

SAFTINet: Scalable Architecture for Federated Translational Inquiries Network

Lisa Schilling, MD, MSPH

University of Colorado School of Medicine

Colorado Health Outcomes Program

April 19, 2011

SAFTINet Overview

- AHRQ ARRA OS: Recovery Act 2009: Scalable Distributed Research Networks for Comparative Effectiveness Research (R01)
- Goal: enhance the capability and capacity of electronic health networks designed for distributed research to conduct prospective, comparative effectiveness research on outcomes of clinical interventions.

Project Requirements

- Develop an electronic health network that collects and links data from multiple and different healthcare delivery settings
- Demonstrate capabilities for conducting methodologically rigorous Comparative Effectiveness Research (CER)
 - Capability for collecting HRQoL measures, other patient-reported outcomes at the POC

Background

- Traditionally clinical trial participants have limited representation
- Health care reform requires a focus on delivery systems, protocols, integrated care
- Principles of primary care, integrated chronic care and patient-centered medical home are central to health care value

A Perfect Storm

- IOM - it's broken
- Health care reform - it's broken, fragmented, and wasteful
- ARRA - we can stimulate the fix

Comparative Effectiveness Milestones

- 2003 - MMA Section 1013 authorizes AHRQ to conduct and support research with a focus on “outcomes, comparative clinical effectiveness, and appropriateness of health care items and services (including prescription drugs)”
- 2009 - ARRA provides \$1.1 Billion to NIH/HHS/AHRQ
- 2010 - Patient Protection and Affordable Care Act

Patient Protection and Affordable Care Act- Public Law 111-148 :Subtitle D

- Patient-Centered Outcomes Research
 - Comparative Clinical Effectiveness Research
- Defined Comparative Clinical Effectiveness Research
 - The terms ‘comparative clinical effectiveness research’ and ‘research’ mean research evaluating and comparing health outcomes and the clinical effectiveness, risks, and benefits of 2 or more medical treatments, services..” as described...

Patient Protection and Affordable Care Act-

- Medical treatments, services, and items described in this subparagraph are health care interventions, protocols for treatment, care management, and delivery, procedures, medical devices, diagnostic tools, pharmaceuticals (including drugs and biologicals), integrative health practices, and any other strategies or items being used in the treatment, management, and diagnosis of, or prevention of illness or injury in, individuals.

Patient Protection and Affordable Care Act- there's more

- Established Patient-Centered Outcomes Research Institute (PCORI), a non-profit corporation with duties including:
 - Identifying national research priorities
 - Establish a research agenda to address these priorities
 - Carry out the research agenda (systematic reviews, primary research, funding)
 - Disseminate

Why this new CER paradigm?

- Improved understanding of the comparative clinical effectiveness of healthcare interventions.
- Contribute to knowledge, counter inefficiencies in time, cost, and limited applicability of RCTs
- Take advantage of the size and expansion of potentially interoperable administrative and clinical datasets.
- Innovative study designs and statistical tools.
- Need to build learning systems in which clinical effectiveness research is a more natural by-product of the care process.
- Engage providers, patients, systems, payers

\$1.1 Billion -ARRA Allocations

- Research
 - Data Infrastructure
 - Dissemination and Adoption
 - Administrative support, inventory, evaluation
- \$681 M (62%)
 - \$268 M (24%)
 - \$132 M (12%)
 - \$ 19 M (2%)

\$1.1 Billion

- **AHRQ** - \$300 million
- **NIH** - \$400 million
- **Office of Secretary, Dept HHS**- \$400 million
- **OS Awards: Data Infrastructure awards,** Dissemination, Translation, and Implementation, Inventory and Evaluation
- **AHRQ Awards:** Horizon Scanning, Evidence Synthesis, Evidence Gap Identification, Translation and Dissemination, Evidence Generation, Training and Career Development, Community Forum

SAFTINet

- Trusted, multi-stakeholder entity to support CER
- Safety-net stakeholders
- Patient-centered outcomes
- Distributed databases
- Network and data stores meet strict security and privacy standards
- Enhanced data collection -patient reported outcomes, practice characteristics, HRQoL

