



AcademyHealth

Emerging Data Innovations in Health Services Research

Dr. Lisa Simpson
President and CEO
August 8, 2012

Agenda

- Overview of AcademyHealth
- Priority Questions & Research Implications
- Emerging Data
- Finding New Knowledge with Existing Data
- Concluding Thoughts



AcademyHealth: Improving Health & Health Care

AcademyHealth is a leading national organization serving the fields of health services and policy research and the **professionals who produce and use** this important work.

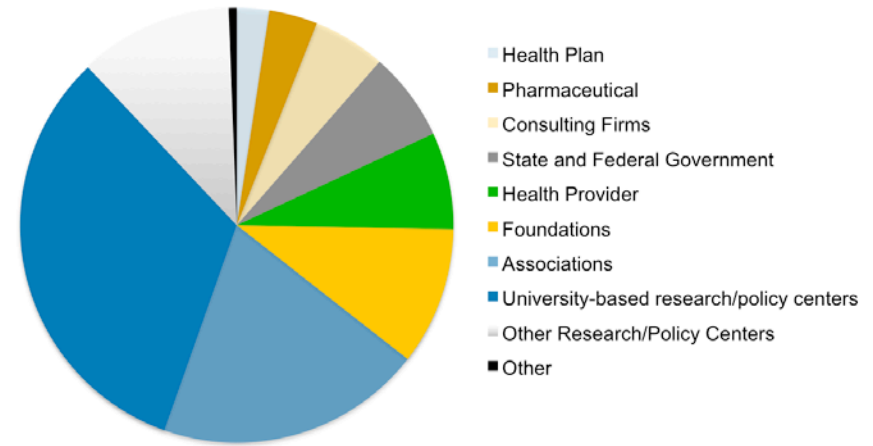
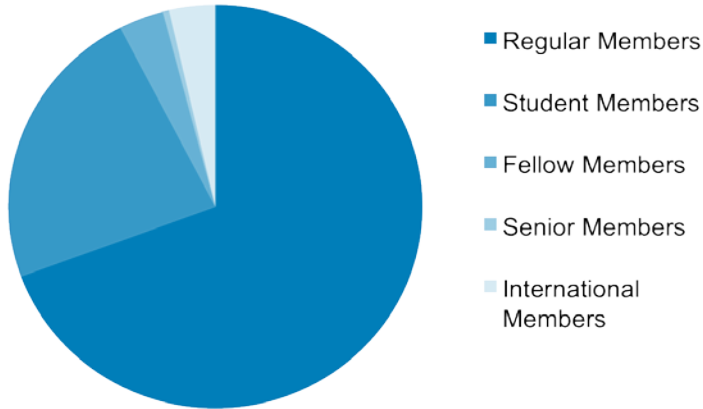
Together with **our members**, we offer programs and services that support the development and use of rigorous, relevant and timely evidence to:

1. Increase the quality, accessibility and value of health care,
2. Reduce disparities, and
3. Improve health.

A trusted broker of information, AcademyHealth brings stakeholders together to address the current and future needs of an evolving health system, inform health policy, and translate evidence into action.



Leveraging >4,600 Diverse, Expert Members & Organizations



AcademyHealth Interest Groups

- Behavioral Health Services Research
- Child Health Services Research
- Disability Research
- Disparities
- Gender and Health
- Health Economics
- Health Information Technology
- Health Workforce
- Interdisciplinary Research Group on Nursing Issues
- Long-Term Care
- Public Health Systems Research
- Quality & Value
- Translation & Communications
- State Health Research and Policy

AcademyHealth Approach

Core Programs

- Generate new knowledge
- Translate evidence into action

Strategic Priorities

- Delivery System Transformation
- Public and Population Health
- Value and Health Care Costs



Agenda

- Overview of AcademyHealth
- Priority Questions & Data Implications



Priority Questions

- What works?
 - *For whom? Under which circumstance? At what cost?*
- How effective?
 - *For whom? Under which circumstance? At what cost?*
- What are the best practices?
 - *On services?*
 - *On health?*
 - *On disparities?*

For both health care
and public health
services and systems



Research Implications

- Comparative effectiveness research
- Public health services and systems research
- Dissemination and implementation research



ACA Definitions

→ CER:

- “research evaluating and comparing health outcomes and the clinical effectiveness, risks, and benefits of 2 or more medical treatments, services, and items.”

→ “medical treatments, services, and items”:

- defined as “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.”



CER Defining Characteristics

- Objective of directly informing clinical or health policy decision
- Compares at least 2 alternatives
- Results at population and subgroup level
- Measures outcomes important to patients
- Methods and data sources appropriate for the decision of interest
- Conducted in real world settings

