# Public Health Monitoring and Research: Experience with Electronic Health Record Data

Rachel Zucker June 3, 2016

**Outline** 

#### What is CHORDS?

- What is PopMedNet?
- Data sharing governance

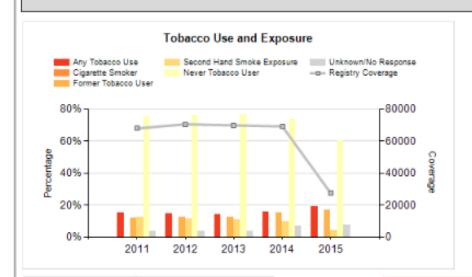
## What is CHORDS?

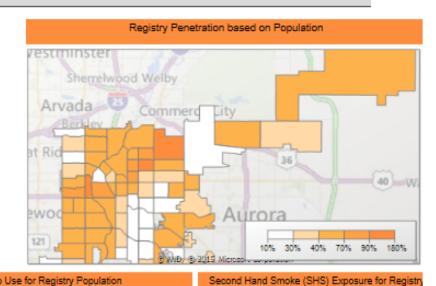
- The Colorado Health Observation Regional Data Service
- Facilitates electronic health record (EHR)
  data sharing and aggregation from 11
  participating healthcare sites representing
  over 3 million registered patients in the
  Denver Metro region.
- Early projects have focused on public health
  - Tobacco use and exposure
  - Obesity
  - Cardiovascular risk



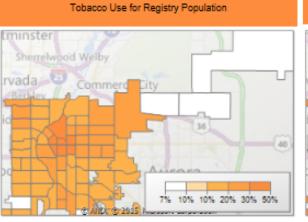
#### 2T1: Tobacco Surveillance Summary

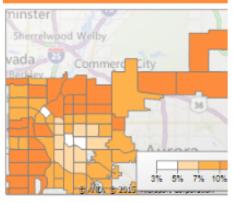
Tobacco, a leading cause of disease and preventable, premature death, is a public health surveillance priority. Using compiled clinical data from local healthcare providers, a regional tobacco registry performs surveillance for tobacco use and exposure. Clinic data does not represent the entire jurisdiction; those neither engaged in primary care nor seeking care during the selected date range are excluded. Clinic data may be subject to bias when analyzed for limited time periods (e.g., less than 1 year) thus, the minimal timeframe for tobacco dashboard analyses is annual summaries.





Total Population	125,027	
Tobacco Status	Number of Residents	
	Contributing to Registry	With this Tobacco Status
Any Current Tobacco Use	297,223	45,485
Cigarette Smoker	297,223	0
Former Tobacco Use	297,223	40,280
SHS Exposure	297,223	31,619
Never Used Tobacco	297,223	225,216
Unknown	297,223	14,051





#### What is CHORDS?

- A collaboration between several Colorado research and health care organizations
  - Technical and policy infrastructure to support regional data sharing for research, patient care, and surveillance



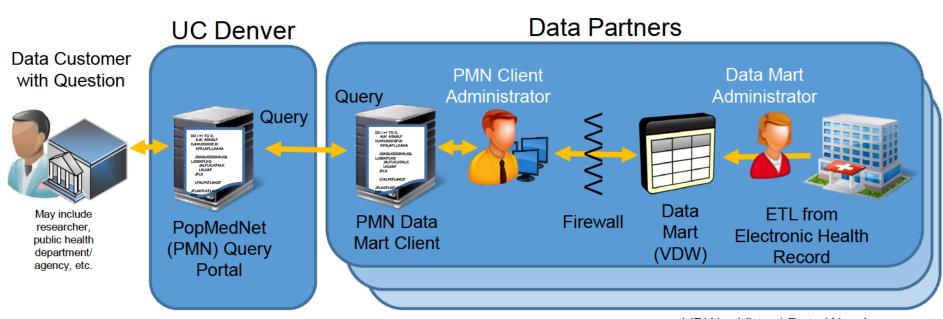
# What is PopMedNet?

- Open source software for distributed ("federated") data sharing networks
  - For institutions that want to share information and analytics but not the underlying data
- Developed by software development company Lincoln Peak Partners on behalf of the Department of Population Medicine at Harvard Pilgrim Health Care Institute
- Originally developed for Mini-Sentinel project; now adopted by multiple national initiatives