Agency for Healthcare Research and Quality

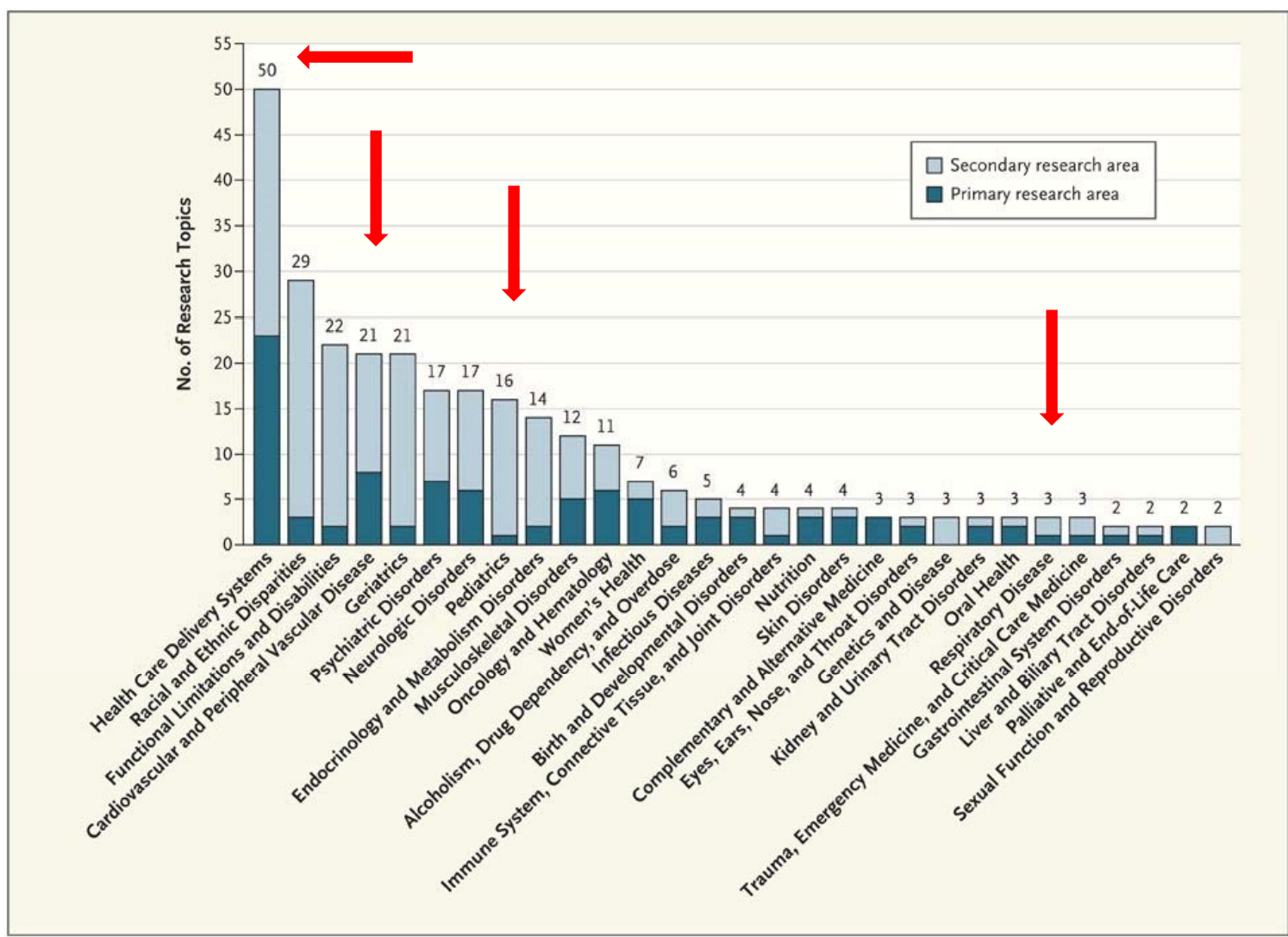
Priority Populations

1. Low-income groups
2. Minority groups
3. Women
4. Children
5. The elderly
6. Individuals with special health-care needs (e.g., disabilities, need for chronic care or end-of-life care, or those who live in inner-city and rural areas)

Priority Conditions

1. Arthritis/joint disorders
2. Cancer
3. Cardiovascular disease
4. Dementia, including Alzheimer's Disease
5. Depression; other mental health disorders
6. Developmental delays, ADHD and autism
7. Diabetes Mellitus
8. Functional limitations and disability
9. Infectious diseases including HIV/AIDS
10. Obesity
11. Peptic ulcer disease and dyspepsia
12. Pregnancy including pre-term birth
13. Pulmonary disease/Asthma
14. Substance abuse

