Building an Electronic Clinical Data Infrastructure to Improve Patient Outcomes

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PCORI Methodology Committee - Electronic Data Workshop

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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)

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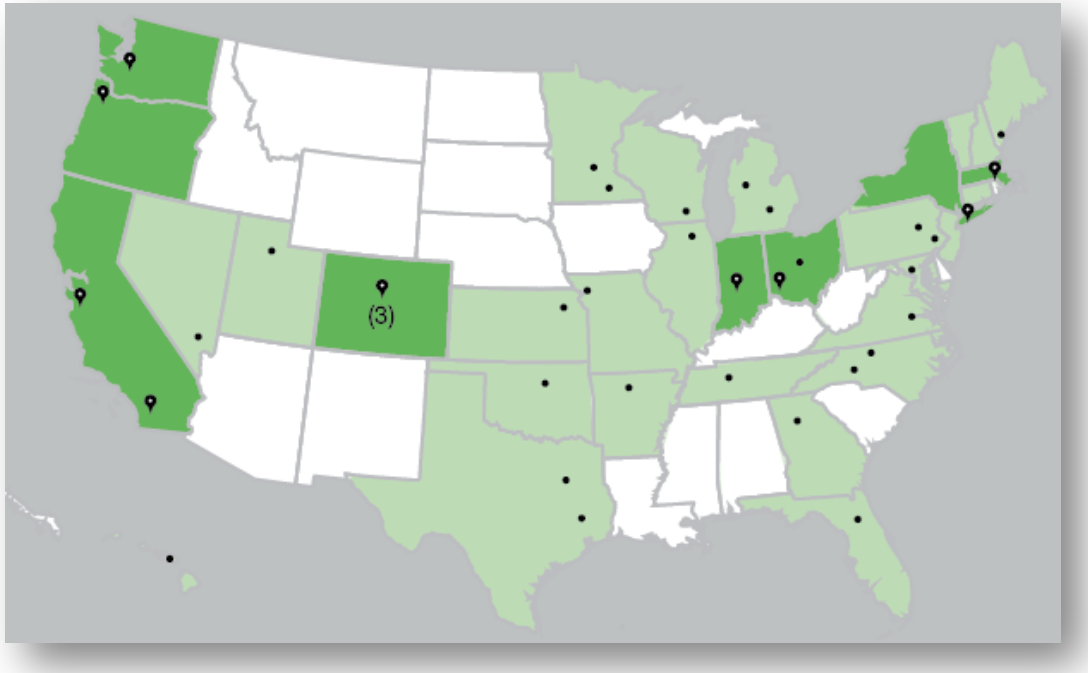
Research Networks in CER and QI



