

# Building an Electronic Clinical Data Infrastructure to Improve Patient Outcomes

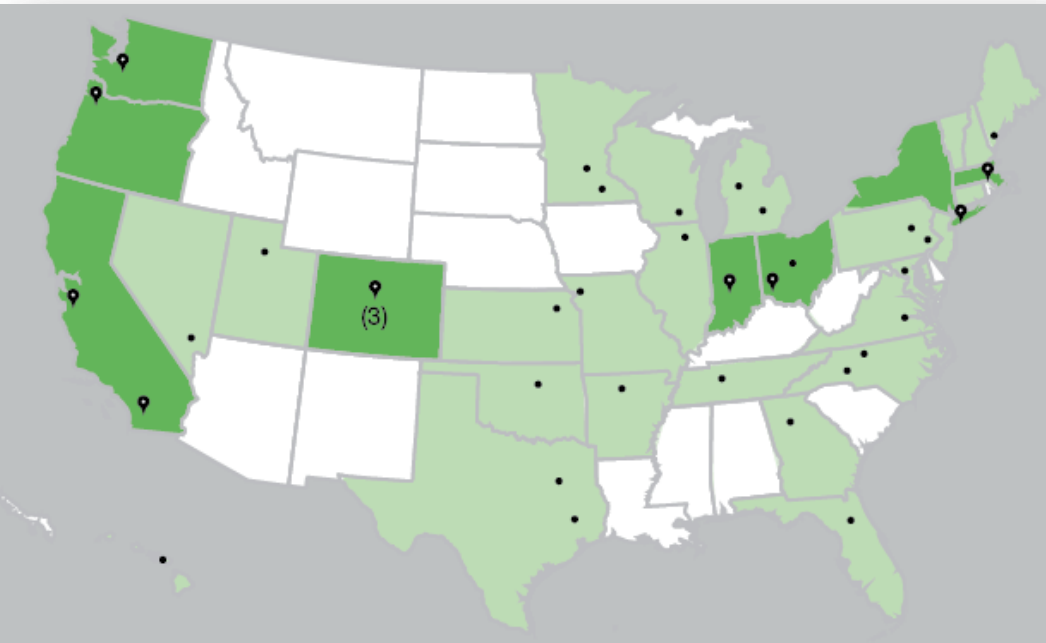
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AcademyHealth

# The Electronic Data Methods (EDM) Forum

- Advancing the national dialogue on the use of electronic clinical data (ECD) for the conduct of:
  - Comparative Effectiveness Research (CER)
  - Patient-Centered Outcomes Research (PCOR)
  - Quality Improvement (QI)