Sean Tunis, 2009

Definition of PCOR

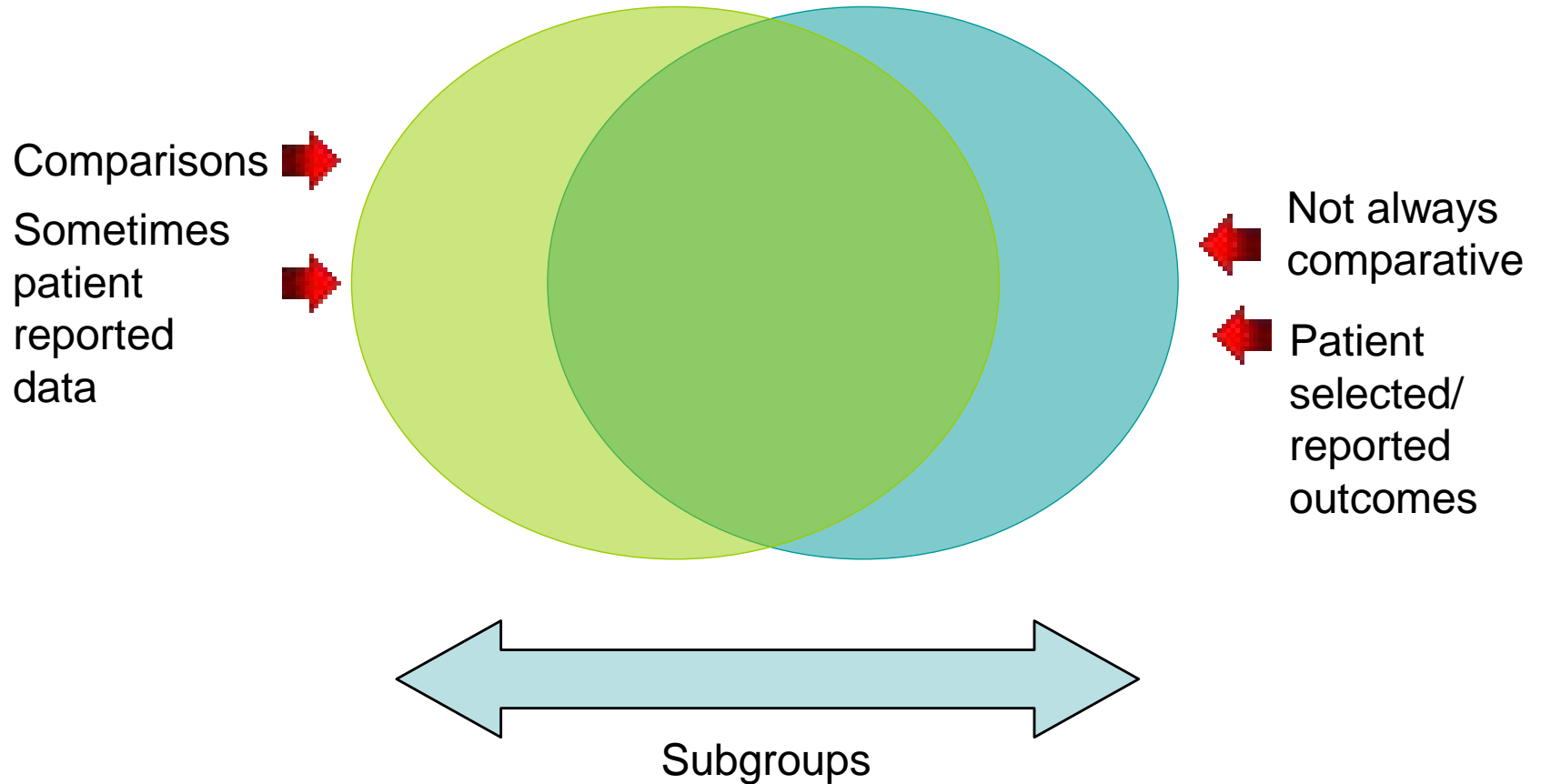
- **Patient Centered Outcomes Research (PCOR) helps people make informed health care decisions and allows their voice to be heard in assessing the value of health care options. This research answers patient-focused questions:**
- “Given my personal characteristics, conditions and preferences, what should I expect will happen to me?”
 - “What are my options and what are the benefits and harms of those options?”
 - “What can I do to improve the outcomes that are most important to me?”
 - “How can the health care system improve my chances of achieving the outcomes I prefer?”



CER vs PCOR: is there a difference?

Comparative Effectiveness Research

Patient-Centered Outcomes Research



PCORI Research Priorities

- Assessment of Prevention, Diagnosis, and Treatment Options
- Improving Healthcare Systems
- Communication and Dissemination Research
- Addressing Disparities
- Accelerating Patient Centered Outcomes Research and Methodological Research



Research Implications

- Comparative effectiveness research
- Public health services and systems research



Public Health Services & Systems Research (PHSSR)

- A multidisciplinary field of study that examines:
 - Organization
 - Financing
 - Delivery, and
 - Quality
- of public health services within communities and the resulting impact on population health outcomes.

PHSSR (cont.)

- The public health system includes governmental public health agencies engaged in providing the ten essential public health services, along with other public and private sector entities with missions that affect public health.
- The term 'services' broadly includes programs, direct services, policies, laws, and regulations designed to protect and promote the public's health and prevent disease and disability at the population level.



PHSSR Priorities

→ Research Agenda

- Released by the National Coordinating Center on PHSSR
- Four areas:
 - Public health workforce
 - Public health system structure & performance
 - Public health financing & economics
 - Public health information & technology



Research Implications

- Comparative effectiveness research
- Public health services and systems research
- **Dissemination and implementation research**



Dissemination & Implementation Research

→ Emerging field in taxonomic turmoil!

D & I
Research

Improvement
Science

Quality
Improvement
Research

Delivery
Systems
Science



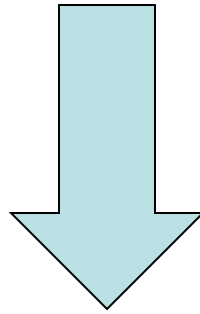
What is it?

