

The Canadian Primary Care Sentinel Surveillance Network: Data Source for Chronic Disease in Primary Care



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



**The College of
Family Physicians
of Canada**

**Le Collège des
médecins de famille
du Canada**

Canadian Association of Health Services and Policy Research Conference
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Objectives

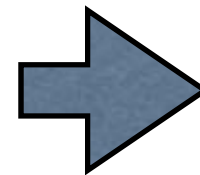
- 1. Need for Primary Care Data Sources**
- 2. Describe CPCSSN infrastructure**
- 3. Issues in Data Collection**



Current Data Sources for Chronic Disease

- ▶ Mortality statistics
- ▶ Hospital discharge data
- ▶ Disease specific registries
- ▶ Provincial billing data
- ▶ National population health surveys

SO.... Where do people with chronic disease receive most of their medical care in Canada?



Primary Care



CPCSSN Background

Purpose

1. Develop an infrastructure for CPCSSN that will underpin the operations of a robust, longitudinal data collection and maintenance of a primary care data repository on chronic disease
2. Demonstrate the ability to extract relevant data from multiple EMRs at multiple primary care practice sites
3. Develop a representative sentinel surveillance network of family practices to monitor chronic disease in Canada
4. Create a usable database that will be a searchable data repository for government, primary care researchers and others in Canada



CPCSSN Key Stakeholders

- ▶ Organized as sub entity of the **College of Family Physicians of Canada**
- ▶ Funded by **Public Health Agency of Canada**
- ▶ Collaborating **Canadian Institute of Health Information**



CPCSSN Background

- ▶ Network of Networks
- ▶ 9 primary care research networks in 6 provinces (Newfoundland, Nova Scotia, Quebec, Ontario, Manitoba and Alberta)
- ▶ Recruited up to 10 practices using Electronic Medical Records (EMR) in each network
- ▶ 9 different EMR systems



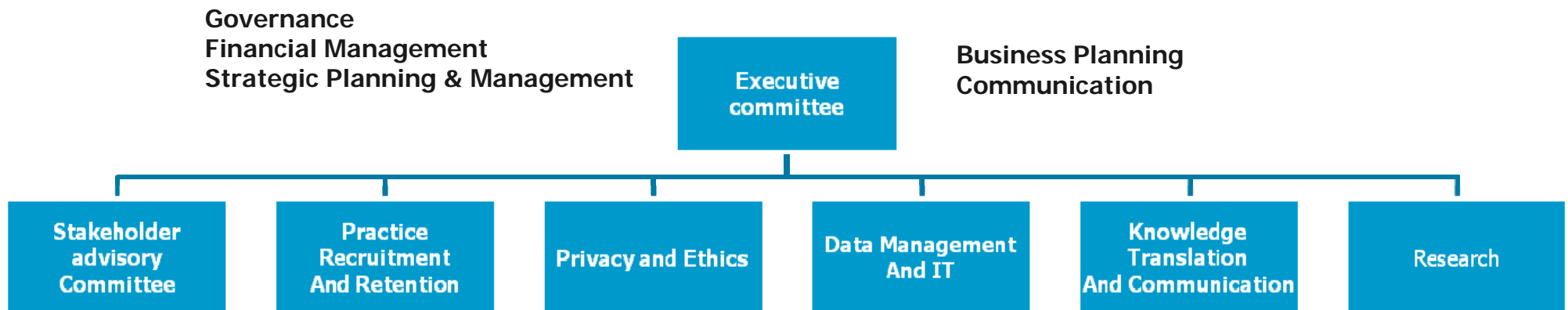
CPCSSN Background

- **Population**

- ▶ Adult patients over the age of 18 who have a chronic disease.
- ▶ The system will collect data on 5 chronic diseases: Diabetes, Depression, COPD, Arthritis and Hypertension.
- ▶ Other diseases may be added at a later time.

