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Building an Electronic Clinical Data Infrastructure to Improve Patient Outcomes

July 2, 2012

PCORI Methodology Committee - Electronic Data Workshop
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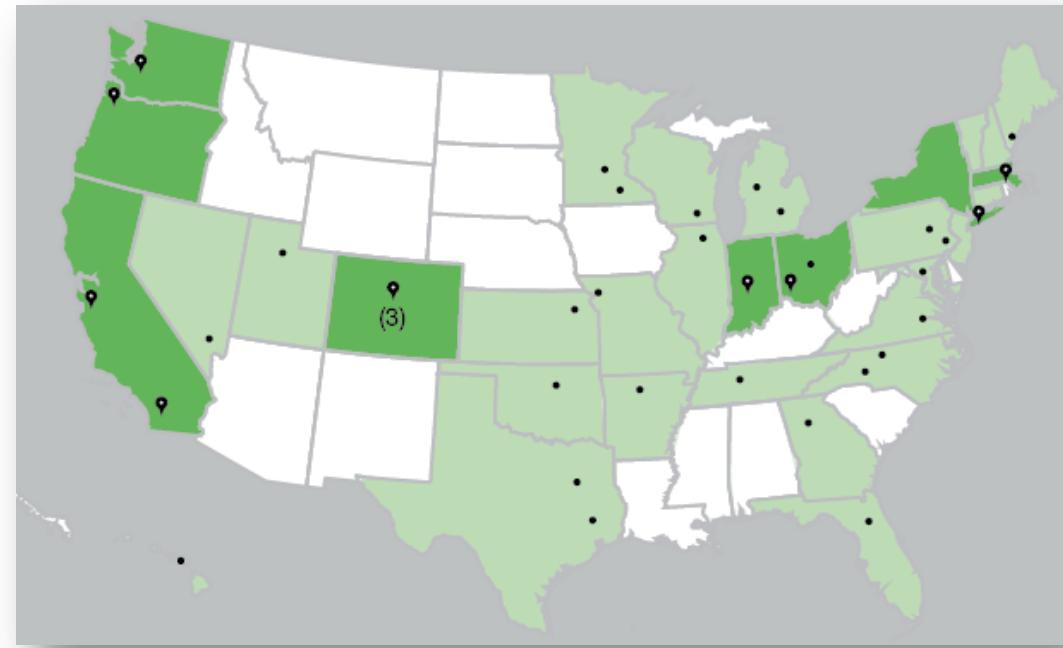
The EDM Forum is supported by the Agency for Healthcare Research and Quality (AHRQ) through the American Recovery & Reinvestment Act of 2009, Grant U13 HS19564-01.

The Electronic Data Methods (EDM) Forum

- Advancing the national dialogue on the use of electronic clinical data (ECD) to generate evidence that improves patient outcomes.
 - Comparative Effectiveness Research (CER)
 - Patient-Centered Outcomes Research (PCOR)
 - Quality Improvement (QI)