- D&I research studies involve extending or adapting generally accepted, efficacious, and/or guideline-based interventions [...] to be able to apply them to **broader real-world populations, settings, and conditions** such as clinic, community, school, and work environments, and other real-world settings.
- In other words, the ultimate goal is to **determine feasible and effective strategies to translate research findings into practice**, to identify determinants of implementation effectiveness at all levels, and to identify ways to accelerate the adoption, integration, and sustainability of evidence into practice and medical decision-making.



Research Implications

- Comparative effectiveness research
- Public health services and systems research
- Dissemination and implementation research



Data Implications



Agenda

- Overview of AcademyHealth
- Developing and Using New Data
- Emerging Innovations to Expand Data Use



Generating Evidence to Build a Learning Health System

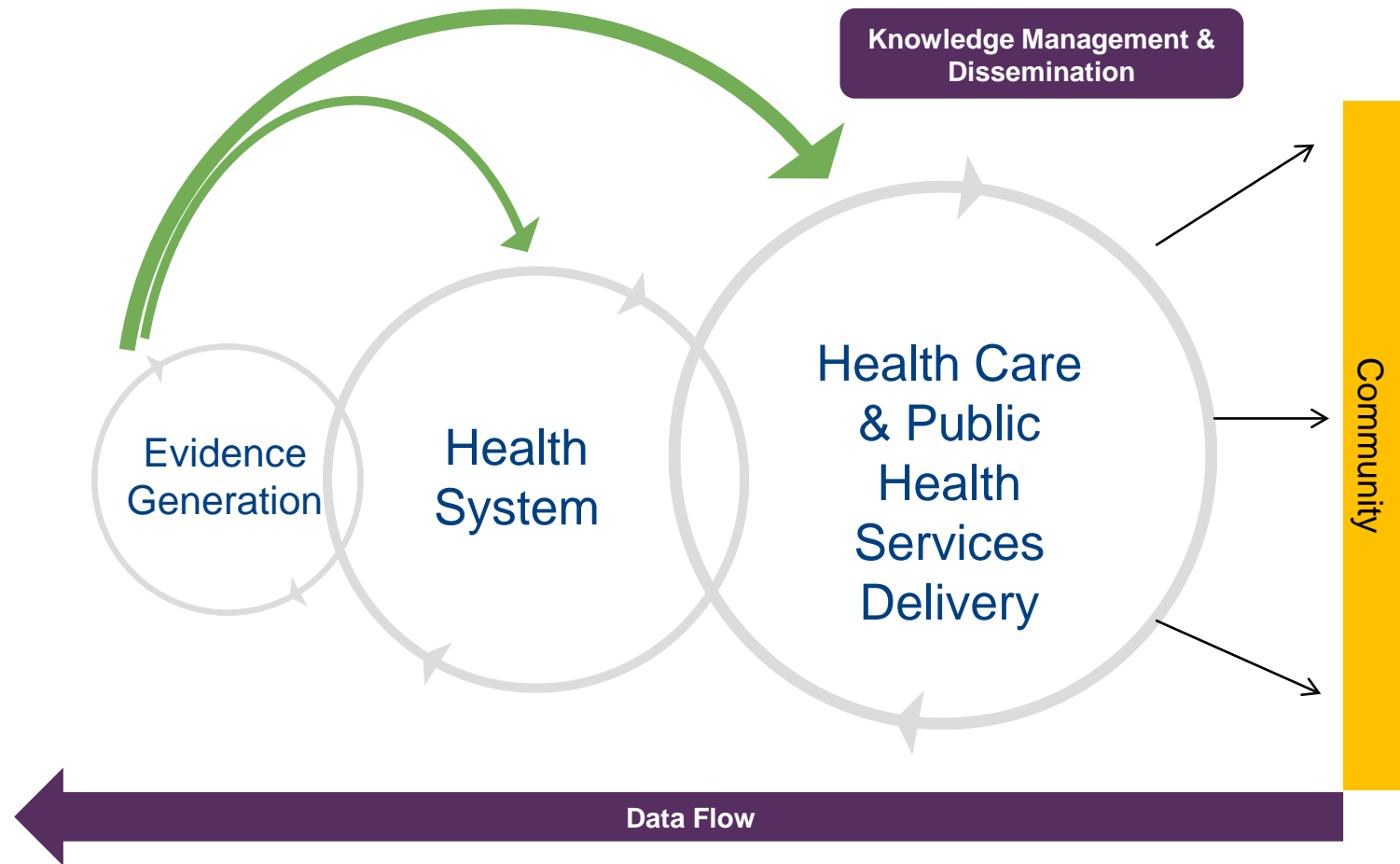
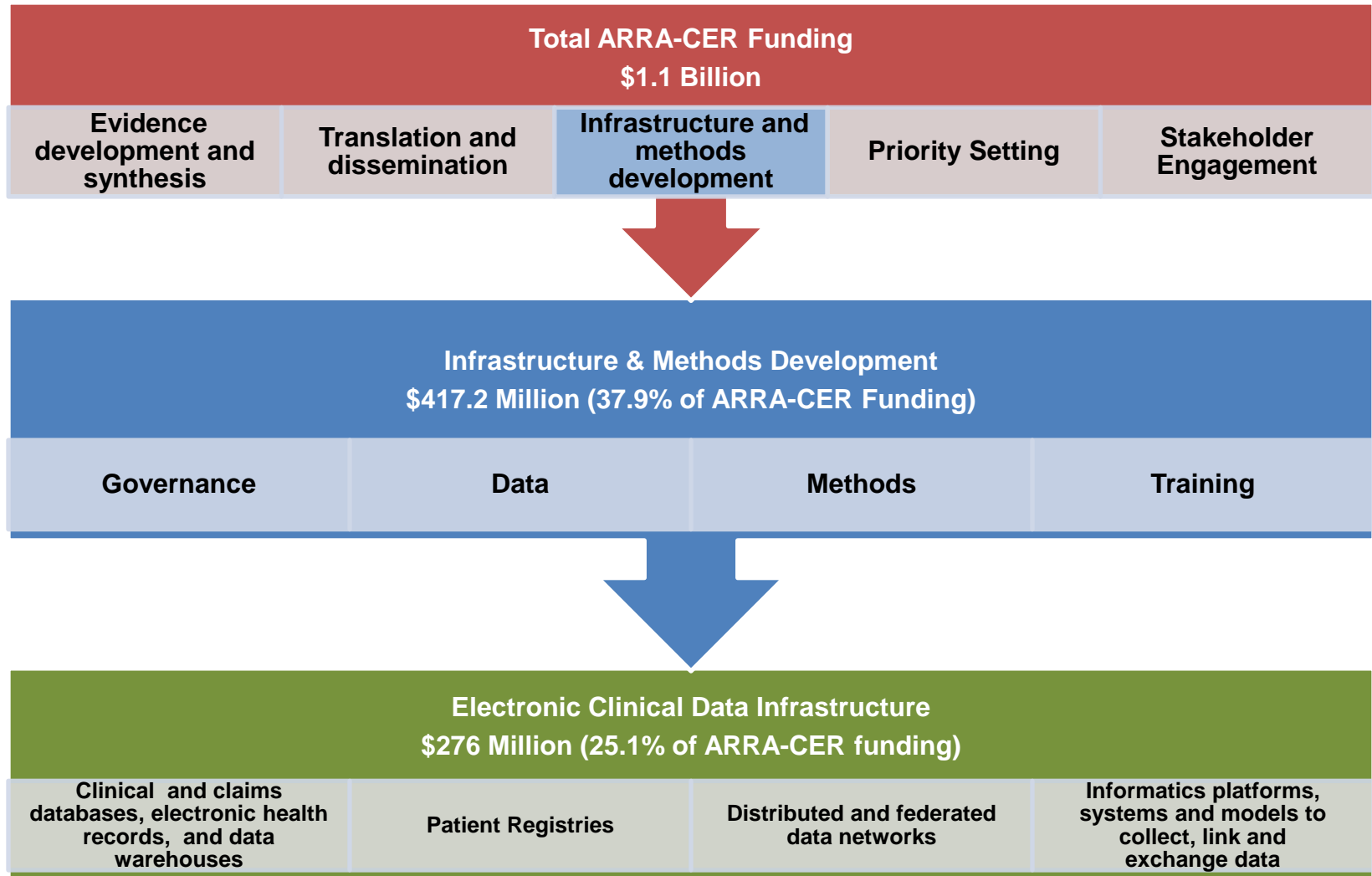