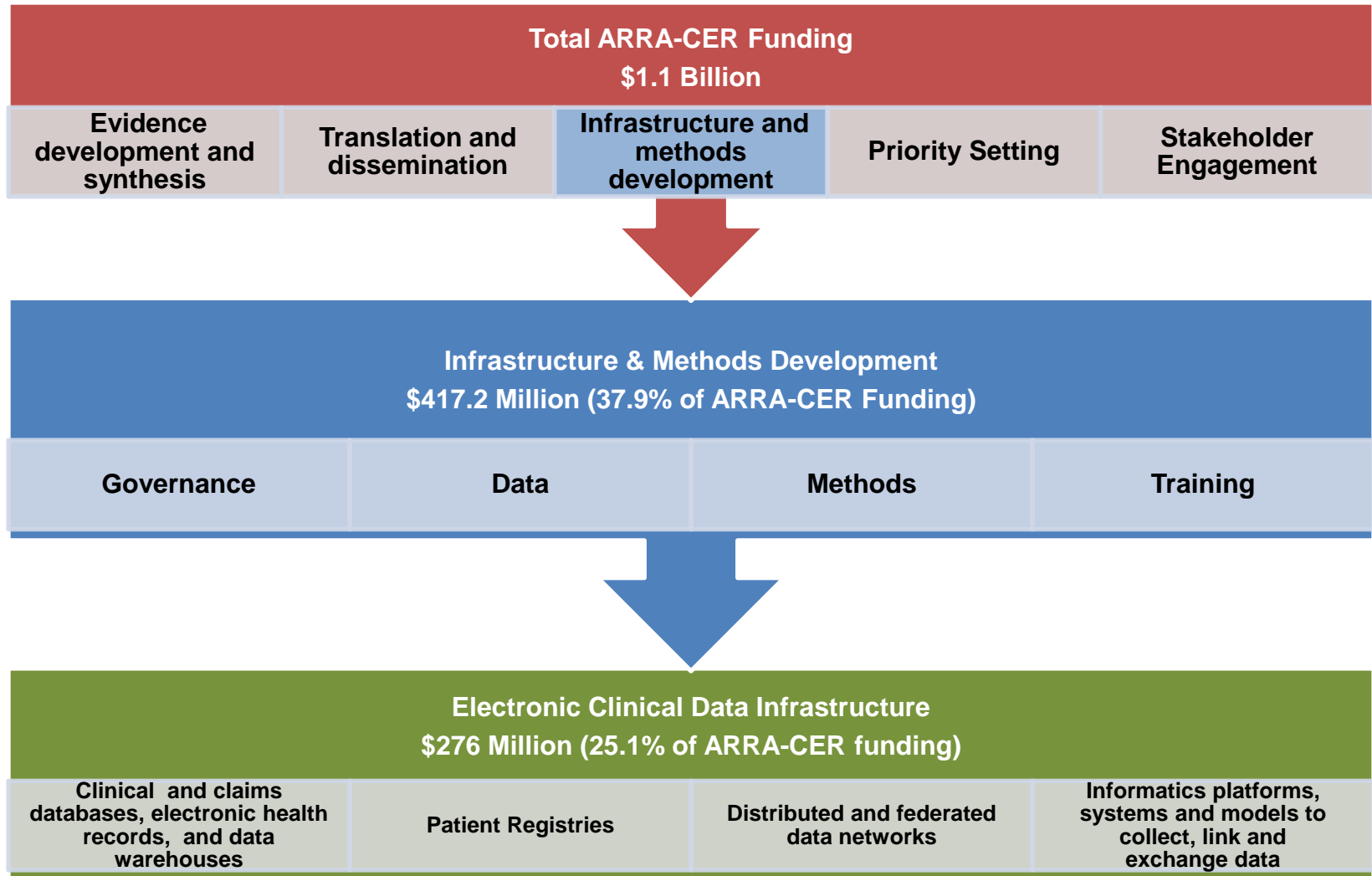


# EDM Forum: Research Networks in CER and QI

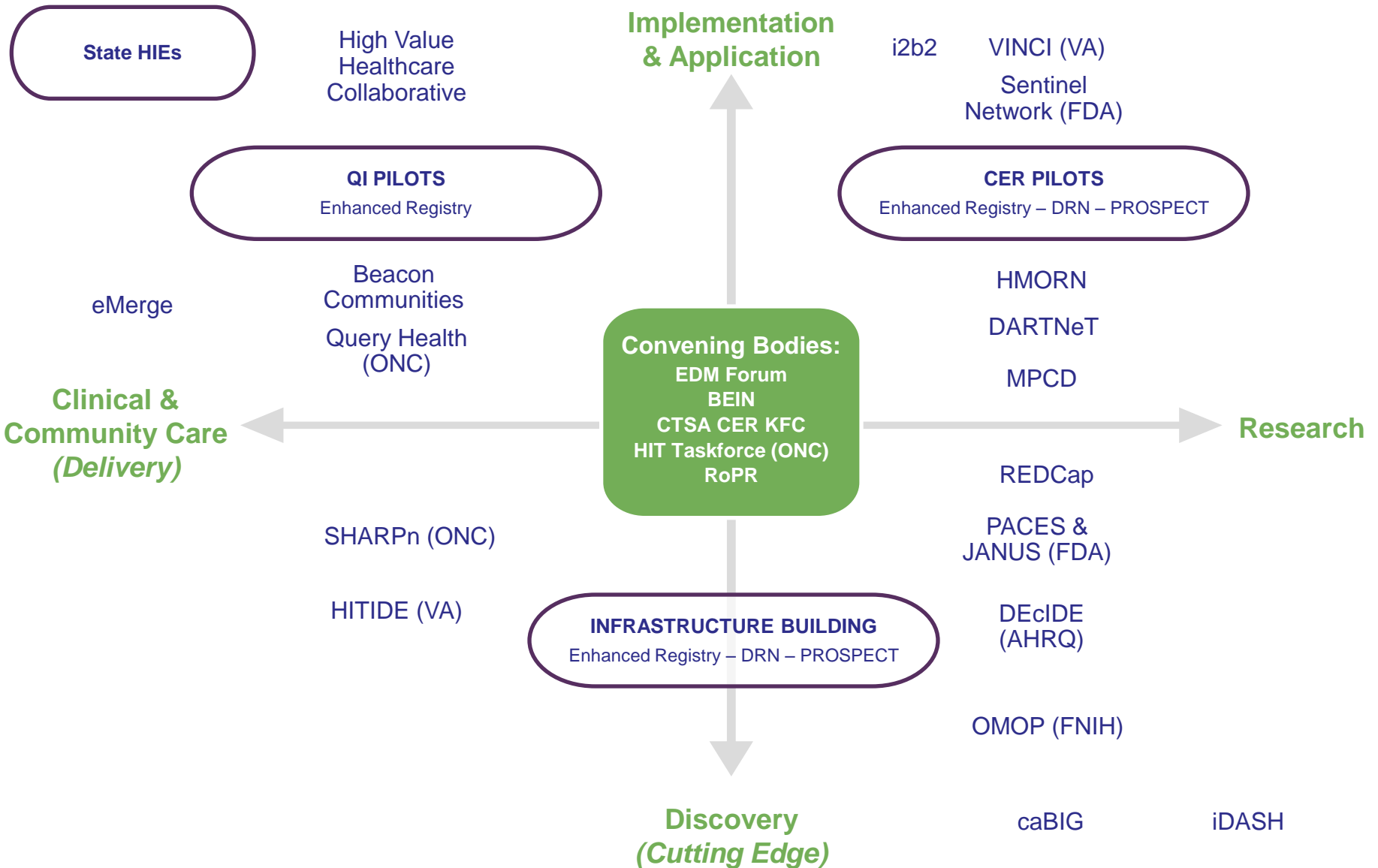


- Networks include between **11,000** and **7.5 million** patients each; more than **18 million** in total
- **38** CER studies are underway or will be conducted
  - Address most of AHRQ's priority populations & Conditions
- Over **300,000** participants in the CER studies