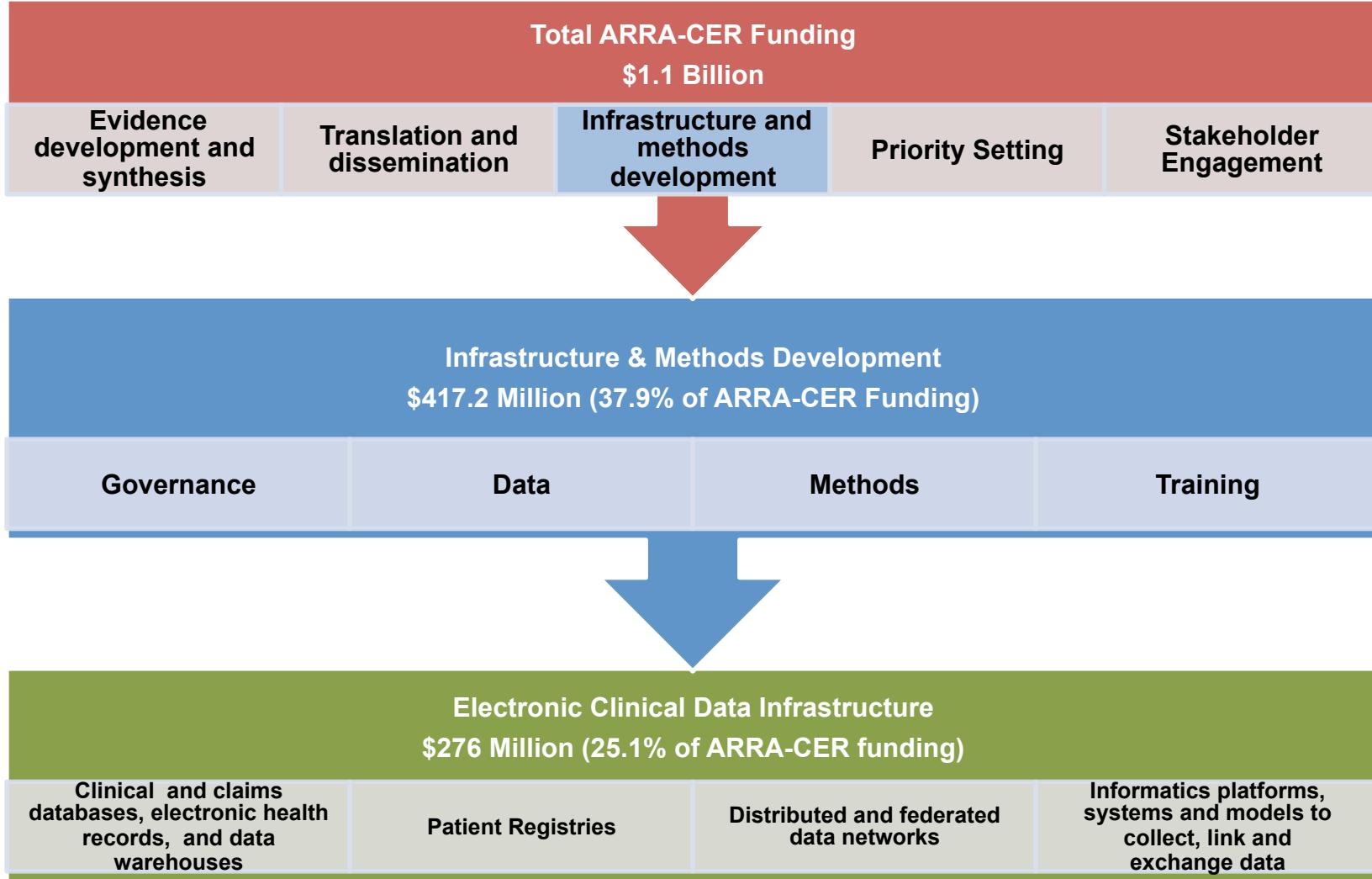


Research Networks in CER and QI

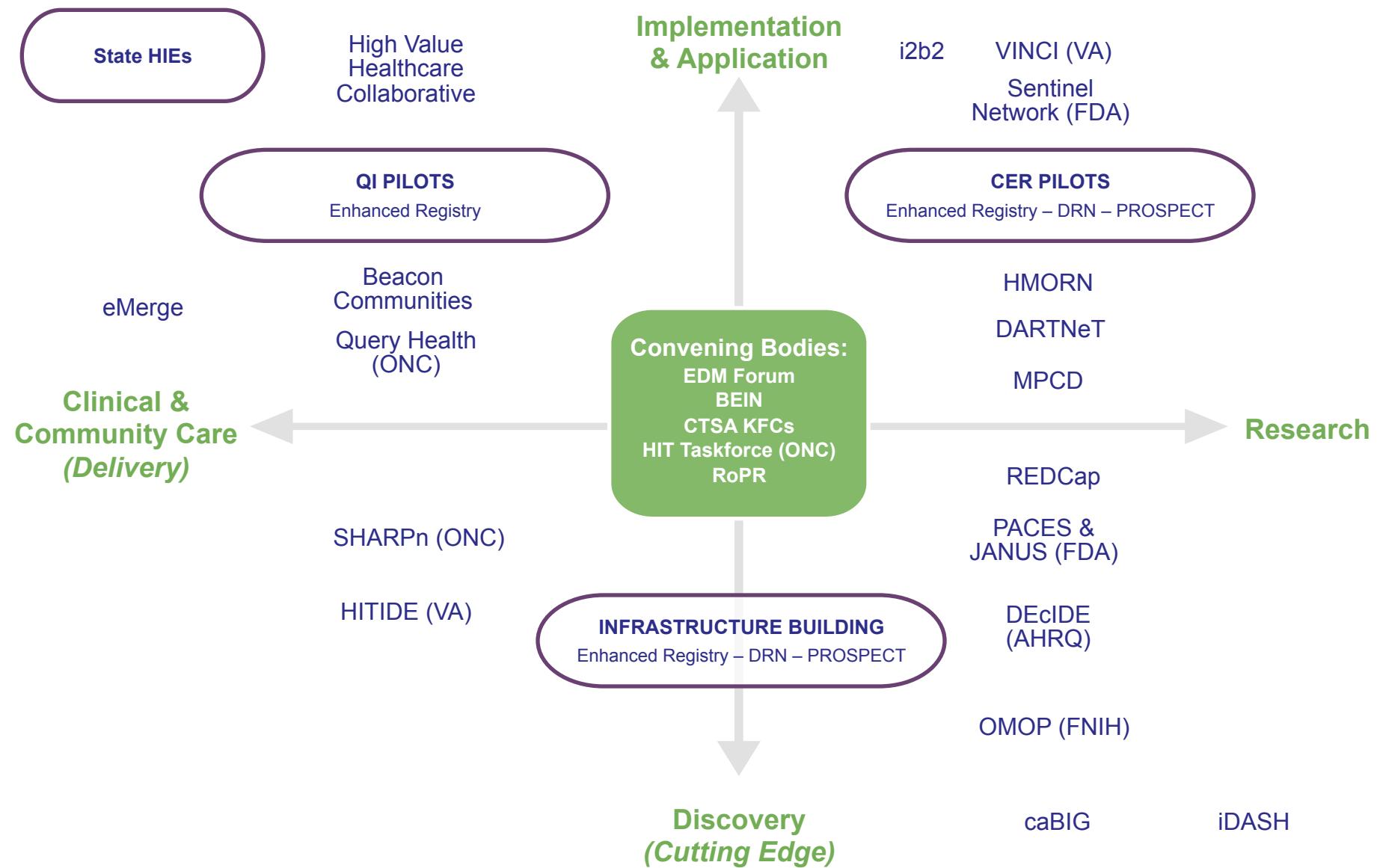


- Networks include between **11,000** and **7.5 million** patients each; more than **18 million** in total
- **38** CER studies are underway or will be conducted
 - Address most of AHRQ's priority populations & Conditions
- Over **300,000** participants in the CER studies

