

DATA TO INFORM PRIMARY CARE: The Canadian Primary Care Sentinel Surveillance Network (CPCSSN)

HEALTH RESEARCH DATA SYMPOSIUM

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Canadian Primary Care Sentinel Surveillance Network
Réseau canadien de surveillance sentinelle en soins primaires

CPCSSN's primary partner is the College of Family Physicians Canada (CFPC) along with DFM practice based research networks (PBRNs) across Canada
May 2008- April 2010

THE COLLEGE OF
FAMILY PHYSICIANS
OF CANADA



LE COLLÈGE DES
MÉDECINS DE FAMILLE
DU CANADA

Funders:

Public Health Agency of Canada



Public Health
Agency of Canada

Agence de la santé
publique du Canada

pilot and feasibility phases I & II plus
a 5 yr contribution agreement between
CFPC & PHAC for Phase III May 2010 – March 2015

Need for good primary care data

Data sources for chronic disease

- Database of Admissions and Discharge
- Provincial Billing Databases
- Community Health Surveys
- Census Data
- No database of activity in primary care
- CIHI Nationally

Many conditions or visits to a family physician are not captured

Difficult to make practice & policy decisions without good data

Potential of Electronic Medical Records (EMRs) as a Primary Care Database

- Most people in Canada have a family physician (85%)¹
- Over 70% visit their family physician at least once a year²
- Family Practice is the basis for almost all chronic disease prevention and screening maneuvers offered by our health care system³

1. The College of Family Physicians of Canada. The College of Family Physicians of Canada Takes Action to Improve Access to Care for Patients in Canada [News Release]. 2009.

2. Dunlop S, Coyte PC, Mclsaac W. Socio-economic status and the utilisation of physicians' services: results from the Canadian National Population Health Survey. *Social Science & Medicine*. 2000;51:123-133.

3. Clinical Prevention Policy Review Committee BcMoH. Establishing Clinical Prevention Policy in British Columbia: Part I What is worth Doing? . British Columbia: Center for Health Services and Policy Research; 2007:i- 46.

EMR data – making sense of nonsense

EMR data is messy - clinicians use the EMR like paper chart

- Lack of Discrete Fields
 - Data – often not coded or free text
- Lack of Data Discipline
 - Standard codes/terms are not used
- Registry
 - Can't extract lists if there are no discrete fields or consistent entry

Example EMR Data - 2012 AFPRN extraction

When data are not entered using a structured approach, coding algorithms can map the data into usable formats

Diabetes

177 unique entries

diabetes mellitus*
Diabetes mellitus
diabetes mellitus* (250)
NIDDM
diabetes
DM II
Diabetic nephropathy
Diabetes Mellitus -Type 2- Non Insulin Dependent
Diabetes Mellitus Non Insulin Dependent (Type 2)
Diabetes Type 2
Diabetes Mellitus type 2
T2DM
type 2 diabetes
type 2 DM
Type II Diabetes
(DM) Diabetes Mellitus -Type 2
diabetes type 1
IDDM

Hypertension

117 unique entries

essential hypertension*
hypertension
htn
hypertension nos (401.9)
essential hypertension
Hypertension - Query
hypertension-white coat
essential hypertension* (401)
Benign essential hypertension
hypertension nos
Hypertension - Borderline
hypertension ,
Hypertensive Disease
benign hypertension
Essential HTN
Hypertension Labile
Arterial hypertension
Arterial Hypertension (HTN)
diastolic hypertension

CPCSSN is the first of its kind

- Anonymized longitudinal multi-disease EMR data
 - Data is collected from EMRs at regular intervals for the purpose of chronic disease surveillance, research, and practice quality improvement
- The system provides feedback reports for participating practitioners about their practice in comparison to others regionally, provincially, and nationally

British Columbia

- BCPCReN, Vancouver - *Wolf*, *OSCAR*

Alberta

- SAPCReN, Calgary - *Med Access*, *Wolf*
- NAPCReN, Edmonton - *Med Access*, *Wolf*

