



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**

CPCSSN privacy, ethics early days...

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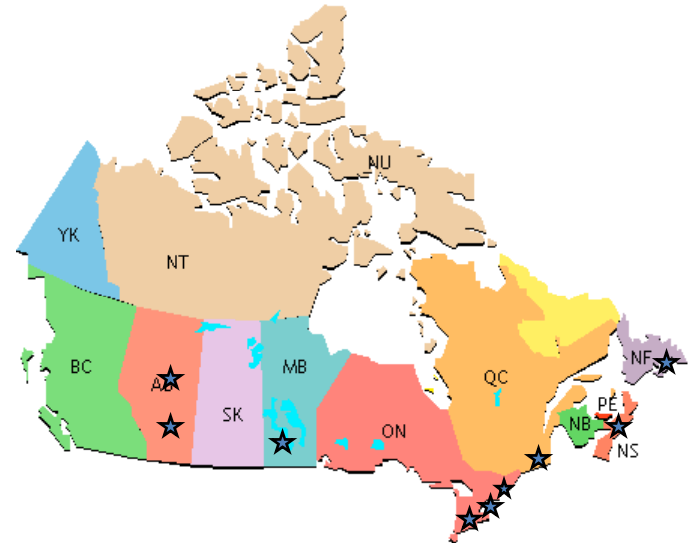
Objectives

- Develop an electronic chronic disease surveillance network while respecting privacy:
 1. establishing a pan-Canadian primary care sentinel surveillance network
 2. extracting and validating chronic disease health information; and
 3. establishing a central primary care chronic disease data repository for the conduct of surveillance and approved research studies

Nine Primary Care Research Networks

Six Provinces & Seven EMRs

- **Alberta**
 - *SaPCReN Calgary – MedAccess
 - *AFPRN Edmonton - MedAccess
- **Manitoba**
 - MaPCReN Winnipeg - Jonoke
- **Ontario**
 - *DELPHI London – Healthscreen
 - *NORTReN Toronto – Nightingale
 - *CSPC Kingston – P&P
- **Quebec**
 - *Q-net Montreal - DaVinci
- **Nova Scotia**
 - MARNet Halifax
- **Newfoundland**
 - *APBRN St. John's - Wolf Medical Systems



* 7 PBRN involved in phase 1, two joined in phase 2 of the project

Privacy Issues

Patient

**De-identified
health information**



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Privacy Issues

- Physician meets surveillance
- Personal information
- Patients' information



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Informed Consent

- **Explicit Consent**
 - Obtained in higher risk situations when identifiable information was collected
 - Obtained from participating physicians as subjects
- **Waiver of individual participant consent (social contract consent)**
 - Obtained in low risk situations when de-identified health data was collected
 - Study information advertised to patients (posters, handouts)
 - Patients are able to refuse participation