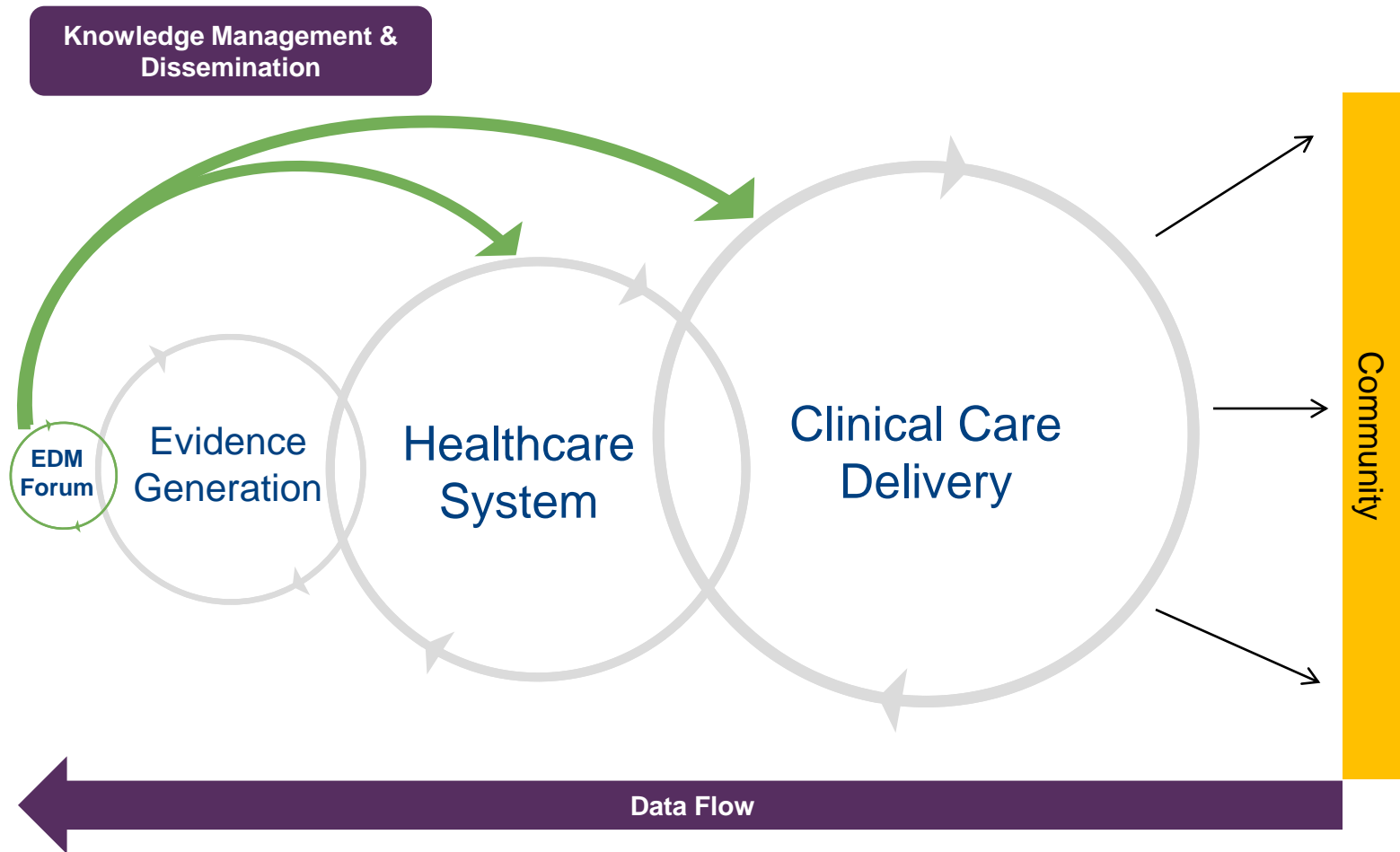
# ARRA-CER Funding Electronic Clinical Data Infrastructure




# Landscape of Electronic Health Data Initiatives for Research



# Generating Evidence to Build a Learning Healthcare System



# Understanding the Landscape

- 
- Discussions to identify priorities and challenges
    - Steering Committee
    - Stakeholder Symposium
  - Connections/collaboration with
    - Relevant e-Health initiatives
    - Stakeholder groups
  - Site Visits (n=6)
  - Stakeholder Interviews (n=50)
  - Literature Reviews
    - Peer-reviewed Literature
    - Grey Literature
  - Structured review of:
    - Relevant resources
    - Social media
    - Translation and dissemination opportunities
  - Issue briefs
  - Commissioned papers