Manitoba

- MaPCReN, Winnipeg - *Jonoke*

Ontario

- DELPHI, London - *Optimed*, *OSCAR*
- UTOPIAN, Toronto - *Nightingale*, *Practice Solutions*, *Bell EMR*
- EON, Kingston - *P&P*, *OSCAR*, *Bell EMR*, *Nightingale*

Québec

- RRSPUM, Montréal - *Da Vinci*, *Purkinje*

Nova Scotia/New Brunswick

- MaRNet, Halifax - *Nightingale*, *Purkinje*

Newfoundland

- APBRN, St. John's - *Wolf*, *Nightingale*

Clinicians and Researchers collaborating on a national project



**10 PC-PBRNs serving 8 provinces,
11 *distinct* EMR systems**

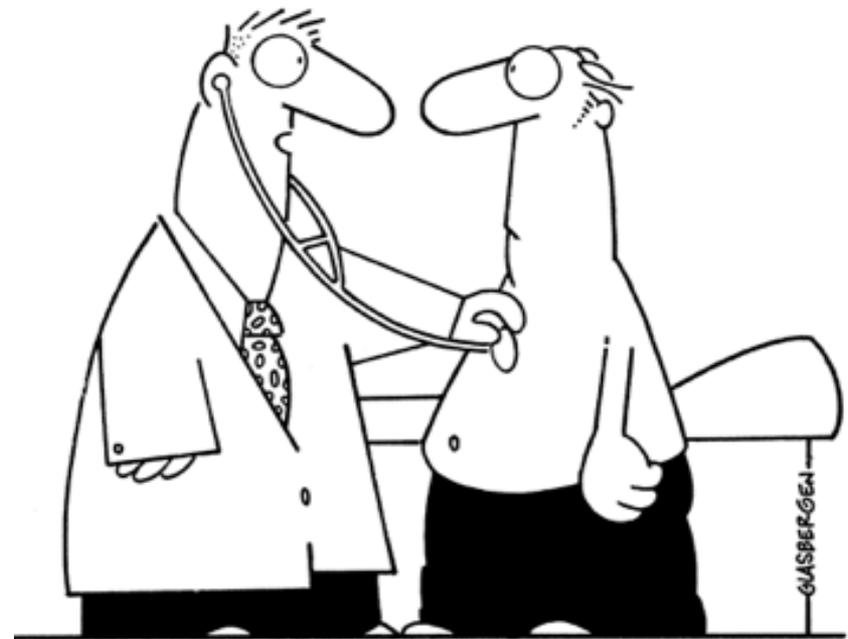


Current Participation in CPCSSN

- Across Canada:
 - >500 sentinels contributing data to CPCSSN
 - data collected for more than 650,000 patients
- In Alberta (**NAPCReN** & **SAPCReN**):
 - 170 active sentinels
 - approx. 178,442 patients
- Goal for Alberta:
 - representative recruitment: patients, providers, clinics

Index conditions of interest:

- Hypertension
- Diabetes
- Depression
- Osteoarthritis
- COPD
- Epilepsy
- Dementia
- Parkinsonism



“It’s easy to tell the difference between good cholesterol and bad cholesterol. Bad cholesterol has an evil laugh.”

All 8 case definitions & case-finding algorithms have been validated, with good sensitivity & specificity

Rich anonymized data that includes:

- Patient demographics
- Medications
- Laboratory results
- Encounters
- Risk factors
- Disease diagnoses
- Referrals
- Family history
- Procedures
- Physical exam results
- Allergies
- Immunizations
- Provider characteristics
- EMR characteristics
- Billing diagnoses
- Socio-economic deprivation scores