ARRA-CER Funding for Infrastructure



Landscape of Electronic Health Data Initiatives for Research



Generating Evidence to Build a Learning Health System

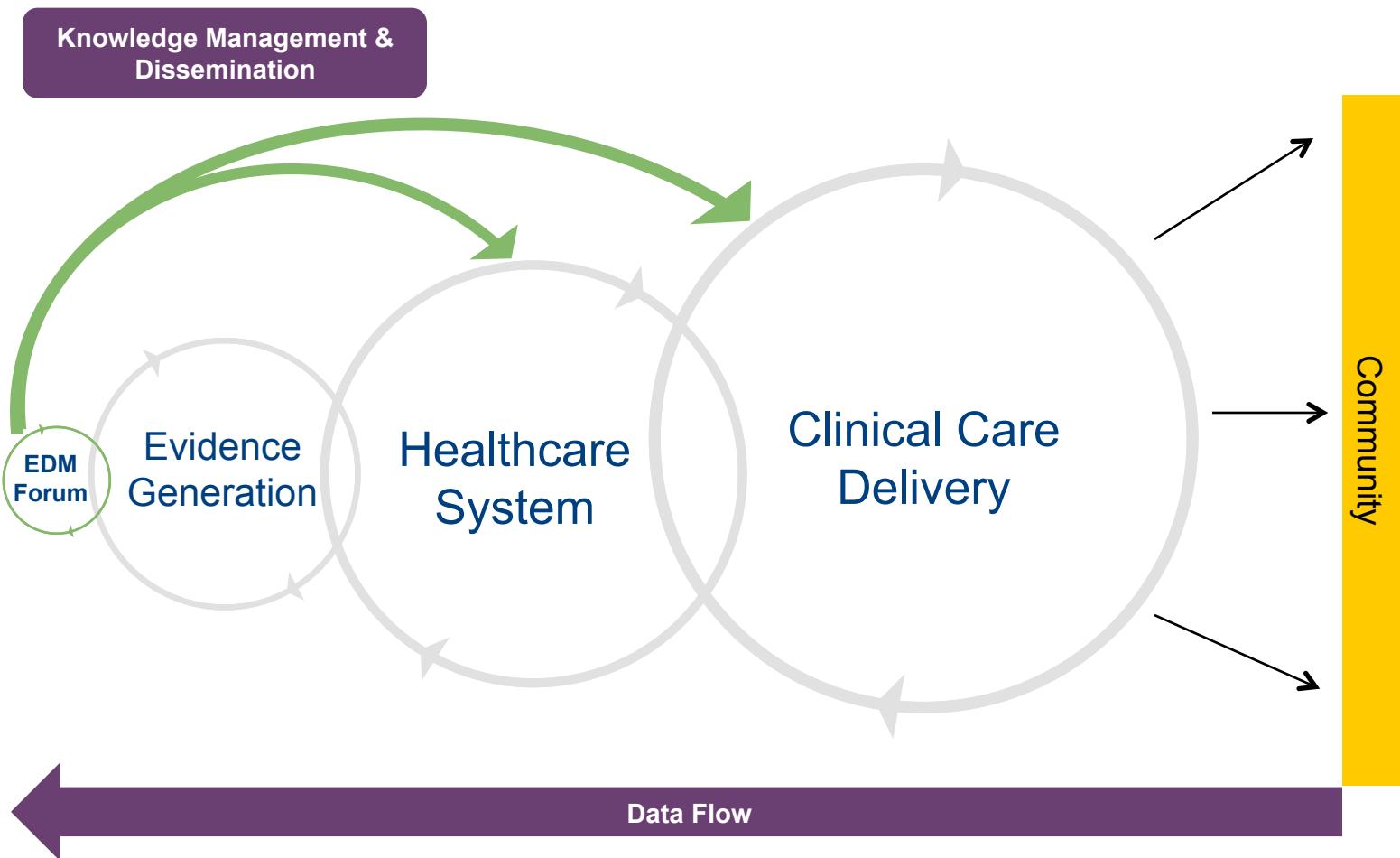


Figure adapted from: IOM (Institute of Medicine). 2011. *Engineering a learning healthcare system: A look at the future: Workshop summary*. Washington, DC: The National Academies Press.



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Understanding the Landscape

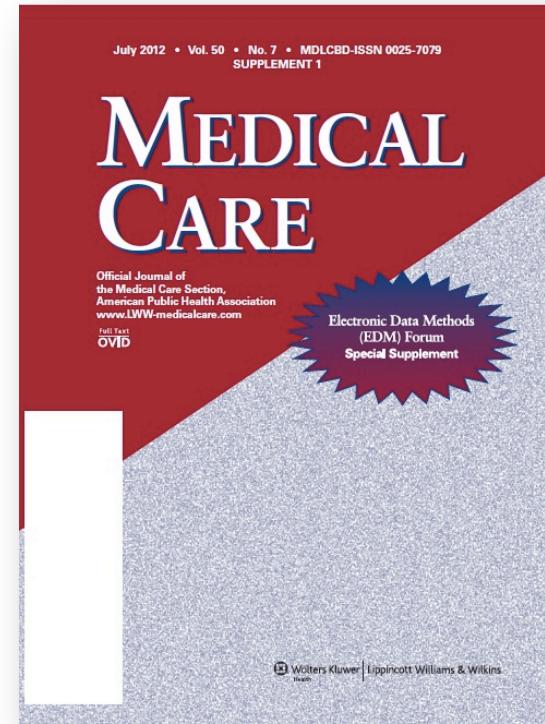


- Discussions to identify priorities and challenges
 - Steering Committee
 - Stakeholder Symposium
- Connections/collaboration with
 - Relevant e-Health initiatives
 - Stakeholder groups
- Site Visits (n=6)
- Stakeholder Interviews (n=50)
- Literature Reviews
 - Peer-reviewed Literature
 - Grey Literature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