# Reviewing the Literature on CER and Clinical Informatics

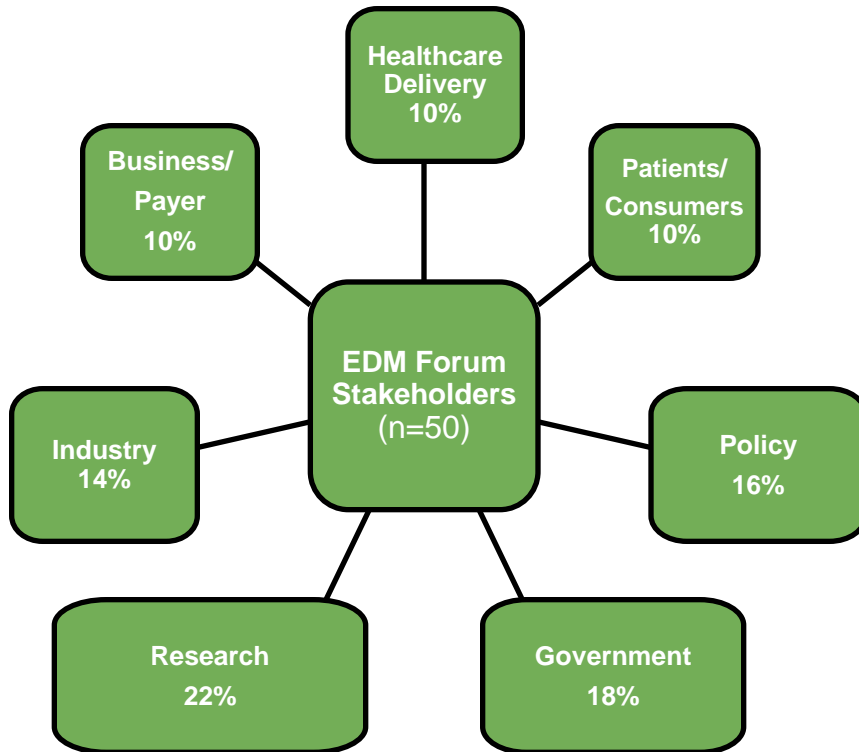
- The literature on CER using ECD is difficult to find and often difficult to cite because this work is so new
- A highly curated search of papers shows focus on the history of HIT for research; platforms, projects, and data initiatives; and Natural Language Processing (NLP) strategies
- Gaps include “cohort identification”, “cloud computing”, or “single point access” to research data
- Gearing up for a surge in new literature:
  - Since last June, have identified ~**460** new papers





# Stakeholder Views

## A tall order on a tight timeframe



- High expectations for CER using ECD
- Implementation challenges: governance, data quality, and methods for observational data
- Defining and attaining “patient-centeredness”
- Need to consider new disseminating strategies for CER
- A ‘culture shift’ may be needed for collaborative science and new approaches to doing research.



# Site Visits: Diverse Projects; Common Challenges

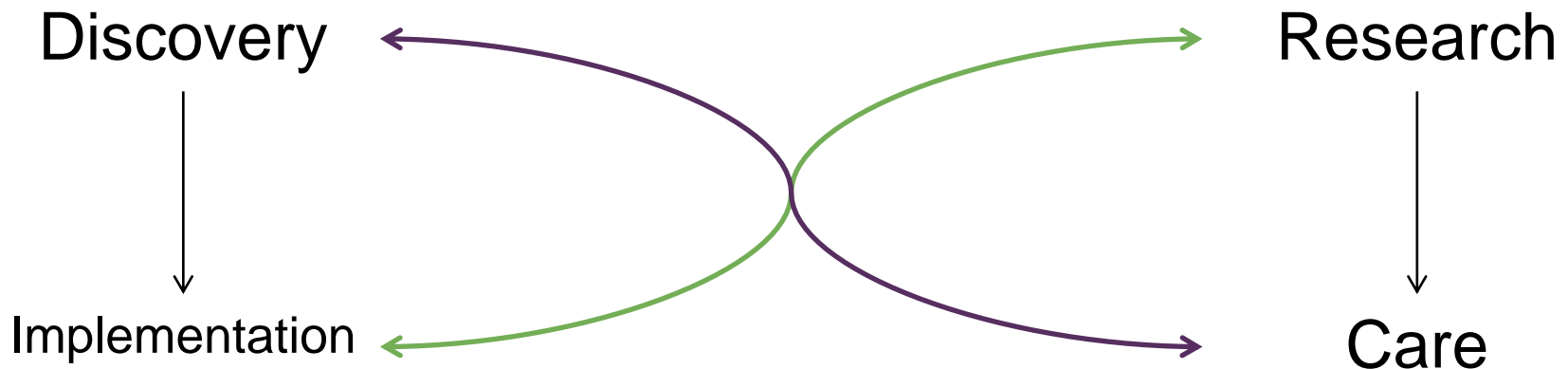
- The projects are employing substantial effort and resources to establish and sustain data sharing partnerships.
- A range of clinical informatics tools, platforms, and models have been developed to enable research with electronic clinical data, but there is a need to understand the strengths and limitations of each.
- There is a need for rigorous methods to assess data validity, quality, and context for multi-site studies.
- There are new opportunities to achieve meaningful patient and consumer engagement and work collaboratively with multi-disciplinary teams.