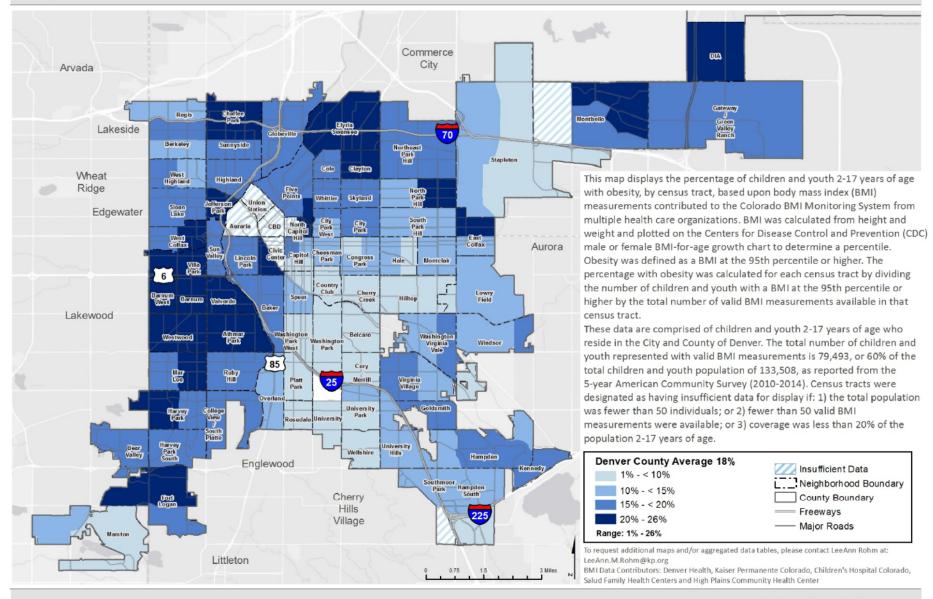
## **CHORDS Federated Query Overview**



VDW = Virtual Data Warehouse ETL = extract transform and load

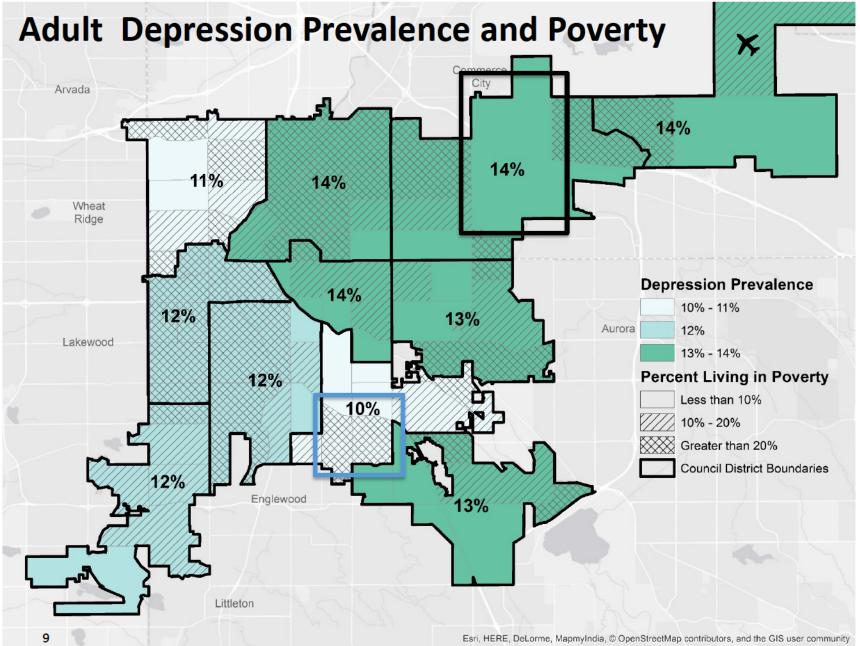


# Estimated Prevalence of Children and Youth with Obesity (2012-2014): City and County of Denver

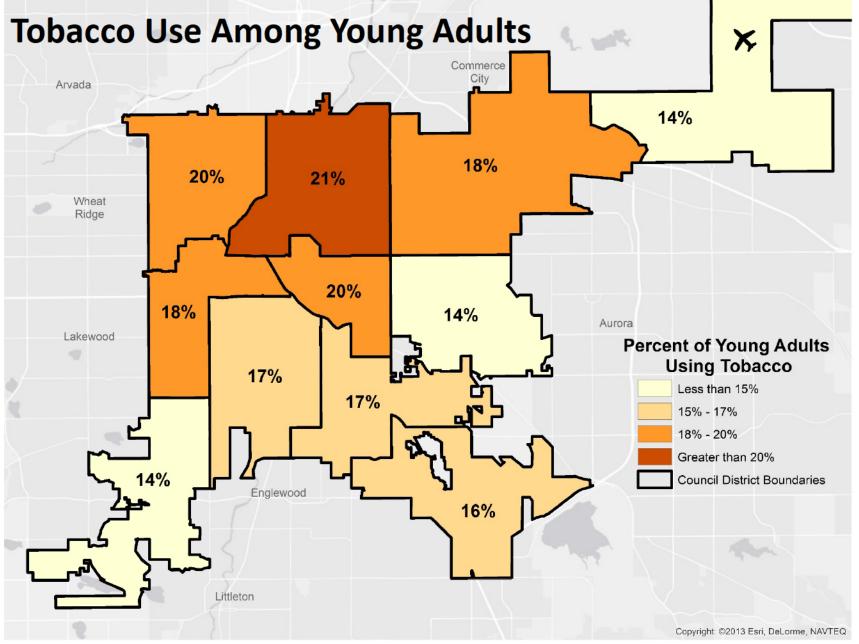


Census Tract Boundary Data: US Census 2010 Map Created March 2016









## **CHORDS Governance**

- Ensuring Data Security:
  - Partners retain full control over data
  - Proposed research is submitted for IRB review and adheres to HIPAA regulations
  - Each research study using CHORDS must obtain its own IRB approval and describe data safety and management procedures
  - All parties must execute any necessary Data Use Agreements,
     Business Associate Agreements, and/or other contracts and legal agreements in advance of data sharing

## **CHORDS Governance**

#### Principles:

- Requestors ask for the minimum data necessary to answer a question of interest
- Queries yielding identifiable results are not permitted
- CHORDS releases only aggregated data and will not identify partner-specific information
- All partners are responsible for ensuring compliance with federal and state laws and regulations, including HIPAA
- Data partners are responsible for compliance with institutional data use/sharing policies

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# Distributed Data Sharing Principles

- Send the questions to the data
- Keep data in the hands of the original data holders
  - Decrease proprietary and liability issues
  - Decrease risk and severity of breaches
  - Data holders know their data; improve value and interpretation of findings
- Minimize data transfer.
- Voluntary data partner autonomy
- Reciprocity value for participation
- Partnership
- Well-defined purpose

<sup>\*</sup> Jeff Brown, PopMedNet User Group Meeting 2012

# **Questions?**

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