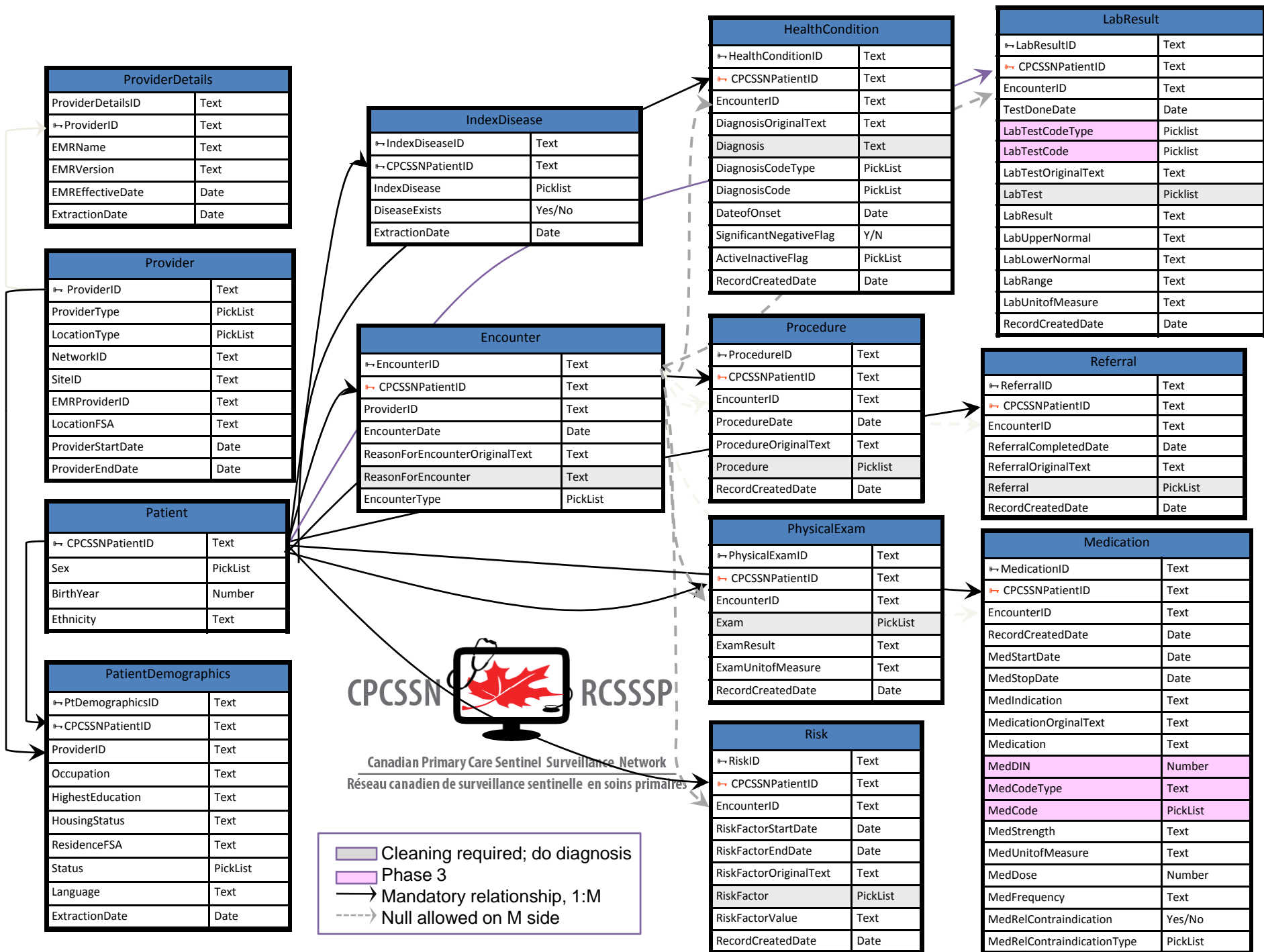
Data Extraction Process

- **At the practice site**
 - **CPCSSN key**
 - Contains identifiers linking data to the patient (CPCSSN number, postal code, DOB, gender, PHCN)
 - Contains no health information
 - Kept at the practice site
 - **Health data related to the disease of interest**
 - Extracted from the EMR
 - Provided with a unique CPCSSN identifier
 - Reviewed to ensure all identifiers are removed
 - Encrypted and copied onto an electronic storage device and then onto a password protected computer or transferred electronically directly to a CPCSSN server



Data Extraction Process

- **At the local network or CPCSSN server**
 - De-identified data will be processed and de-identification software will be used prior to sending to the Central Repository
- **Central Repository**
 - Secure server located at the High Performance Computing Virtual Laboratory (HPCVL) at Queen's University, Kingston, On
 - De-identified and processed health data will be sent to the Central Repository for merging with regional data and processing



ProviderDetails	
ProviderDetailsID	Text
ProviderID	Text
EMRName	Text
EMRVersion	Text
EMREffectiveDate	Date
ExtractionDate	Date

Provider	
ProviderID	Text
ProviderType	PickList
LocationType	PickList
NetworkID	Text
SiteID	Text
EMRProviderID	Text
LocationFSA	Text
ProviderStartDate	Date
ProviderEndDate	Date

Patient	
CPCSSNPatientID	Text
Sex	PickList
BirthYear	Number
Ethnicity	Text

PatientDemographics	
PtDemographicsID	Text
CPCSSNPatientID	Text
ProviderID	Text
Occupation	Text
HighestEducation	Text
HousingStatus	Text
ResidenceFSA	Text
Status	PickList
Language	Text
ExtractionDate	Date