# Transforming the Research Enterprise

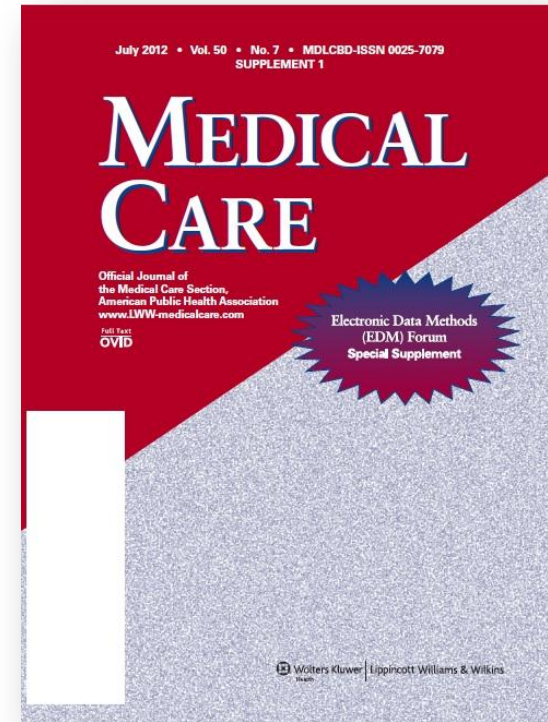
“The challenge we have is learning how to use it [the data], how to actually harness it, ask questions and actually take the data to the next step. I have to tell you that is a big deal. That is a bigger deal than people anticipated.”

- *Delivery system representative*



# Fresh off the 'Presses' - Lessons from the Frontier

- 24 commissioned and invited papers on governance, informatics, analytic methods, and the learning healthcare system
- > 90 collaborators; >40 institutions



# 2012 Symposium: Advancing the Dialogue

- Case examples highlight work in delivery systems to learn from electronic clinical data and improve patient outcomes
- Breakout groups will discuss papers in three domains:
  - Analytic Methods (Pelican 1, blue)
  - Clinical Informatics (Pelican 2, red)
  - Governance (Lark, green)
- Summary Discussion
- From Pilot to Practice – Leveraging New Infrastructure to Improve Patient Outcomes



# Join the discussion! [www.edm-forum.org](http://www.edm-forum.org)

## Current Features:

- **New!** *Medical Care* supplement
- Issue Briefs:
  - Meaningful Engagement
  - Protected Health Information
- CER Project Profiles
- eHealth data initiatives for research & QI

## Coming Soon:

- Webinar registration
- e-Publication announcements

## Join the Discussion

Sign up at [edmforum@academyhealth.org](mailto:edmforum@academyhealth.org)

The screenshot shows the EDM Forum website homepage. At the top is the EDM Forum logo. Below it is a navigation menu with links for HOME, ABOUT, PUBLICATIONS, EVENTS, and SUBMIT COMMENTS. A search bar is located on the right. A large banner image features three people at a conference with the text: "Building a community to advance the use of electronic health data for CER". Below the banner is a map of the United States with green dots indicating project locations. To the right of the map is a section for "New! Special Supplement" titled "MEDICAL CARE", which includes a small image of the supplement cover and text describing its release on June 22, 2012. Below the map and supplement information are sections for "Announcements" and "EDM UPDATES", with the latest update titled "SUPREME-DM Publishes New Article" dated June 14, 2012.