Lessons from Experts at the Frontier

- 24 commissioned and invited papers on governance, informatics, analytic methods, and the learning healthcare system
- > 90 collaborators; >40 institutions
- First half of these just published in Medical Care



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By Design, Papers Address Current Gaps in the Literature

- A review of challenges of traditional research designs and data that can potentially be addressed using electronic clinical data (Holve et.al)
- A framework for comprehensive data quality assessment (Kahn et.al)
- Cohort identification strategies for diabetes and asthma (Desai, et. al.)
- A review of informatics platforms for research, including i2b2, RedX, HMORN VDW, INPC, SCOAP, CER Hub (Sittig et.al.)
- Desirable attributes of common data models (Kahn, et.al)
- Comparison of data collection methods including paper, websites, tablet computers (Wilcox et.al.)
- Privacy-preserving strategies for hard-coded data (Kushida et. al.)
- Comparison of processes to facilitate multi-site IRB review (Marsolo)



Breakouts and Important Areas for Further Discussion

- Governance
- Informatics
- Methods

and

- Patient Reported Health Information
- Innovative Approaches
- Training

*Dissemination/Incentives to Collaborate



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Patient Reported Health Information

- Electronically collecting patient-reported information can
 - Offer a unique, important, and patient-centered perspective for clinical care, QI, and research
 - Increase the efficiency of information exchange with potential to make a difference in real-time
- Known and anticipated challenges for collecting, using, and implementing patient report of data and information for PCOR lays out an extensive research agenda



Innovators & Game Changers

ePatients; Citizen Science

- Patient Contributed Data, mHealth, Biomonitoring, and Crowd-Sourced Data
 - Patients Like Me
 - tuDiabetes
 - www.asthmapolis.com
 - www.quantifiedself.com
 - Google Flu
 - personalexperiments.org
 - Wellvisitplanner.org
- Portable legal consent



Training (EDM and Beyond)

- How will social diffusion of new methods and emerging standards take place?
 - For trainees
 - For those currently in the field
 - Experiential learning opportunities likely key
 - Delivery System Science Fellowship
 - Geisinger, Intermountain, PAMFRI
- Engaging BIG data requires
 - Data sandboxes & Data playgrounds
 - Teaching governance
 - Design and UI for HIT/mHealth
 - Training observational researchers in exp methods



In a Dynamic, Learning System Dissemination Should Facilitate the Journey, Not Just Describe the Destination

- HSR and medical journals focus on research results. Not ideally designed for:
 - Process (e.g. Lab/study notes)
 - Novel designs/approaches
 - Quick turnaround
 - Discussion
 - Engaging non-research audiences
- Stakeholders increasingly perceive a need to rapidly disseminate “street knowledge” that is:
 - Peer reviewed
 - Open access

eGEMS

- Guidance on the conduct of research and QI:
Papers;
Visualizations;
Other media (audio/video)
- Contributions evaluated on
Usefulness;
Credibility;
Novelty