Institutes of Medicine Top 100 Priority Areas



Partner Engagement

- **Specific Aim 1:** Establish a broad, safety-net focused, research partnership and learning community to govern relationships, establish priorities, provide data quality oversight, and evaluate the purpose and value of the community's effort
 - Create a trusted, valued multi-state community of safety net stakeholders and researchers to lead and participate in a learning community to address evidence-gaps relevant to the safety net populations

Technology

- **Specific Aim 2:** Build, deploy and assess a safety-net focused distributed research network combining ambulatory and inpatient clinical data and Medicaid claims and eligibility data for clinical and research purposes
 - Federated infrastructure
 - Common data model
 - Translational Informatics and Data Management Grid (TRIAD)

Comparative Effectiveness Research

- **Specific Aim 3:** Develop and enhance four sentinel cohort pairs of patients with asthma (pediatric and adult), hypertension, and hypercholesterolemia distinguished by their care delivery characteristics for comparative effectiveness research.
 - Enhance the available data by implementing point of care data collection tools

Key Partners

Great overlap in partner roles/expertise

- Partners with diverse populations/clinical data
 - Colorado Community Managed Care Network (CCMCN) and CO Associated Community Health Information Enterprise (CACHIE)
 - Denver Health and Hospital Authority
 - Intermountain Health - Community Health Centers
 - Cherokee Health Systems
- Partners with administrative data
 - Health Care Policy and Financing, CO
 - Utah Department of Health
 - TennCare

Key Partners

- Technology Partners
 - University of Utah, Center for High Performance Computing
 - QED Clinical, Inc., d/b/a CINA
 - CACHIE
 - DHHA
- Comparative Effectiveness Research
 - Clinical partners
 - IMH
- Leadership/Partner Engagement
 - American Academy of Family Physicians
 - Clinical partners

Gurvaneet Randhawa, MD, MPH,
AHRQ Project Officer

Lisa Schilling, MD, MSPH
Principal Investigator

Bethany Kwan, PhD, MSPH
Project Manager

David West, PhD
Co-investigator
Project Oversight

Michael Kahn, MD, PhD
Co-investigator
Lead SAFTINet
Informatics

Cathy Bryan, RN, MHA
QED Clinical, Inc. d/b/a
CINA

Julio Facelli, PhD
Univ of Utah Center for
High Performance
Computing

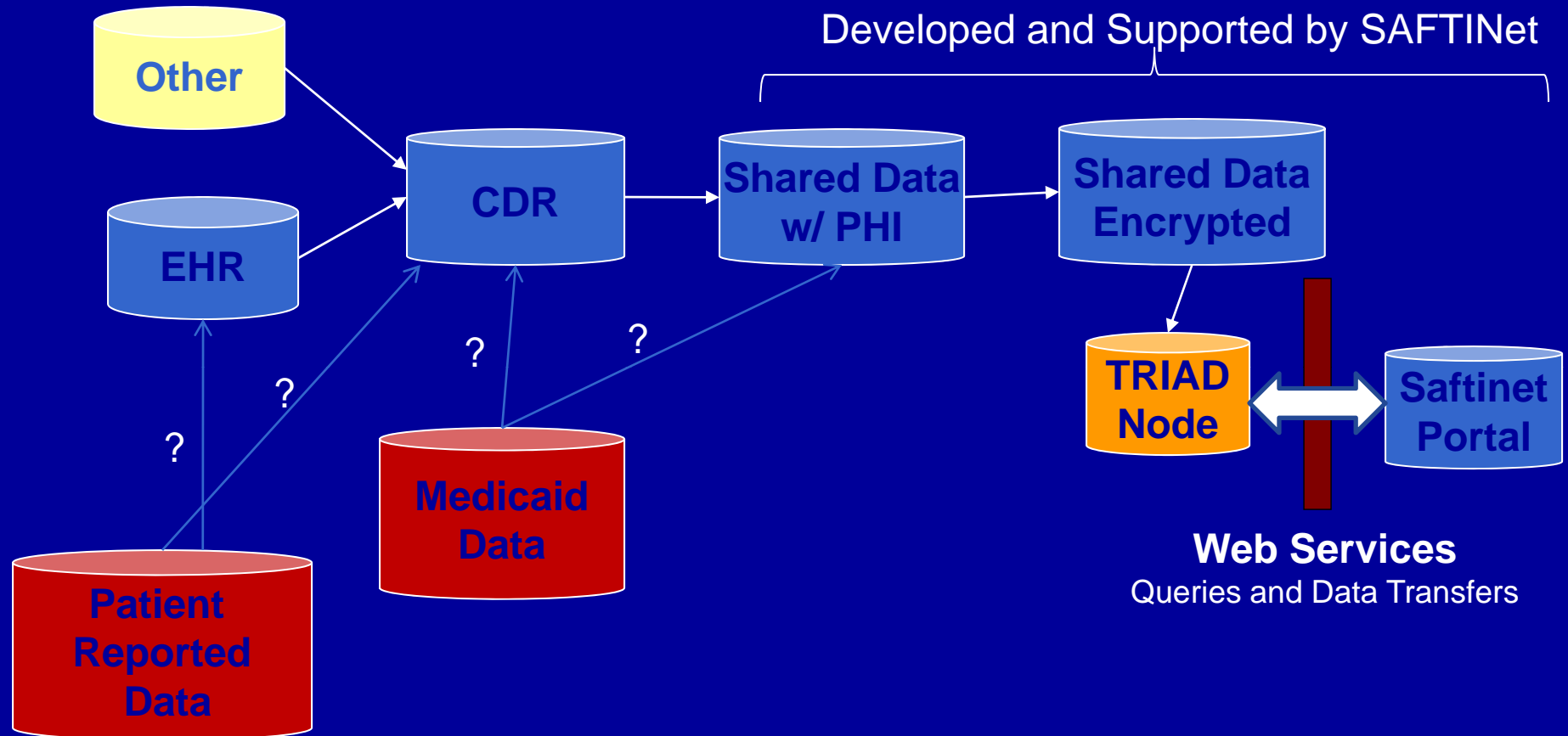
Art Davidson, MD, MSPH
Co-investigator
DH Informatics,
Medicaid
Relationships