Privacy and Ethics

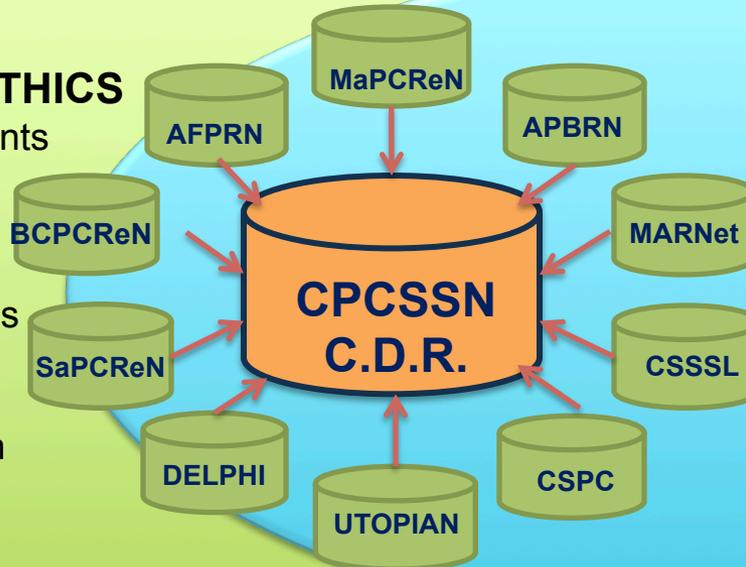
- Anonymized database
- Secure
- Social contract consent
- Approval from 10 University REBs and Health Canada



Intra-dynamics of Privacy & Information System Security

RESEARCH PRIVACY & ETHICS

- Privacy Impact Assessments
- TCP2 & applicable laws
- Privacy Policy
- Patient & Custodian notification/opt-out process
- Best Practices
 - Compliance Checklist
 - Orientation & Education
 - Annual PIA & analysis



INFORMATION SYSTEM SECURITY

- *Privacy by Design* Principles
- Enterprise Risk Management
 - Threat-Risk Assessment
 - Penetration Test
- Information Security Documents
 - Policies & Procedures
 - Standard Operating Procedures
 - ISO 27001/2 Compliance

CPCSSN



RCSSSP

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CPCSSN's privacy program:

CPCSSN's comprehensive organizational, physical and technological safeguards are built into the full life cycle of the CPCSSN data.

Research Privacy & Ethics Officer Jannet Ann Leggett has been named a Privacy by Design Ambassador by Ontario's Information & Privacy Commissioner, Ann Cavoukian



Ann Cavoukian, Ph.D.
Information & Privacy Commissioner
Ontario, Canada



CPCSSN's privacy program:

Awarded the 2013 Innovation Award by the International Association of Privacy Professionals(IAPP) award for organizations of 5,000 or fewer employees organization category.



Photograph Courtesy of the IAPP. © Mike Nakamura



Data validations accomplishments

- Cross-sectional data validation study of CPCSSN's chronic disease case definitions
 - 126 sentinels participated
 - 1,920 patient charts reviewed
 - Definitions - excellent sensitivity & specificity

CPCSSN QUARTERLY REPORT: AFPRN / SENTINEL 001

A. DEMOGRAPHICS (YCG)

Indicators	CPCSSN	AB	AFPRN	Site	Sentinel
Age (mean years)	49	47.1	47.3	48.2	50.3
% paediatric (<18 yrs)	5.6	6.4	5.5	6.1	6.4
% adult (18-65 yrs)	72.1	75.3	75.7	73.8	75.5
% geriatric (>65 yrs)	22.2	18.4	18.8	20.1	18.1
Sex (% male)	40.1	40.0	35.0	37.2	24.8
	193,402	31,542	14,473	2,263	343

B. PREVALENCE (%)

Conditions	CPCSSN	AB	AFPRN	Site	Sentinel
Hypertension	19.5	18.3	18.7	20.4	26.4
Diabetes	8.7	8.2	8.0	9.4	9.5
Depression	12.9	15.4	19.6	21.5	31.1
COPD	3.1	2.7	2.8	3.7	1.9
Osteoarthritis	9.4	10.9	11.6	14.0	19.9
Parkinson's	0.3%	0.2%	0.2%	0.1%	0.2%
Epilepsy	0.8%	1.0%	1.1%	1.2%	1.7%
Dementia	1.6%	1.0%	1.0%	1.1%	1.2%
N (YCG, UCF)	239,955	40,254	18,274	2,856	421