IndexDisease	
IndexDiseaseID	Text
CPCSSNPatientID	Text
IndexDisease	PickList
DiseaseExists	Yes/No
ExtractionDate	Date

Encounter	
EncounterID	Text
CPCSSNPatientID	Text
ProviderID	Text
EncounterDate	Date
ReasonForEncounterOriginalText	Text
ReasonForEncounter	Text
EncounterType	PickList

HealthCondition	
HealthConditionID	Text
CPCSSNPatientID	Text
EncounterID	Text
DiagnosisOriginalText	Text
Diagnosis	Text
DiagnosisCodeType	PickList
DiagnosisCode	PickList
DateofOnset	Date
SignificantNegativeFlag	Y/N
ActiveInactiveFlag	PickList
RecordCreatedDate	Date

Procedure	
ProcedureID	Text
CPCSSNPatientID	Text
EncounterID	Text
ProcedureDate	Date
ProcedureOriginalText	Text
Procedure	PickList
RecordCreatedDate	Date

PhysicalExam	
PhysicalExamID	Text
CPCSSNPatientID	Text
EncounterID	Text
Exam	PickList
ExamResult	Text
ExamUnitofMeasure	Text
RecordCreatedDate	Date

Risk	
RiskID	Text
CPCSSNPatientID	Text
EncounterID	Text
RiskFactorStartDate	Date
RiskFactorEndDate	Date
RiskFactorOriginalText	Text
RiskFactor	PickList
RiskFactorValue	Text
RecordCreatedDate	Date

LabResult	
LabResultID	Text
CPCSSNPatientID	Text
EncounterID	Text
TestDoneDate	Date
LabTestCodeType	PickList
LabTestCode	PickList
LabTestOriginalText	Text
LabTest	PickList
LabResult	Text
LabUpperNormal	Text
LabLowerNormal	Text
LabRange	Text
LabUnitofMeasure	Text
RecordCreatedDate	Date

Referral	
ReferralID	Text
CPCSSNPatientID	Text
EncounterID	Text
ReferralCompletedDate	Date
ReferralOriginalText	Text
Referral	PickList
RecordCreatedDate	Date

Medication	
MedicationID	Text
CPCSSNPatientID	Text
EncounterID	Text
RecordCreatedDate	Date
MedStartDate	Date
MedStopDate	Date
MedIndication	Text
MedicationOriginalText	Text
Medication	Text
MedDIN	Number
MedCodeType	Text
MedCode	PickList
MedStrength	Text
MedUnitofMeasure	Text
MedDose	Number
MedFrequency	Text
MedRelContraindication	Yes/No
MedRelContraindicationType	PickList