- 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

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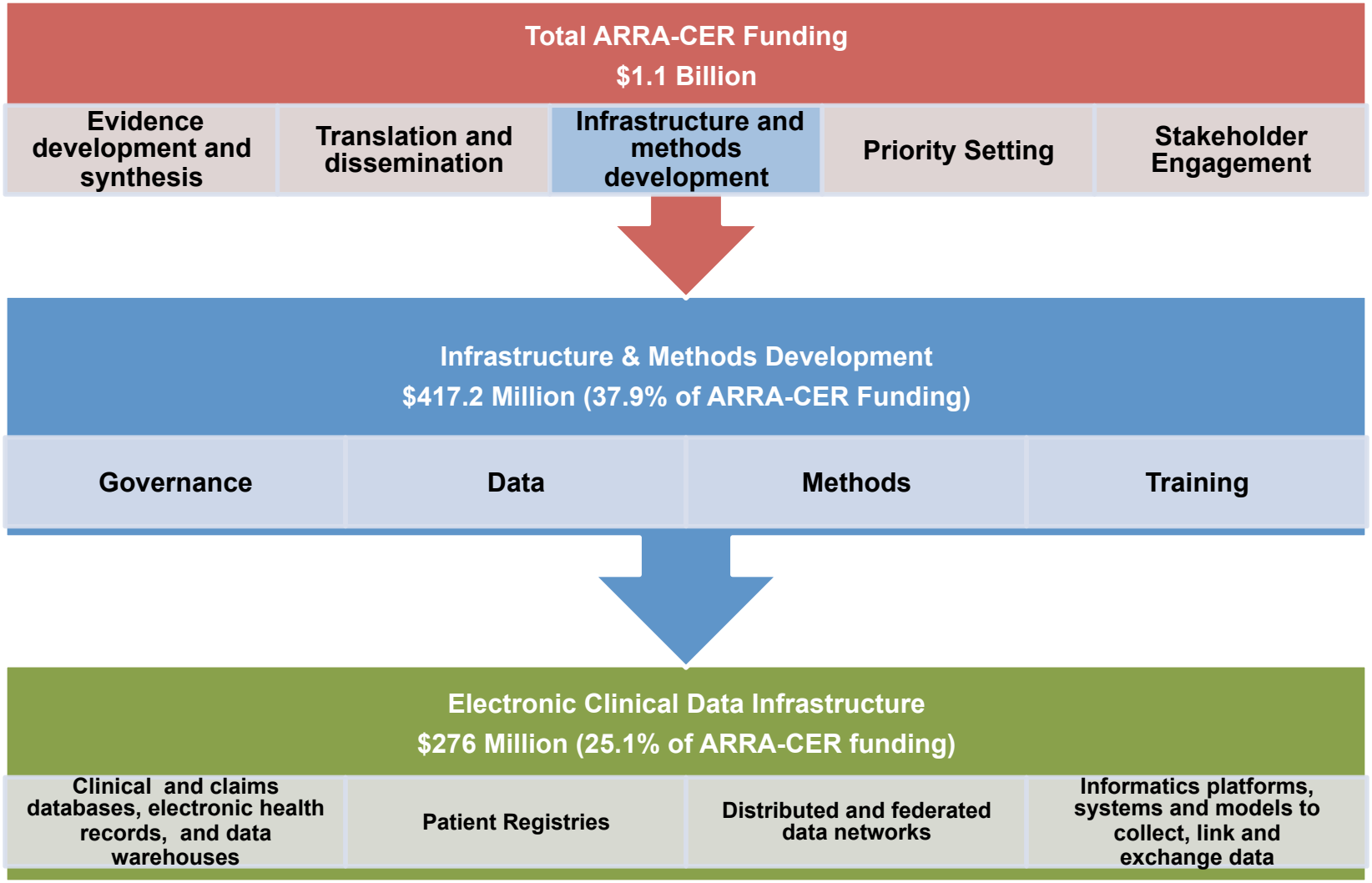
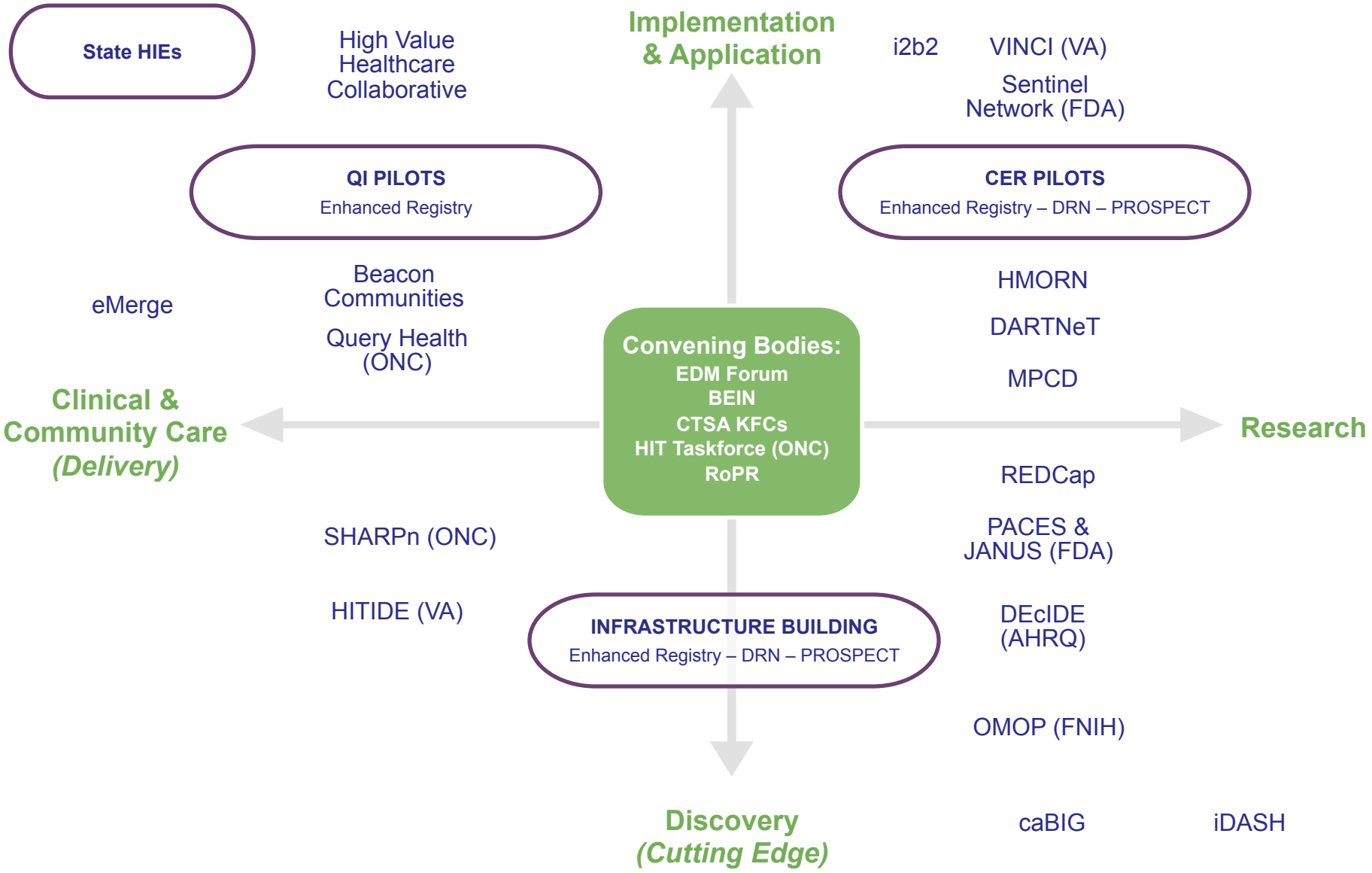
ARRA-CER Funding for Infrastructure