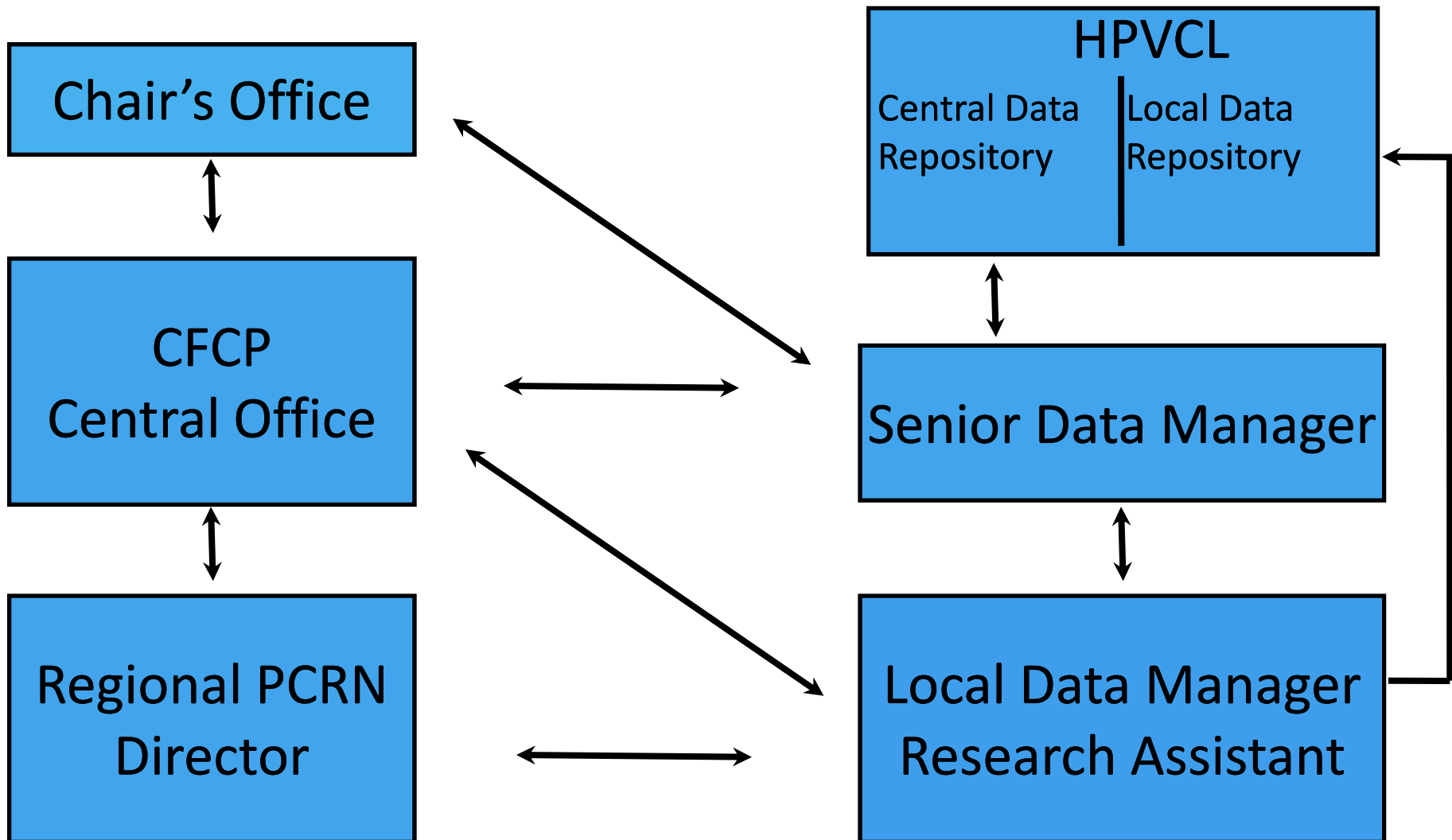


CPCSSN Organization





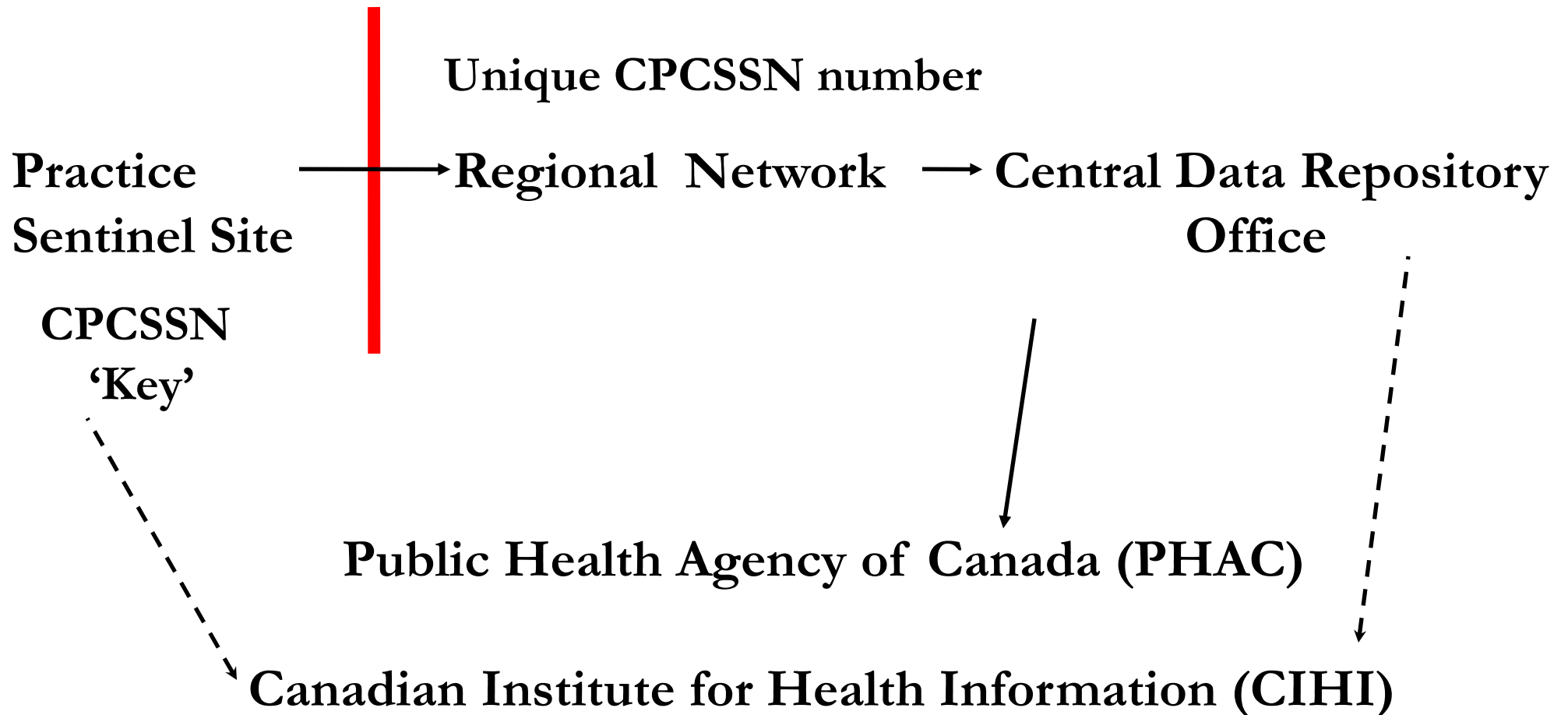
CPCSSN Operations





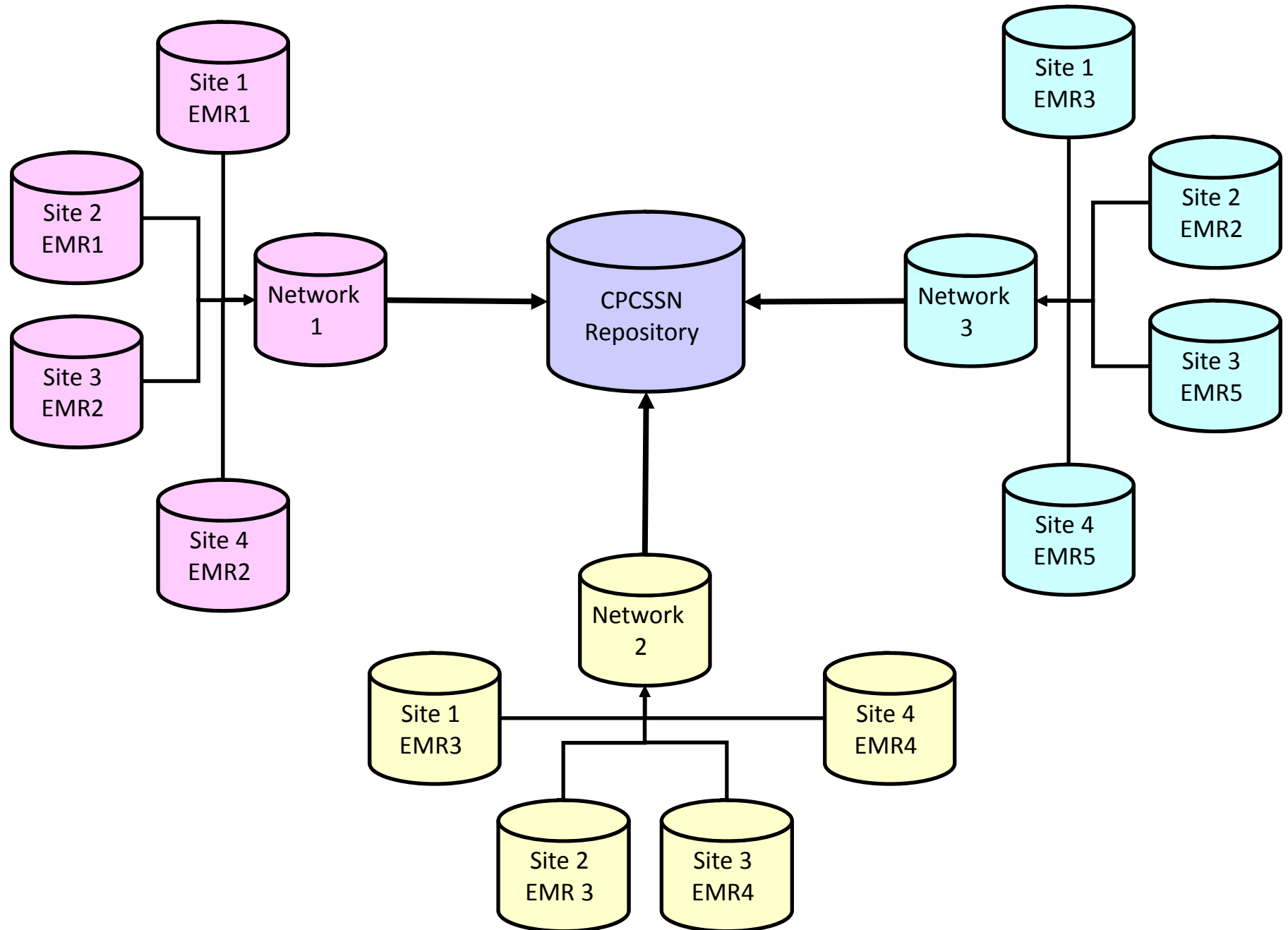
Data Extraction and Flow

Patient Privacy and data flow





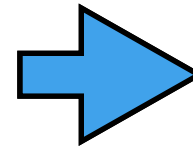
Network Architecture





CPCSSN EMR Data

- Health Provider and Practice characteristics
- Patient demographics
- Health conditions
- Patient encounters
- Physical exam findings
- Risk factors
- Medications
- Referrals
- Procedures
- Diagnostic test results

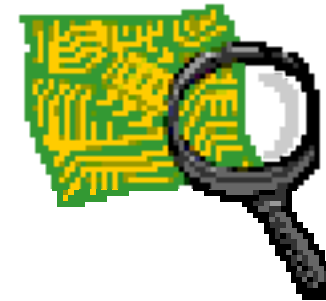


**Structured
Database**



Data Issues

- **Data standardization and cleaning**
 - EMR variation in data capture
 - Data field mismatches
- **Data quality**
 - Data Validity
 - Dirty and missing data
 - Inconsistent and cloudy data
 - Lacking metadata





The Need for full time data managers

- Develop expertise and knowledge of local EMRs
- Develop and maintain personal relationship with practices.
- Provide crucial research capacity at site