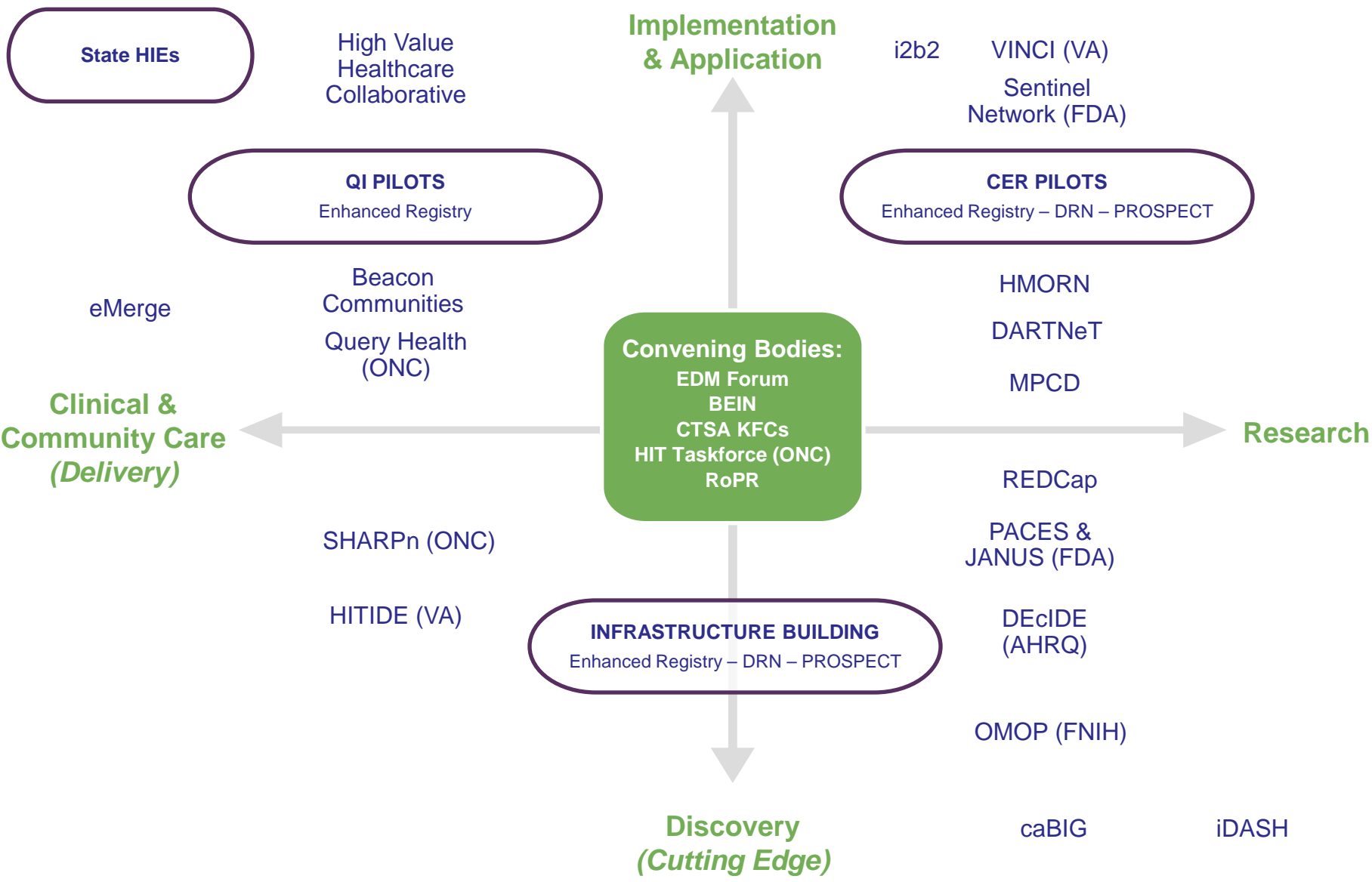
Figure derived from: IOM (Institute of Medicine). 2011. *Engineering a learning healthcare system: A look at the future: Workshop summary*. Washington, DC: The National Academies Press.