Landscape of Electronic Health Data Initiatives for Research



Generating Evidence to Build a Learning Health System

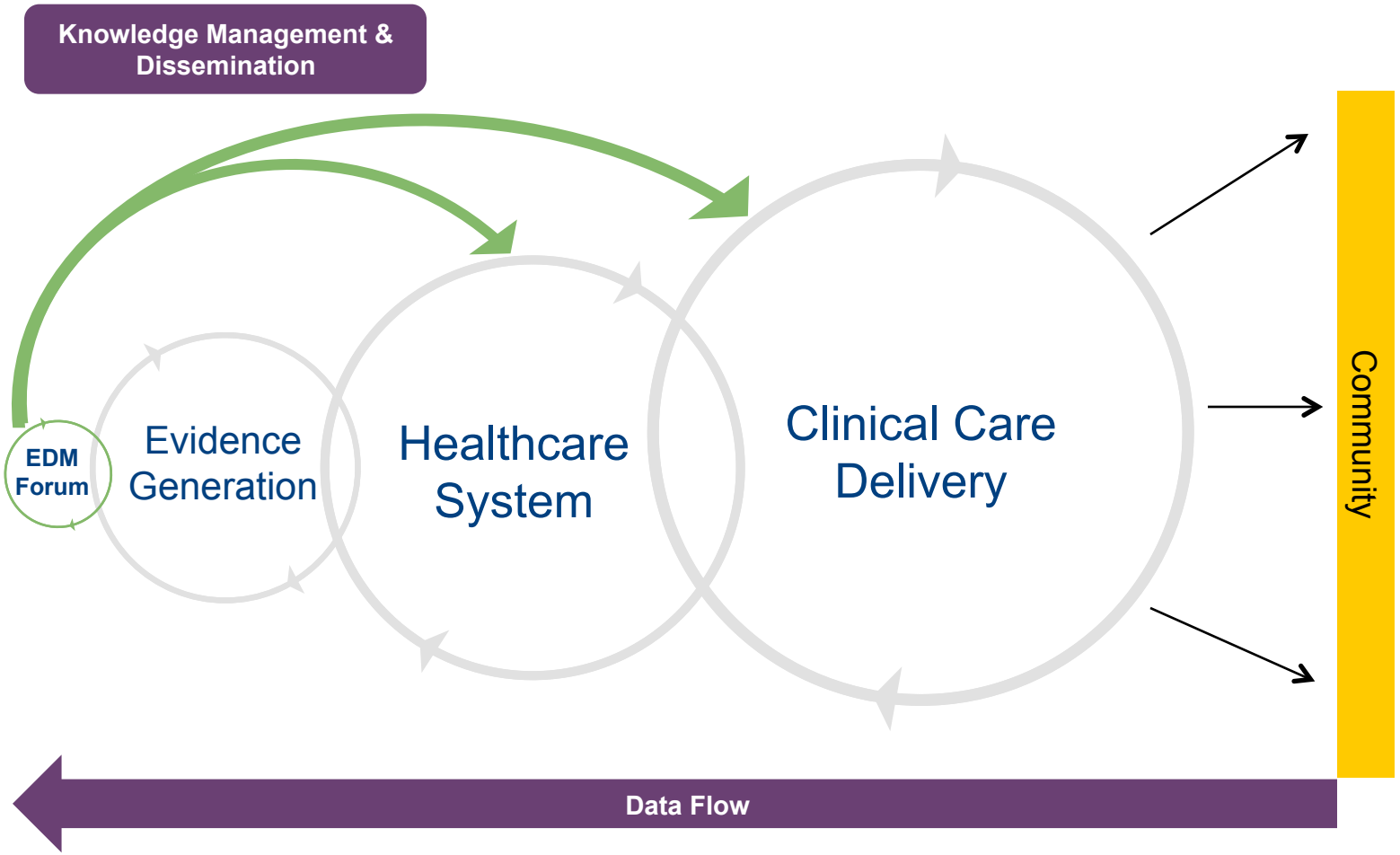


Figure adapted from: IOM (Institute of Medicine). 2011. *Engineering a learning healthcare system: A look at the future: Workshop summary.* Washington, DC: The National Academies Press.

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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

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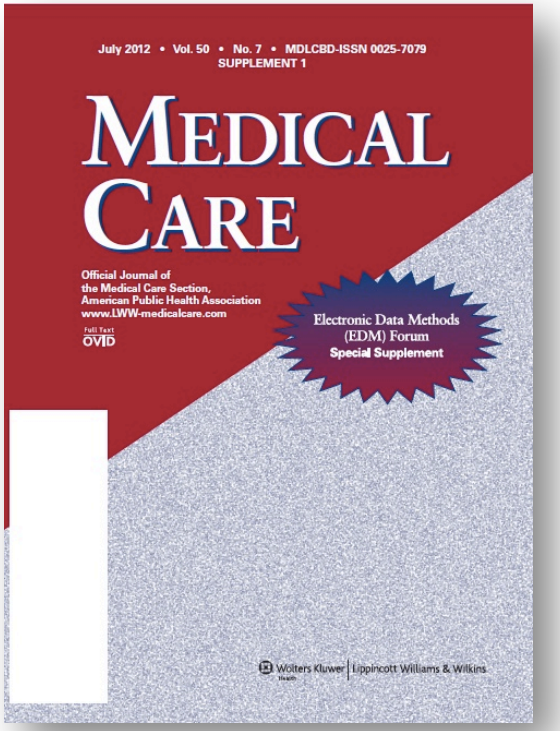
Lessons from Experts at the Frontier