Data Cleaning & Data Standardization

- **Different EMRs capture data differently**
 - Smoker, current smoker, non-smoker/ex-smoker
 - HbA1c 7% vs 0.07
 - ICD9 vs ICDA (Ontario)
- **Data field mismatch**
 - Medication: Indocid 25 mg bid--is that 2, 3 or 4 fields?
 - Labs: Na 135 mmol/L (132 -140) N – Normal range could be one field or two
 - Significant negative not captured



Canadian Primary Care
Sentinel Surveillance
Network

✓ **“Dirty data”** (misspellings, extra words in field, strings (ex smoker, ex-smoker), multiple ... a single field)

Data Quality Issues

➤ Can be cleaned by data managers

✓ **“Missing data”** (dosages, dates of onset, occupation, ethnicity)

➤ Cannot be fixed, other than having it entered

✓ **“Inconsistent data”** (Diagnoses stored in different places –notes, PMH, problem list, Inconsistent Risk Factors coexisting –smoker, ex-smoker)

➤ Need to find the best source of data for each EMR

✓ **“Cloudy data”** (referral to xray or Dr. Jones)



Data Quality Issues

- ✓ **“Lacking Meta Data”** (Diagnosis not in problem list, Medication in encounter notes)
 - Cannot be fixed, other than enter pre-formatted
- ✓ **“Lacking standardization”** (multiple, changing, inconsistent names or results for lab tests –HbA1C, glycosylated hemoglobin, 7% vs. 0.07 for test results)
 - Must be fixed by national lab standards
- ✓ **“Lacking data feeds”** (lab results not coming in electronically)
 - Needs to be fixed at clinic level



Summary

- CPCSSN is a national surveillance system for chronic disease
- CPCSSN is an opportunity to develop primary care research capacity in Canada
- many challenges yet to meet !
 - ✓ Epidemiological
 - ✓ IT
 - ✓ EMR related

Thanks to all Funders, Stakeholders & Partners



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The College of Family Physicians
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du Canada

National Research System (NaReS)
Système de recherche national (NaReS)



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for Health Information
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