Wilson Pace, MD
Co-investigator
DARTNet/SAFTINet
Informatics

Marion Sills, MD, MPH
Co-investigator
CER, Cohort
Development

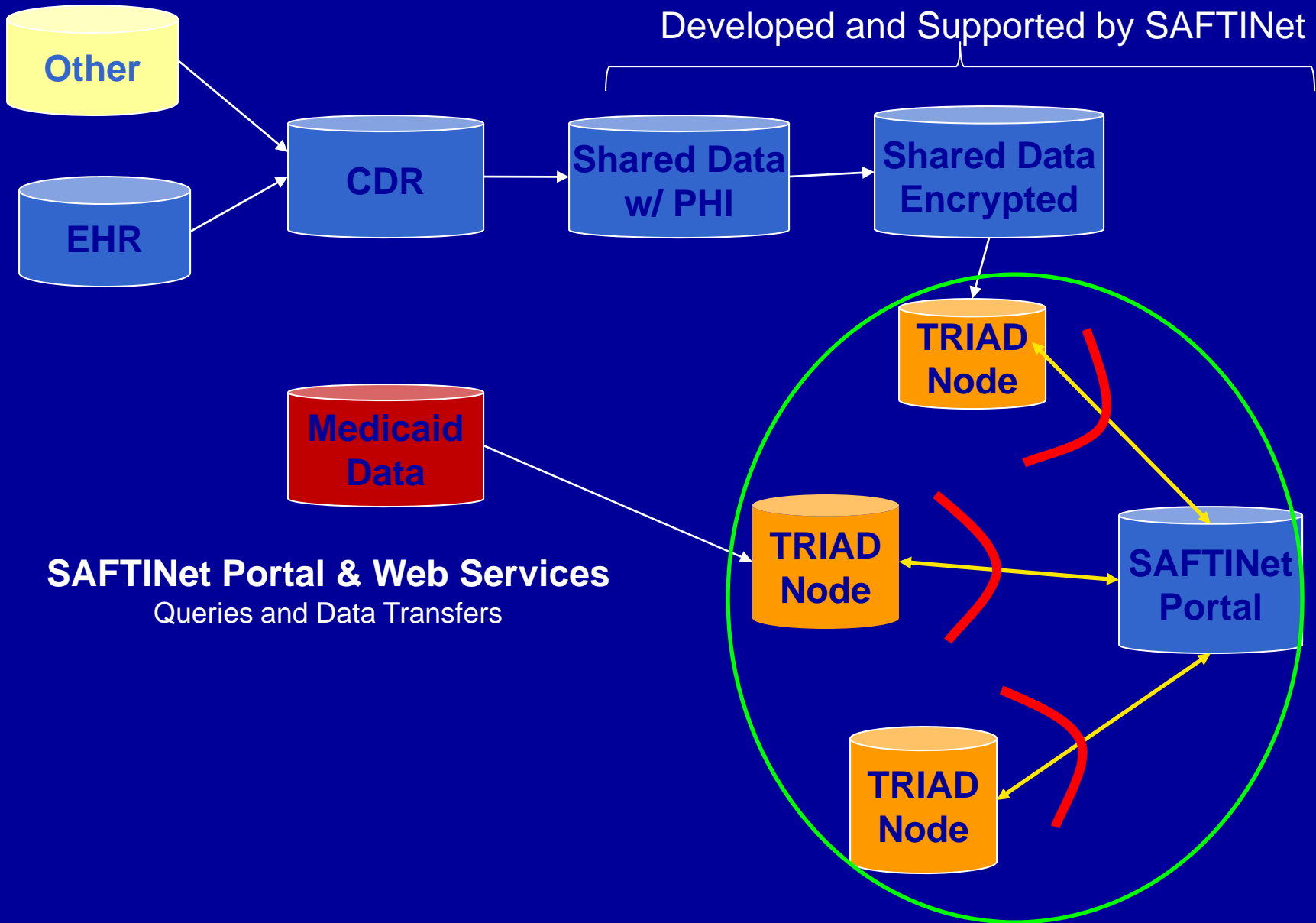
Debbie Graham, MSPH
AAFP/NRN
Partner
Engagement
Community