- 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

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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

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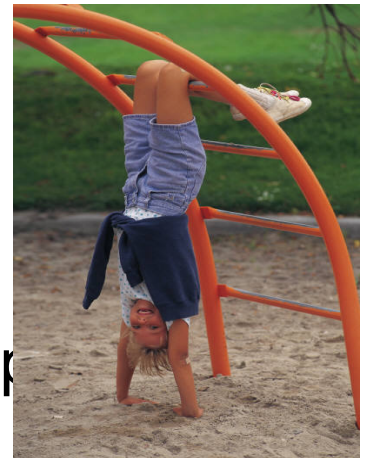
Training (EDM and Beyond)

- 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



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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

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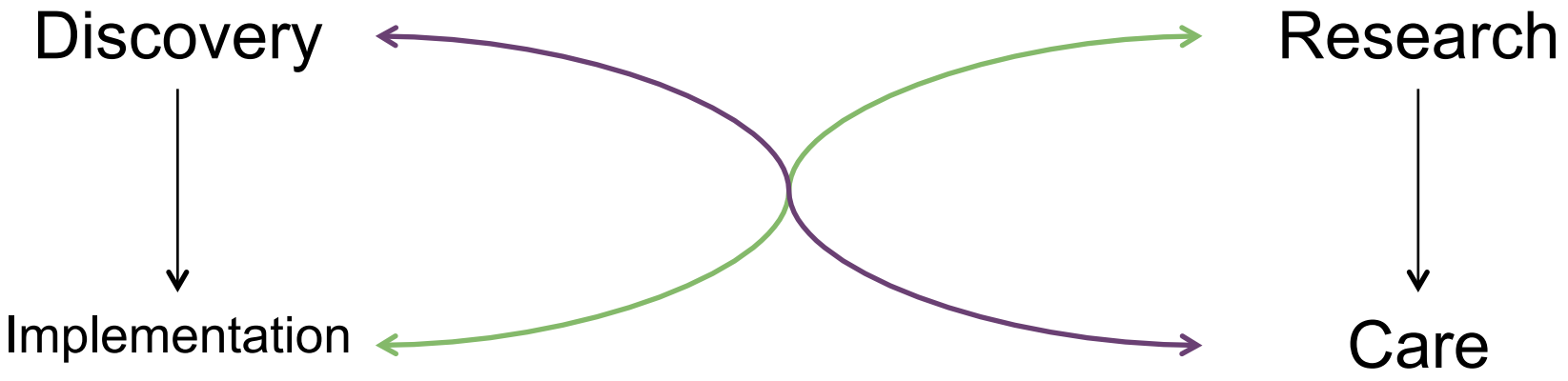
Transforming the Research Enterprise

