

Building a Learning Health System

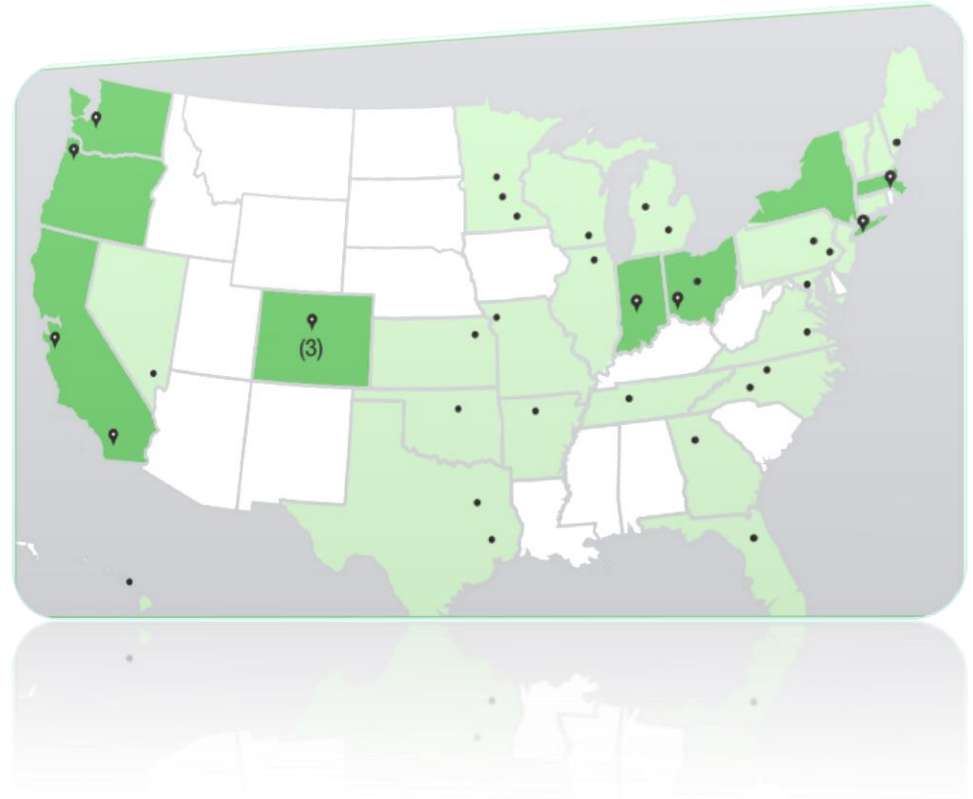
Where have We Been, Where are We Going?

EDM Forum Stakeholder Symposium
June 22, 2013

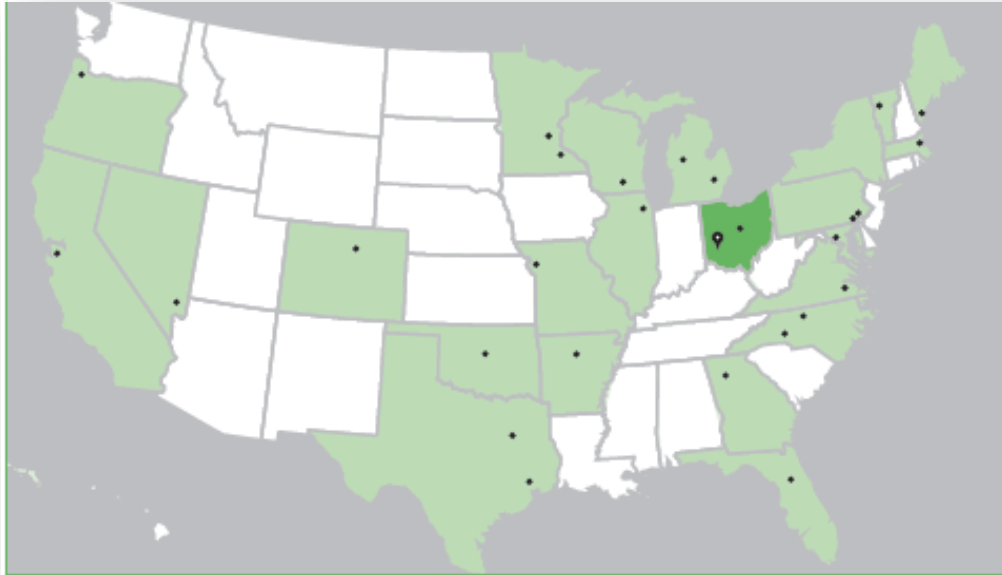
Learning from Learning System Leaders

Chair: Ned Calonge, The Colorado Trust

- Peter Margolis, Cincinnati Children's Hospital Medical Center (Pediatric Enhanced Registry)
- Suzanne Bakken, Columbia University (WICER)
- Lisa Schilling, University of Colorado, Denver (SAFTINet)
- John Steiner, Kaiser Permanente Colorado (SUPREME DM)



Pediatric Enhanced Registry



Goals:

