database (UK)
Gender, year of birth, ethnicity, practice location, BMI, height, weight, smoking and alcohol consumption recorded routinely by download.

Nijmegen Academic Family Practice Network (Netherlands)
Age, gender, social class, family composition and smoking recorded routinely (in 1995) by download.
Patient Information Form

In order to improve the quality of care that you receive from your doctor, we are updating our patient records on potential risk factors for disease. Your honest responses are appreciated.

We ask you to take a few minutes to complete as much information as possible prior to your appointment. Thank you for your cooperation.
Patient Information Form
Please respond to the following questions, identifying the option that best applies to you.

Alberta Health Care # *This number is located on your patient label

Postal Code

Live Alone  ○ Yes  ○ No

Marital Status  ○ Single  ○ Common Law / Married  ○ Divorced / Separated  ○ Widowed

Language spoken at home

Ethnicity  Canadian born Non-Aboriginal

Please Choose all that apply

-  □ Caucasian ("White")  □ Asian
-  □ Afro-Caribbean ("Black")  □ South Asian ("Indian")
-  □ Hispanic  □ West Asian / North African ("Middle Eastern")

Next
Does a 1st degree member of your family (biological parent or brother or sister) have any of the following? (check all that apply)

<table>
<thead>
<tr>
<th>Health Condition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>Yes</td>
</tr>
</tbody>
</table>

Is your father deceased?  
☐ Yes  ☐ No

Cause of Death (if known): ____________________________

Is your mother deceased?  
☐ Yes  ☐ No

Cause of Death (if known): ____________________________
HEALTH BACKGROUND: Please enter as much information as you can. It is not required to fill in all details.

How would you rate your general health?  ☐ Poor  ☐ Fair  ☐ Good  ☐ Very Good  ☐ Excellent

Do you currently smoke?  ☐ Yes  ☐ No

Packs per week:  

How many years have you been smoking?  

Do you drink alcohol?  ☐ Yes  ☐ No
**HEALTH BACKGROUND:** Please enter as much information as you can.
It is not required to fill in all details.

On average, how many times per day, week or month do you consume...
(if not applicable, enter '0' in the #Times box)

<table>
<thead>
<tr>
<th></th>
<th># Times</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>100% fruit juices (e.g. orange, grapefruit, or tomato juice)</td>
<td></td>
<td>Per</td>
</tr>
<tr>
<td>Fruit</td>
<td></td>
<td>Per</td>
</tr>
<tr>
<td>Potatoes (NOT including french fries, fried potatoes or potato chips)</td>
<td></td>
<td>Per</td>
</tr>
<tr>
<td>A green salad</td>
<td></td>
<td>Per</td>
</tr>
<tr>
<td>Carrots</td>
<td></td>
<td>Per</td>
</tr>
<tr>
<td>Other vegetables</td>
<td></td>
<td>Per</td>
</tr>
</tbody>
</table>

Do you usually take multi-vitamins or other vitamin supplements?  
[ ] Yes  [ ] No
HEALTH BACKGROUND: Please enter as much information as you can. It is not required to fill in all details.

In the last 7 days, how many hours did you spend doing the following types of exercise:

- **Vigorous physical activities** (eg. heavy lifting, digging, aerobics, or fast cycling):
  - [ ] Hours

- **Moderate physical activities** (eg. carrying light loads, swimming, or tennis):
  - [ ] Hours

- **Walking** (including at home, work, getting from place to place recreation, or sport):
  - [ ] Hours

How much time did you usually spend sitting on a week day (at a desk, visiting friends, in a car, watching TV):

- **Average Time / Day**
  - [ ] Hours

---

Patient Information Form Complete

Thank you for taking the time to fill out this form!
The Canadian Primary Care Sentinel Surveillance Network or CPCSSN (pronounced sipsin) is a new collaboration. CPCSSN is Canada’s first multi-disease electronic record surveillance system. Essentially, CPCSSN can be thought of as a library of digital information on health; specifically a database on chronic diseases.

The information gathered will help physicians better understand chronic disease and improve the care Canadians with chronic disease receive. It is expected that CPCSSN will share information and reports with governments, physicians, nurses and other healthcare team members, researchers, and planners to improve primary health care.