C. CHRONIC CONDITIONS (%)

Conditions	CPCSSN	AB	AFPRN	Site	Sentinel
None	63.2	63.3	59.9	55.3	44.7
1 Condition	22.6	21.9	24.0	26.3	30.6
2 Conditions	10.0	10.1	11.0	11.8	15.4
3 Conditions	3.3	3.6	3.8	5.0	6.6
4 Conditions	0.8	1.0	1.1	1.4	2.6
5 Conditions	0.1	0.2	0.2	0.1	0.0
6 Conditions	0.0	0.0	0.0	0.0	0.0
7 Conditions	0.0	0.0	0.0	0.0	0.0
8 Conditions	0.0	0.0	0.0	0.0	0.0
N (YCG, UCF)	239,955	40,254	18,274	2,856	421

D. INDICATORS (YCG)

	CPCSSN	AB	AFPRN	Site	Sentinel
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D1. HYPERTENSION

Total with HTN (n):	46,806	7,352	3,414	582	111
# HTN with BP (n):	44,907	7,304	3,390	581	111
% systolic BP <140:	71.0	71.1	73.2	70.1	74.8
% diastolic BP <90:	88.7	85.7	86.5	90.4	95.5
Missing (n):	1,899	48	24	1	0

D2. DIABETES

Total with DM (n):	20,831	3,283	1,468	268	40
# DM with HbA1C (n):	17,331	2,156	1,367	248	36
% HbA1C <7:	53.6	47.9	47.9	47.2	72.2
% HbA1C 7-8:	26.1	27.3	27.7	28.2	22.2
% HbA1C >8:	20.3	24.8	24.4	24.6	5.6
Missing (n):	3,500	1,127	101	20	4
# DM with BP (n):	19,657	3,244	1,449	268	40
% systolic BP <130:	50.6	52.7	55.3	53.7	60.0
% diastolic BP <80:	65.0	63.3	64.1	66.4	80.0
Missing (n):	1,174	39	19	0	0
# DM with LDL (n):	18,357	3,030	1,330	249	40
% LDL <2:	42.2	39.9	40.0	48.2	42.5
Missing (n):	2,474	253	138	19	0

D3. COPD

Total with COPD (n):	7,544	1,100	516	106	8
#COPD with smoking(n):	3280	860	394	102	8
Smoking Current:	42.8	36.9	39.1	46.1	37.5
Past:	36.2	24.1	18.0	35.3	50.0
Never:	21.0	39.1	42.9	18.6	12.5
Missing (n):	4,264	240	122	4	0



Linking information

- The full postal code = a proxy for social determinants of health
 - Deprivation score developed by Canadian Institutes of Health Information (CIHI)
 - publically available information
 - Assigns a score 1 (least deprived) to 5 (most deprived)
 - To map CPCSSN data to the anonymized CPCSSN data the full postal code is required



Linking information

- The full postal code extraction
 - Health Canada and regional research ethics approval to extract full postal codes for the limited purpose of using the Postal Code Conversion File from Statistics Canada
 - CPCSSN data extracted from EMRs is transformed into “anonymized” information (TCPS2 definition)
 - Full postal code is not directly identifying information
 - CPCSSN takes further steps to mitigate risks of possible re-identification

Reducing the risk of re-identification

- Researchers enter into data sharing agreements
 - Cannot use CPCSSN data for linking or merging with other data bases, unless under expressed REB(s) approval
- CPCSSN Pledge-of-Confidentiality and Privacy agreements signed by staff and researchers
- Before releasing data to a researcher the data requested is run through the Privacy Analytics Tool (PARAT) software

Reducing the risk of re-identification

- Privacy Analytics Tool (PARAT) software
 - Looks at three parameters (gender, date of birth, and postal code) in the pool of data
 - ≤ 5 fields in a data pull = $\geq 20\%$ risk of re-identification
 - The software automatically removes one or more digits from the postal code and/or data of birth until the fields have a larger result mitigating the risk or re-identification
 - <http://www.privacyanalytics.ca/software/>



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<http://www.cpcssn.ca>



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