- Enhance an existing **network of pediatric registries**
- Leverage i2b2 and SHRINE to populate the registry with “**data-in once**”
- Support QI and CER, with pilot projects focused on **inflammatory bowel disease (IBD)**



Pediatric Enhanced Registry

Populations, Conditions, Settings

→ Priority Populations

- Children
- Low-Income
- Individuals in inner-city areas
- Individuals who live in rural areas
- Individuals who need chronic care

→ Priority Conditions

- Digestive system conditions
 - Inflammatory bowel disease and Crohn's Disease

~12,000 pediatric IBD patients

→ Healthcare Settings

- Ambulatory primary care clinics
- Pediatric specialty clinics
- Academic medical centers
- Outpatient hospitals



Washington Heights/Inwood Informatics Infrastructure for Community-Centered Comparative Effectiveness Research (WICER)



→ Goals

- Create a **robust community-focused data infrastructure** including a research data warehouse integrating patient data from community survey
- **Build a Research Data Explorer (RedX) tool** to support data queries, and EHR “plug-ins” to facilitate research tasks in the context of clinical care processes
- CER studies focused on **hypertension diagnosis, treatment, and management.**



WICER

Populations, Conditions, Settings

→ **Priority Populations**

- Individuals in inner-city areas
- Minority groups, with a focus on Hispanic Americans
- Low-income Groups
- Women
- Elderly
- Individuals with disabilities
- Individuals who need chronic care

→ **Priority Conditions**

- Hypertension
- Obesity
- Breathing Conditions

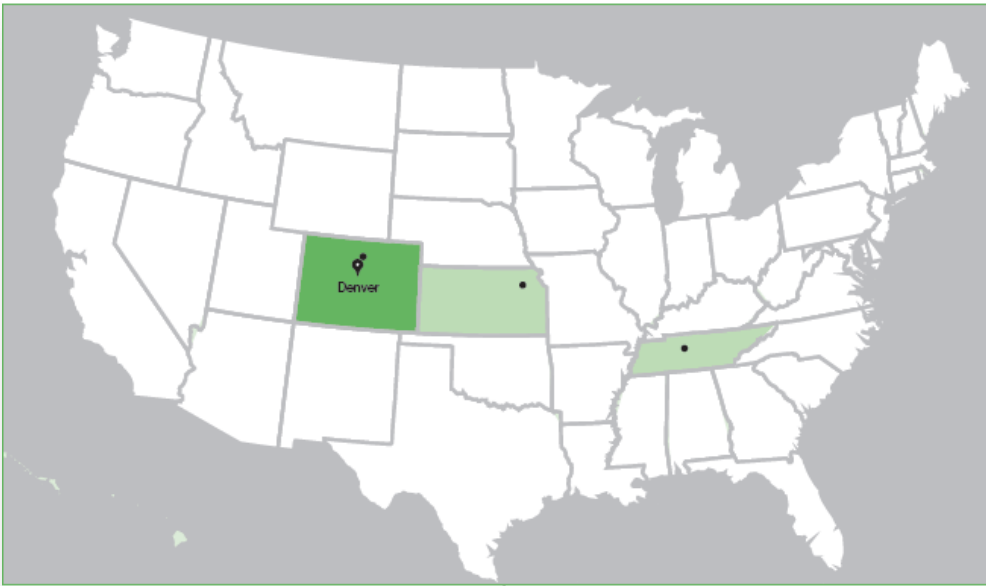
270,677 community members

→ **Healthcare Settings**

- Community Health Center
- Ambulatory
- Care Network Clinics
- Inpatient
- Community Households
- Home Care
- Long-Term care



Scalable Architecture for Federated Translational Inquiries Network (SAFTINet)



→ Goals

- Develop a **collaborative learning system of stakeholders** in the care of safety net populations and a technology infrastructure.
- Enhance the **capacity and capability of a safety net-focused distributed research network** to conduct prospective CER.
- **Leverage TRIAD grid technology and the OMOP common data model** to support data sharing and use for research and QI



SAFTINet

Populations, Conditions, Settings

→ Priority Populations

- Individuals who live in inner-city areas
- Minority groups, with a focus on Hispanic Americans
- Low-income Groups
- Women
- Elderly
- Individuals with disabilities
- Individuals who need chronic care