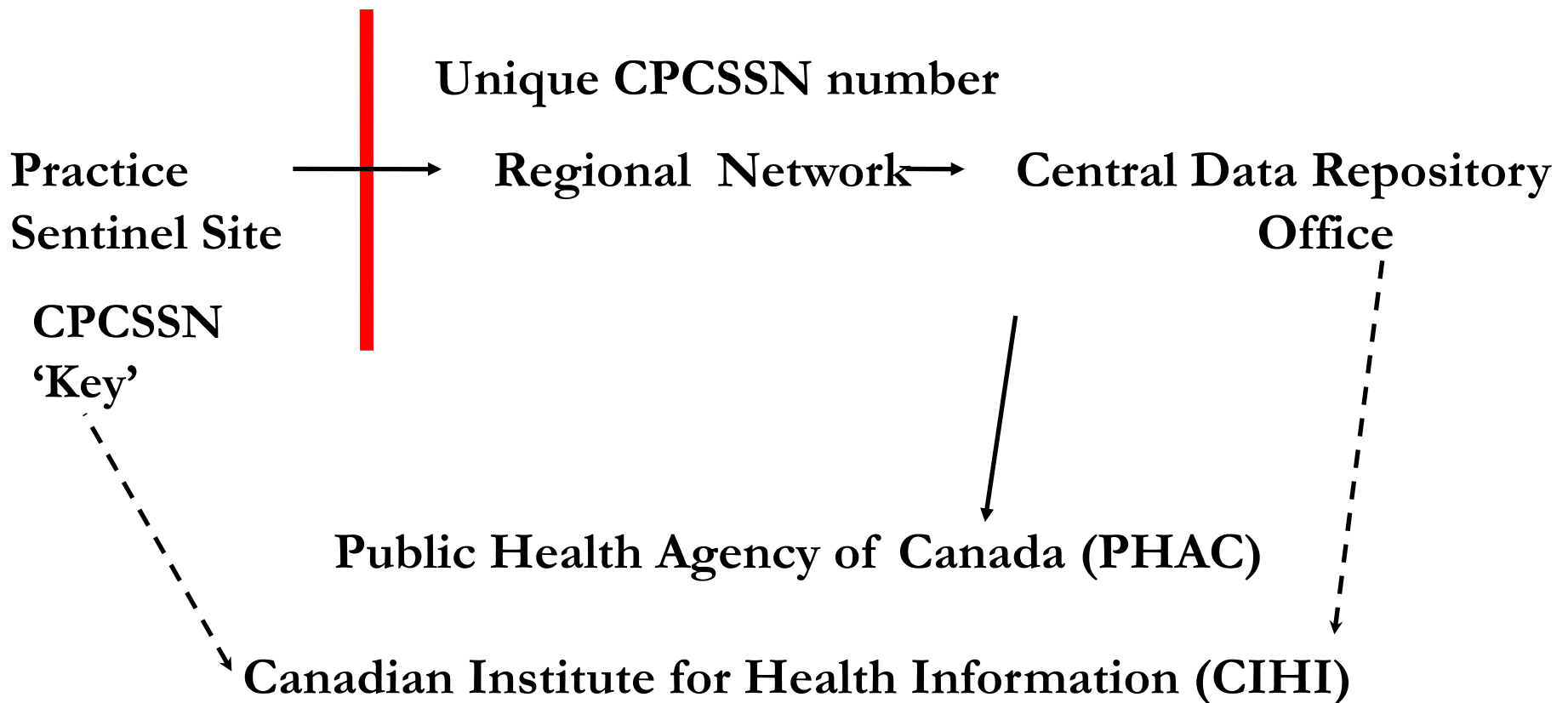


Canadian Primary Care
Sentinel Surveillance
Network

Data Flow

Identity stops at...

Patient Privacy and data flow



Obtaining REB Approval from different REBs

- **First REB submission – Queen’s**
 - First to submit for expedited review
 - Developed templated documents shared with others
- **Secure CPCSSN Resource Website**
 - Posted Queen’s REB application & related documents
 - Posted REB approvals from each network



REB Approval

- **Expedited Approval was requested**

- 6/7 Networks obtained REB approval

- Two required full review

- One obtained REB & the other obtained REB in the second phase

- Explicit Consent was required by

- One REB in Edmonton for EMR laboratory data extraction since this populates the EMR through the *netcare* portal
- One REB in Quebec required from each patient (Full REB approval was obtained in Phase 2)



Common REB Questions

- Advertising the option not to participate in the project
 - What about those who cannot learn about the project? (deceased, minors, etc)
- How does one deal with destroying the data after 7 years if the goal is to create a lasting (renewable) database followed longitudinally over time?
- What data elements will be kept at each practice (“CPCSSN key”)
- Exactly how will data be de-identified for flow from each practice to the local network repository and eventually to a central repository?
- Where exactly will the central repository sit or will it be virtual?

Process Established to Address Privacy & HIA Issues

- **Research agreements**
 - Between custodians of the data and the researchers
- **Unique EMR sign-on**
 - obtained for access to EMR data
- **De-nominalization & De-identification**
 - Of data extracted from the EMR prior to leaving the practice
 - Then again through software to minimize the risk of re-identification*
- **Confidentiality agreements**
 - signed by all involved in the project



*El Emam K, Brown A, AbdelMalik P. Evaluating predictors of geographic area population size cut-offs to manage re-identification risk. J Am Med Inform Assoc. 2009 Mar-Apr;16(2):256-66. Epub 2008 Dec 11. PMID: 19074299

Conclusion

- We developed pan-Canadian strategies to collect and de-identified health information from EMRs that will
 - Help us to establish a chronic disease repository
 - Protect patients' right to privacy
 - Address concerns of custodians who protect their patients' data



Thanks to all Funders, Stakeholders & Partners



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Système de recherche national (NaReS)



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for Health Information
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