"Make the idea bigger"

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



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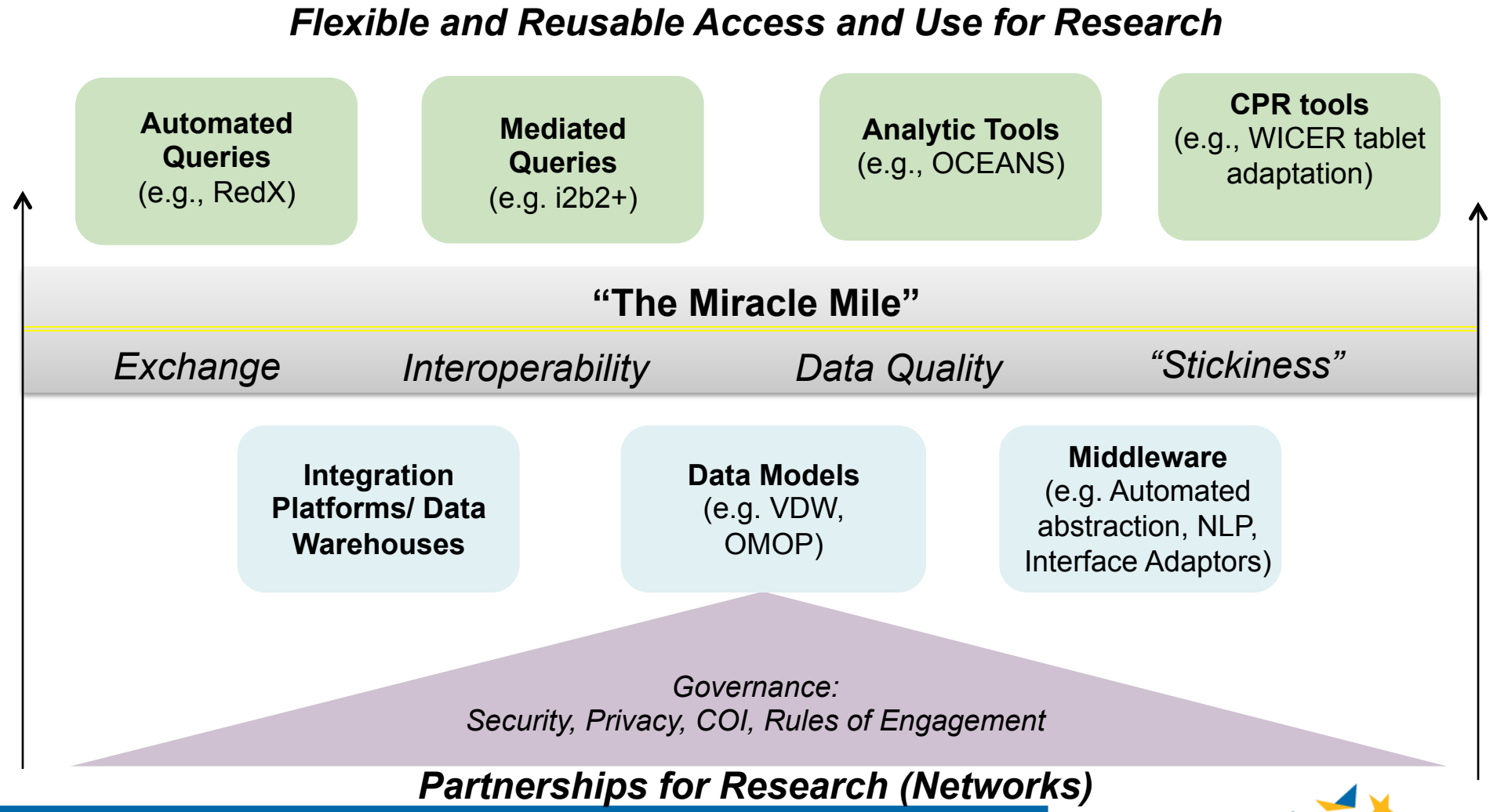
A New Marketplace for PCOR Data and Tools



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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

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