ARRA-CER Funding Electronic Clinical Data Infrastructure



Landscape of Electronic Health Data Initiatives for Research



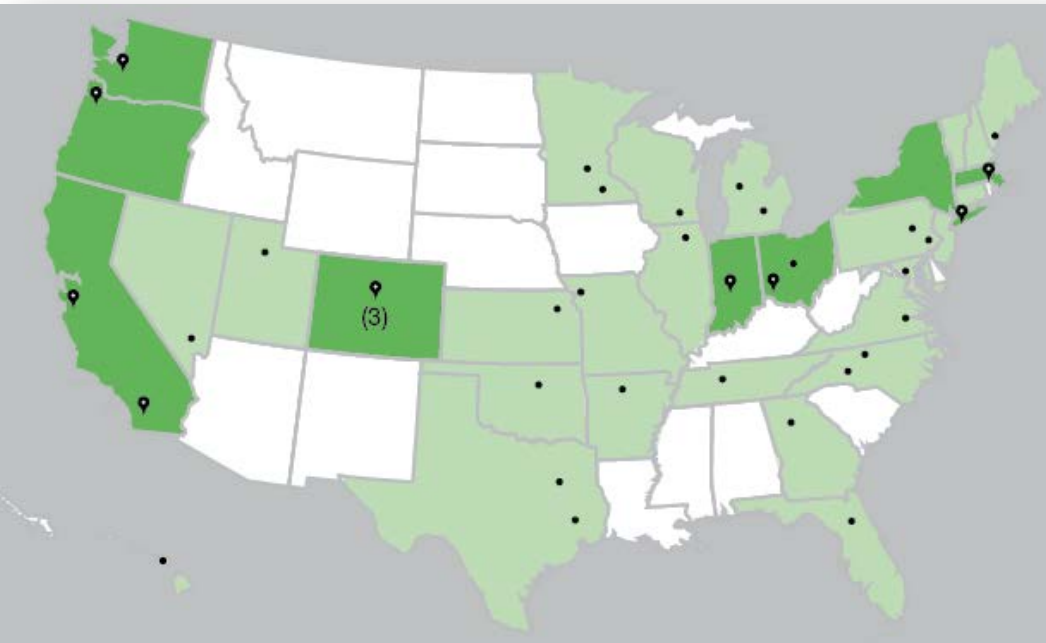
The Electronic Data Methods (EDM) Forum

- 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



Collaborative Research with Electronic Clinical Data

- Collaborative Research Environments
 - AHRQ ARRA Grants to Build Infrastructure for CER:
 - PROSPECT Studies
 - Enhanced Registries
 - Distributed Research Networks (DRN)
 - Electronic Data Methods (EDM) FORUM
 - Provide input at www.edm-forum.org
 - DARTNet
 - Mini-Sentinel (FDA)
 - Observational Medical Outcomes Partnership (OMOP)
 - HMO Research Network (HMORN)
 - AHRQ Effective Healthcare Program (DEcIDE)
 - Dartmouth Care Collaborative
 - VA Informatics and Computing Infrastructure (VINCI)
 - NCRR - CTSA projects: Physio-MIMI, i2b2, TRIAD, REDCap

Informatics Strategies for CER

- Distributed & Federated Research Networks
 - Moving away from centralized data repositories
- Platforms enable:
 - Application development,
 - Use of new tools
 - Data harmonization
 - Data extraction (e.g., Limited Data Sets)
 - End-user interface for research
 - Ability to aggregate data across settings and systems
 - Analytic tools for researchers (e.g., cohort development)
 - Data visualization and statistical tools



Distributed Health Data Networks

- An alternative to centralized, all-payer, databases that supports research needs and addresses data holders concerns about participation
- Can be used for comparative effectiveness research, medical product safety evaluation, and quality measurement, and more
- Example: Temporal trends in medication use and diagnoses at 5 separate sites