→ Priority Conditions

- Hypertension and hypercholesterolemia
- Asthma

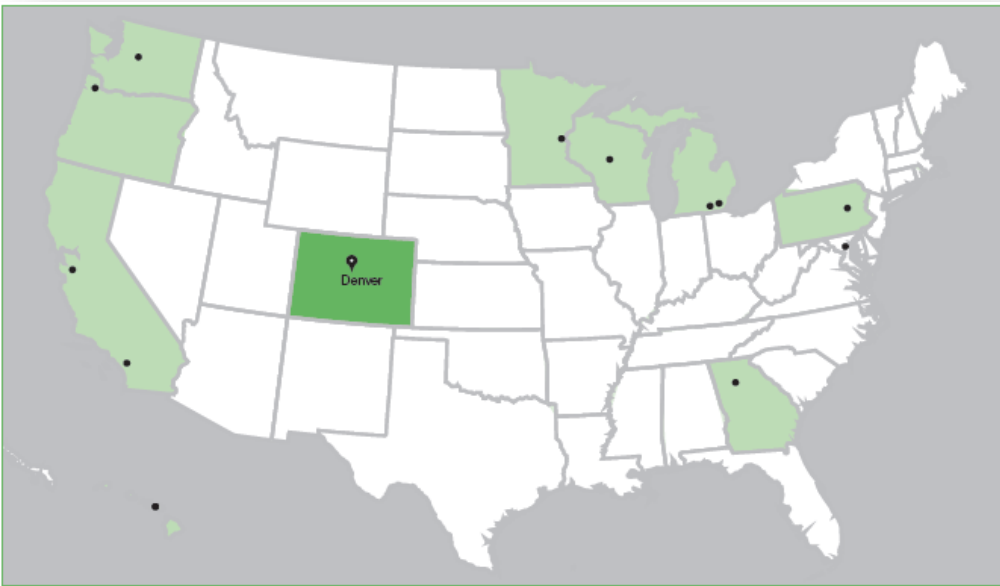
440,109 patients

→ Healthcare Settings

- Low-income groups
- Minority Groups
- Women
- Children
- Elderly
- Individuals who live in inner-city areas
- Individuals who live in rural areas
- Individuals who need chronic care



SURveillance, PREvention, and ManagEment of Diabetes Mellitus (SUPREME-DM)



→ Goals

- Build a **national research network** and multisystem distributed database (DataLink)
 - Capture and standardize detailed demographic and longitudinal electronic clinical data
- **Conduct CER and surveillance in treatment and prevention of diabetes mellitus**



SUPREME-DM

Populations, Conditions, Settings

→ **Priority Populations**

- Pregnant Women
- Children
- Elderly
- Low-income groups
- Minority Groups
- Individuals who live in inner-city areas
- Individuals who live in rural areas
- Individuals who need chronic care

→ **Healthcare Settings**

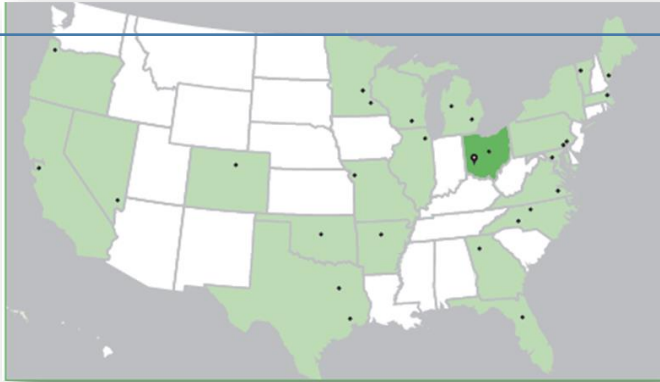
- All healthcare settings

1.1 million
diabetes patients

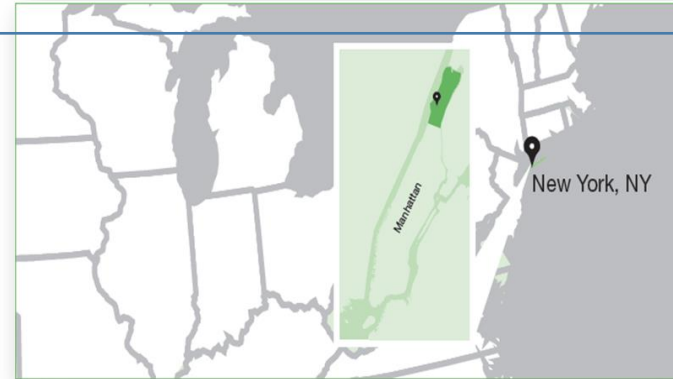
→ **Priority Conditions**

- Diabetes Mellitus including Type 1, Type 2,
- and pre-Diabetes
- Pregnancy, with a focus on women with
- gestational diabetes
- Obesity
- Heart and blood vessel conditions





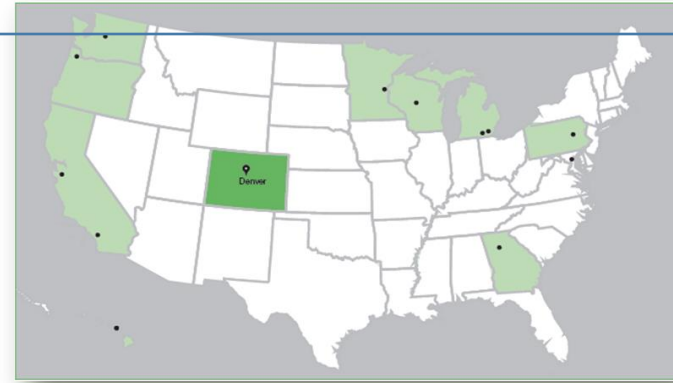
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LESSONS LEARNED AND NEXT STEPS FOR CER, PCOR, AND QI