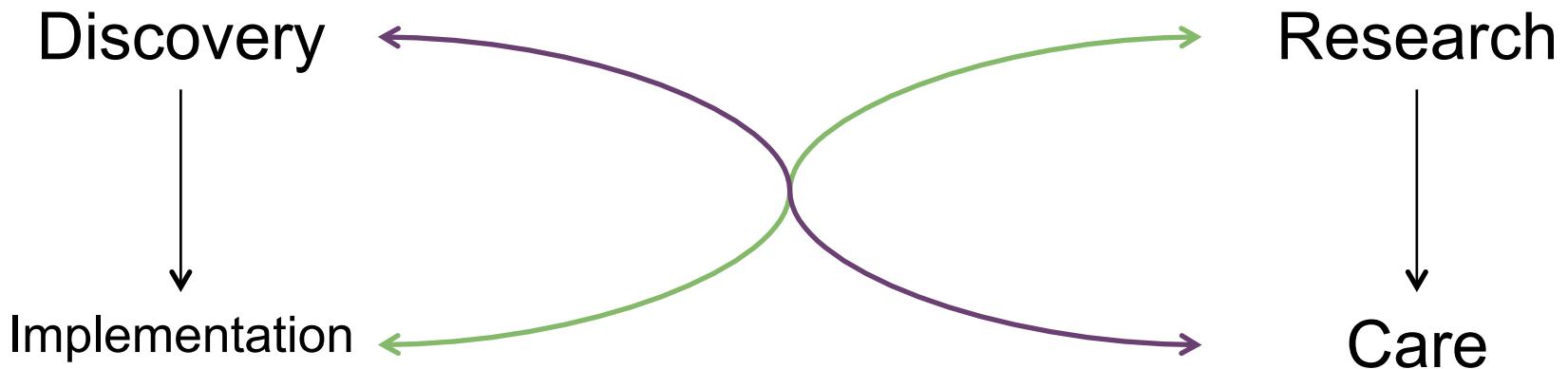
* Facilitates discussion and collaboration
* Encourages transparency and reproducibility



Transforming the Research Enterprise

“Make the idea bigger”

How to link emerging data and tools in a marketplace of people and ideas committed to transforming clinical research?



A New Marketplace for PCOR Data and Tools

Flexible and Reusable Access and Use for Research

Automated Queries
(e.g., RedX)

Mediated Queries
(e.g. i2b2+)

Analytic Tools
(e.g., OCEANS)

CPR tools
(e.g., WICER tablet adaptation)

“The Miracle Mile”

Exchange

Interoperability

Data Quality

“Stickiness”

Integration Platforms/ Data Warehouses

Data Models
(e.g. VDW, OMOP)

Middleware
(e.g. Automated abstraction, NLP, Interface Adaptors)

Governance:

Security, Privacy, COI, Rules of Engagement

Partnerships for Research (Networks)



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Join the discussion! www.edm-forum.org

Current Features:

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

Coming Soon:

- Webinar registration
- eGEMs updates (August '12)

Join the Discussion

Sign up at edmforum@academyhealth.org



The screenshot shows the homepage of the EDM Forum website. The header features the "EDM Forum" logo with a grid of gray dots to the left. The main navigation menu includes links for HOME, ABOUT, PUBLICATIONS, EVENTS, and SUBMIT COMMENTS, along with a "Search" bar and "Admin | Contact Us" links in the top right. A banner image at the top right shows three people at a conference: a man in a suit and tie, a woman in a grey blazer, and another man in a suit. The banner text reads: "Building a community to advance the use of electronic health data for CER". Below the banner is a "Printer-Friendly Version" link. The main content area has a sub-header "Electronic Data Methods (EDM) Forum". To the right, a "New! Special Supplement" section is highlighted, featuring a map of the United States where states are shaded in green to indicate the location of projects. A thumbnail image of a document titled "MEDICAL CARE" is shown. The text in this section describes the release of an open access supplement on "Medical Care" on June 22, 2012, which includes 15 commissioned and invited papers on innovative strategies for CER, PCOR, and QI using electronic clinical data. A multi-disciplinary group of experts contributed to the supplement, representing 41 investigators and 23 organizations/institutions. Below this is an "Announcements" section with a "EDM UPDATES" header. A recent article titled "SUPREME-DM Publishes New Article" is listed, dated June 14, 2012, 11:50 AM. The announcement text discusses the SUPREME-DM's new article in the CDC's "Preventing Chronic Disease" journal, which discusses their registry - the SUPREME-DM DataLink. The registry, which contains de-identified information on about 1.1 million people with diabetes, is utilizing electronic health record data from various sources.