PCORI Proposes Data Standards



Patient-Centered Outcomes Research Institute

Draft Methodology Report:
“Our Questions, Our Decisions: Standards for
Patient-centered Outcomes Research”

PCORI Methodology Committee

Mark Helfand, Alfred Berg, David Flum, Sherine Gabriel,
and Sharon-Lise Normand, *Editors*

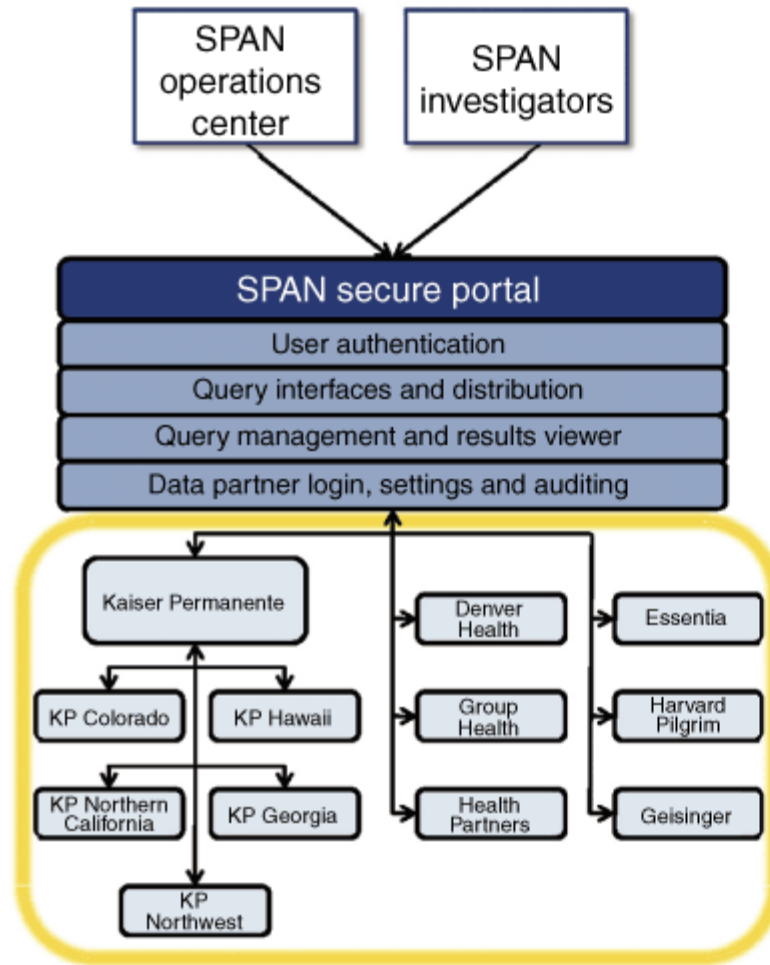
Published for Public Comment July 23, 2012

- Standards for Preventing and Handling Missing Data
- Data Networks as Research-facilitating Infrastructures
- Standards for data registries



AcademyHealth

Scalable Partnering Network for CER



SPAN functions

1. Governance
2. Assignment of user right
3. Creation of data resources and formats
 - Common data model
 - Several "supersets" based on study criteria (ADHD and obesity)
4. Coordination of analyses performed via programs distributed by the secure portal
 - Data partners control execution

PopMedNet services to SPAN

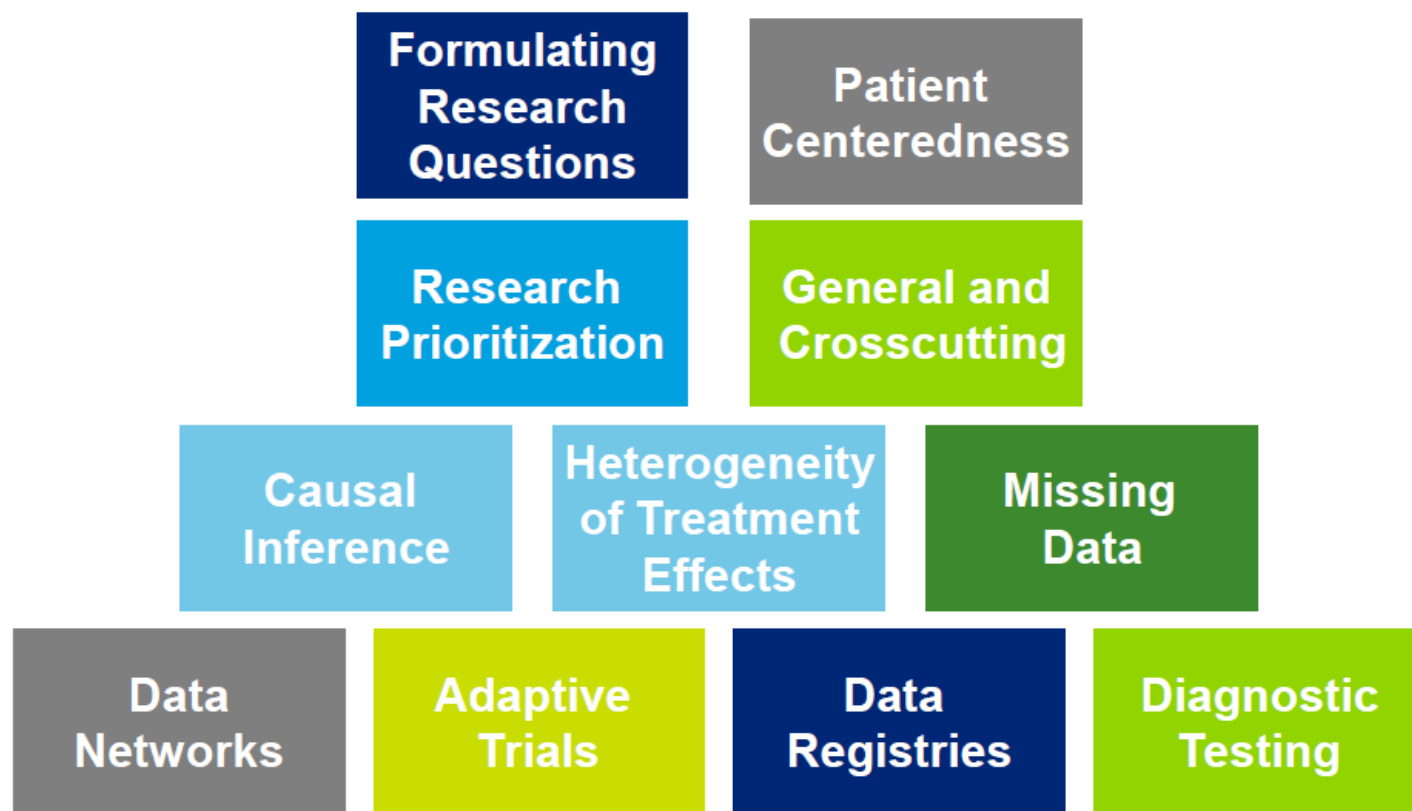
1. Distributed network creation and support
2. Documentation
3. Software development
4. Administrative leadership
5. Secure portals