The CPCSSN initiative is funded by the Public Health Agency of Canada under a contribution agreement with the College of Family Physicians of Canada on behalf of nine practice based research networks (PBRNs) associated with departments of Family Medicine across Canada. CPCSSN also works together with the Canadian Institute of Health Information.
# CPCSSN sociodemographic and risk factor questionnaire

<table>
<thead>
<tr>
<th>Total Records:</th>
<th>37</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Postal Code</strong></td>
<td>36 97.30%</td>
</tr>
<tr>
<td><strong>Alberta Health Care #</strong>:</td>
<td>36 97.30%</td>
</tr>
<tr>
<td><strong>Live Alone</strong>:</td>
<td>36 97.30%</td>
</tr>
<tr>
<td><strong>Marital Status</strong>:</td>
<td>35 94.59%</td>
</tr>
<tr>
<td><strong>Language Spoken</strong>:</td>
<td>36 97.30%</td>
</tr>
<tr>
<td><strong>Ethnicity Group</strong>:</td>
<td>34 91.89%</td>
</tr>
<tr>
<td><strong>Ethnicity Details</strong>:</td>
<td>28 75.68%</td>
</tr>
<tr>
<td><strong>Country of Origin</strong>:</td>
<td>2 5.41%</td>
</tr>
<tr>
<td><strong>Highest Level of Education</strong>:</td>
<td>32 86.49%</td>
</tr>
<tr>
<td><strong>Current Employment</strong>:</td>
<td>33 89.19%</td>
</tr>
<tr>
<td><strong>Job Skill Level</strong>:</td>
<td>27 72.97%</td>
</tr>
<tr>
<td><strong>Job Title</strong>:</td>
<td>23 62.16%</td>
</tr>
<tr>
<td><strong>Housing Status</strong>:</td>
<td>33 89.19%</td>
</tr>
<tr>
<td><strong>Household Income</strong>:</td>
<td>30 81.08%</td>
</tr>
</tbody>
</table>
CPCSSN sociodemographic and risk factor questionnaire

- Family Hx - COPD  26  70.27%
- Family Hx - Dementia  24  64.86%
- Family Hx - Diabetes  24  64.86%
- Family Hx - Epilepsy  25  67.57%
- Family Hx - Hypertension  29  78.38%
- Family Hx - Depression  26  70.27%
- Family Hx - Osteoarthritis  24  64.86%
- Family Hx - Parkinson's Disease  24  64.86%

- Father Deceased  28  75.68%
- Father Cause of Death:  13  35.14%
- Mother Deceased:  28  75.68%
- Mother Cause of Death:  10  27.03%
CPCSSN sociodemographic and risk factor questionnaire

- General Health Status 33 89.19%
- Smoking Status 37 100.00%
- Smoking (packs/week) 4 10.81%
- Smoking (years smoking) 4 10.81%
- Smoking (ever smoked) 22 59.46%
- Smoking (quit year) 6 16.22%
- Drink Alcohol 29 78.38%
- Drink Alcohol (drinks / week) 21 56.76%
CPCSSN sociodemographic and risk factor questionnaire

- Drink 100% Fruit Juice (#times): 29  78.38%
- Drink 100% Fruit Juice (frequency): 26  70.27%
- Eat Fruit (# times): 30  81.08%
- Eat Fruit (frequency): 29  78.38%
- Eat Green Salad (#times): 30  81.08%
- Eat Green Salad (frequency): 30  81.08%
- Eat Potatoes (#times): 30  81.08%
- Eat Potatoes (frequency): 30  81.08%
- Eat Carrots (#times): 30  81.08%
- Eat Carrots (frequency): 30  81.08%
- Eat Other Vegetables (#times): 30  81.08%
- Eat Other Vegetables (frequency): 30  81.08%
- Take multi-vitamins: 29  78.38%
CPCSSN sociodemographic and risk factor questionnaire

- Vigorous Physical Activity 24 64.86%
- Moderate Physical Activity 27 72.97%
- Walking 24 64.86%
- Sitting 29 78.38%
CPCSSN sociodemographic and risk factor questionnaire

Time Taken Averages (Site 2 only - N=27)

- Page 1  82s
- Page 2  6s
- Page 3  70s
- Page 4  46s
- Page 5  28s
- Page 6  247s
- Page 7  53s

- Average Time per questionnaire: 9.3min
Conclusions and implications

Adding sociodemographic data to the EMR record via electronic patient questionnaire is feasible

Enables standardized sociodemographic data entry for purposes of CPCSSN surveillance and research without the need for external data linkage.

Provides encouragement to linked projects investigating the inclusion and use of risk factor data into EMRs and clinical interaction (eg RFIT)

Requires validation
Thanks to our funders, stakeholders, partners and sentinel physicians