SAFTINet Tech Infrastructure

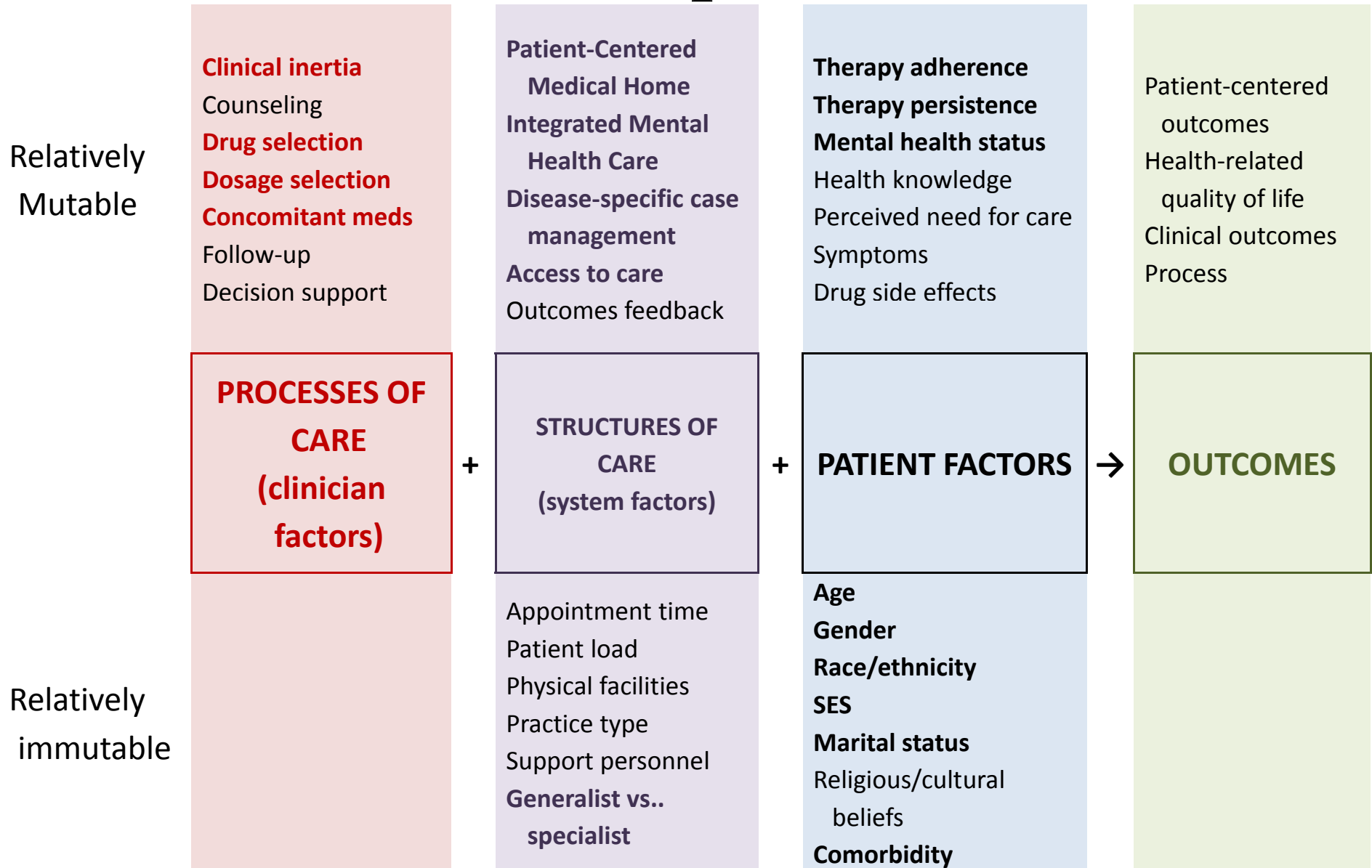


- **EHR:** Electronic Health Record
- **Other** data sources include: claims, hospital, and third party databases
- **CDR:** Clinical Data Repository
- **TRIAD:** Translational Informatics and Data management

SAFTINet Tech Infrastructure

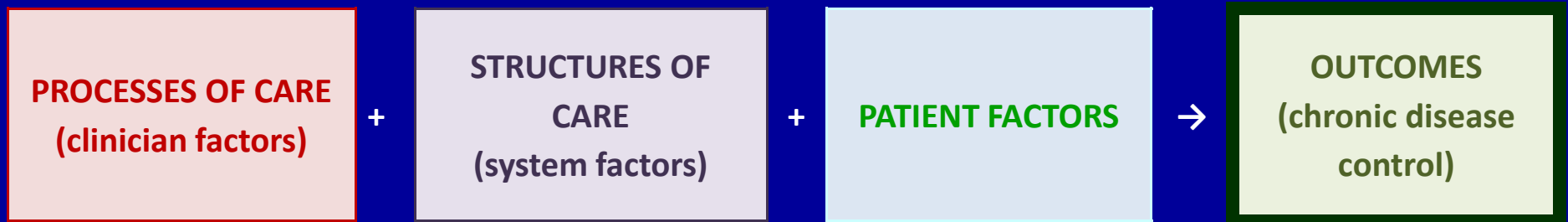


CER Conceptual Model



CER Hypotheses

- Health care delivery system factors, such as the patient-centered medical home,



Are associated with improved **control** of asthma, high blood pressure and hypercholesterolemia.

Aligning with Stakeholder Initiatives

- Meaningful use
- Accountable care organizations
- Patient-centered medical home
- All Payer Claims Database
- Medicaid Information Technology Architecture
- RHIOs

Current CER Efforts

- Demonstrate the capability to collect and accurately link patient-level clinical and claims data necessary for CER
- Prototype CER
 - Comparative effectiveness of different health care delivery system factors for disease control
 - Patient Centered Medical Home
 - Integrated Mental Health Care