SPAN involves two subnetworks targeting different CER questions. Each subnetwork further divides into study teams of various sizes. All networking and role-based access control (who can query what) are handled by the PopMedNet software.

4 Methodology Report – Generation



Through consensus, the MC recommends methodologic standards across ten research domains



Data Needs in PHSSR

1. MEPS for public health:
where the \$ comes from
and where it goes
2. NAMCS for public health:
structure, services,
staffing
3. NHIS and NHANES for
public health: how the
total system functions



NCHS Data Linking Initiatives

- Record linking program maximizes value of NCHS's population based surveys:
 - Air Quality
 - Mortality data
 - Medicare Enrollment and Claims data (CMS)
 - Medicaid/CHIP Enrollment and Claims data (CMS)
 - Social Security Benefit History data (SSA)



Ohio Perinatal Quality Collaborative

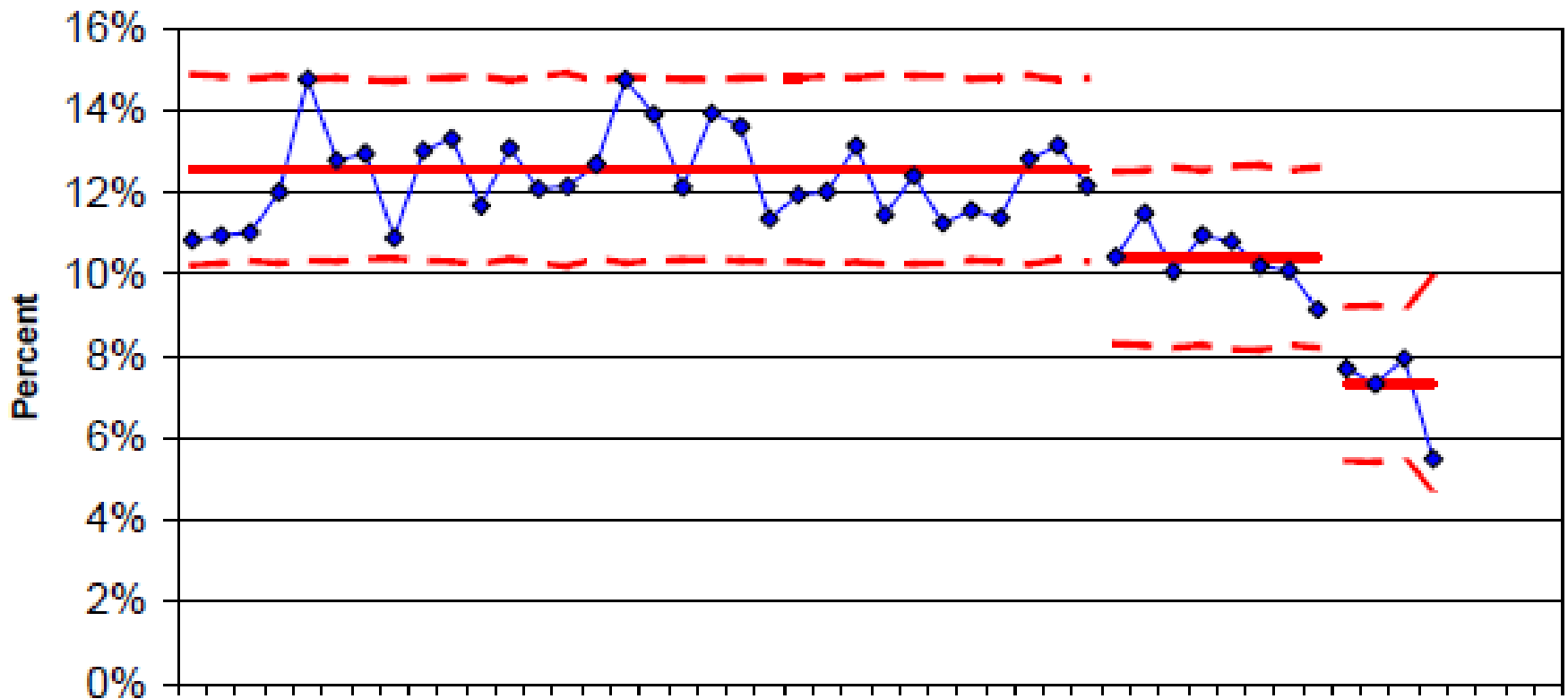
- Statewide, multi-stakeholder network dedicated to improving perinatal health in the state established in 2007
- 45 participating clinical teams from 25 Ohio hospitals
- 21 OB teams are trying to decrease scheduled deliveries between 36 and 39 weeks gestation.



Ohio Perinatal Quality Collaborative : Birth Certificate Data for OPQC Hospitals

Percent of Births at 36 to 38 Weeks Induced Without Medical or Obstetric Indication

Baseline: January, 2006 through December, 2007



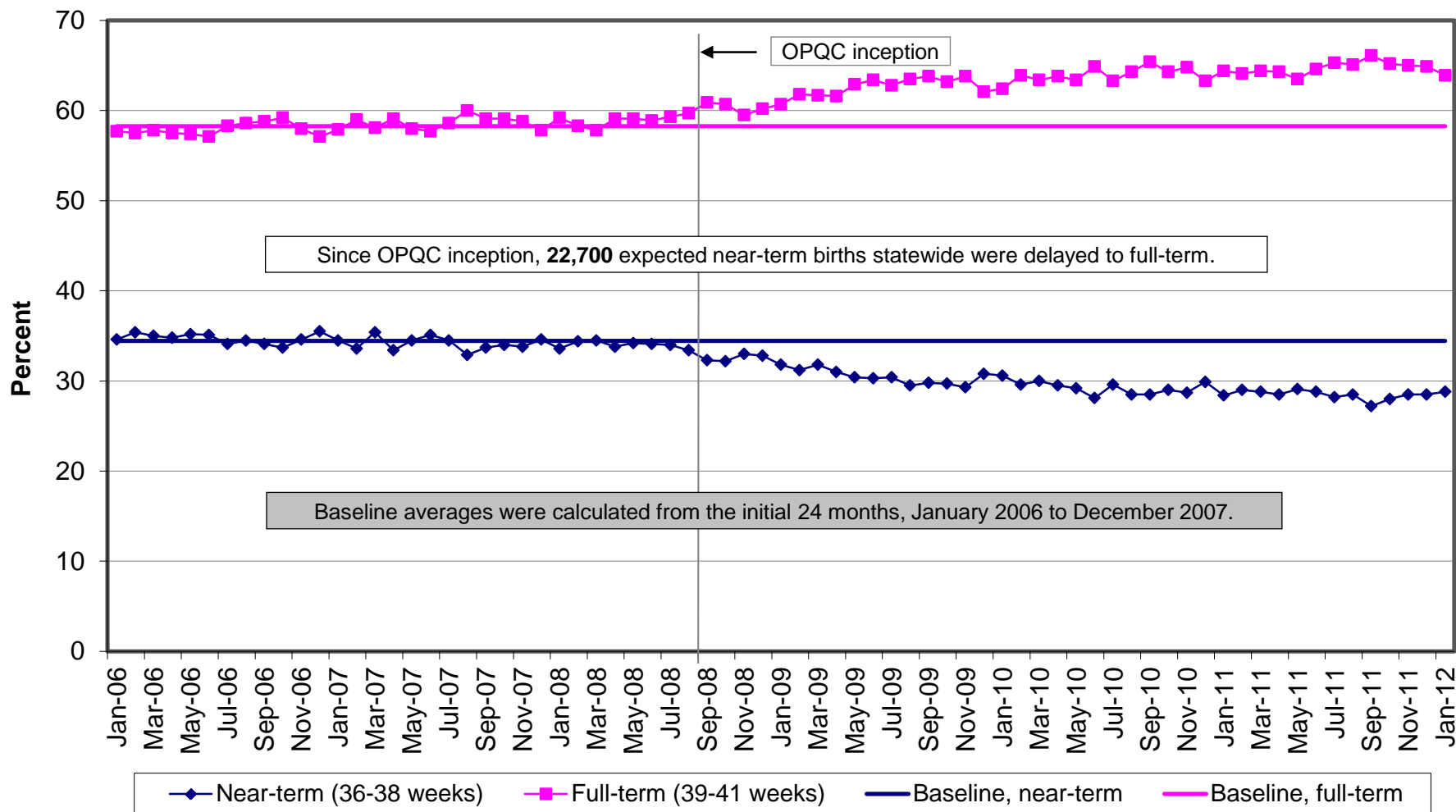
Source: Ohio Perinatal Quality Collaborative



All Ohio Births, 36-38 weeks gestation (blue) & 39-41 weeks gestation (pink)

Data source ODH vital stats

Percent distribution of Ohio full-term and near-term births, by month January 2006 to January 2012



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What does success look like?



Generate relevant and timely evidence with patient buy-in to help build the infrastructure that can answer the questions that people care about.



Questions?

*Lisa Simpson, MB, BCh, MPH, FAAP
President and CEO*