 - Four disease cohorts: Adult and childhood asthma, hypertension, hypercholesterolemia
 - Mental health co-morbidities
- Patient-reported outcomes and enhanced data

Current Tech Efforts

- Data Model
 - Extension of the OMOP common data model
- CER Data Dictionary
- Federated Query Scalability
- Encryptions and Privacy Protected Record Linkage
- Data use agreements

Project team investigators

Partner Engagement Community

- Debbie Graham (AAFP)
- Jeanne Rozwadowski (DHHA)
- Lucy Savitz (IMH)
- Parinda Khatri (CHS)
- Heather Stocker (CCMCN)
- Bethany Kwan (UCD)
- Lisa Schilling (UCD)

Technical Team

- Michael Kahn (UCD)
- Wilson Pace (UCD)
- Julio Facelli (Utah)
- Cathy Bryan (CINA)
- Ron Price (Utah)
- Jim May (CINA)
- Art Davidson (DHHA)
- Nathan Hulse (IMH)
- Lisa Schilling (UCD)

Project team investigators

CER Team Investigators

- Marion Sills (UCD)
- Elaine Morrato (UCD)
- Lisa Schilling (UCD)
- Karl Hammermeister (UCD)
- Monica Federico (UCD)
- Ben Miller (UCD)
- Rob Valuck (UCD)
- Diane Fairclough (UCD)
- Bethany Kwan (UCD)
- Barbara Yawn (consultant)
- Lucy Savitz (IMH)
- Brian Sauer (Utah)

