Chicago Area Patient Centered Outcomes Research Network (CAPriCORN)
Goals

• **Rationale** for PCORnet
• **Who** is CAPriCORN
• **What** CAPriCORN is expected to do in 18 months ($7M contract)
• **Health System Leadership Meeting** (June 20, 2014 at National Academies of Sciences)
Rationale for a National Patient-Centered Clinical Research Network (PCORnet)

- Current clinical research system – productive, yet
  - High percentage of clinical decisions not supported by evidence
  - Health outcomes and disparities not improving
  - Does not answer questions that matter most to patients & clinicians
  - Is not designed to address needs of health systems
    - Too slow
    - Too expensive
Rationale for PCORnet (continued)

- Researchers and funders recognize the value in integrating clinical research networks

- PCORnet goals
  - Link existing networks to increase efficiency
  - Ensure patients, providers, and scientists form true “communities of research”
  - Create “interoperability”
    - networks can share sites / data
29 CDRN and PPRN awards approved on December 17, 2013 by PCORI’s Board of Governors

This map depicts the number of PCORI funded Patient-Powered or Clinical Data Research Networks that have coverage in each state.
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Who is CAPriCORN?

CAPriCORN Partners:

Blue Cross Blue Shield of Illinois  ○  Center for Medical Technology Policy  ○  Chicago Asthma Consortium  ○  Chicago Health IT Regional Extension Center (CHITREC)  ○  Comer Children’s Hospital  ○  Have a Heart for Sickle Cell Anemia Foundation  ○  Illinois Hospital Association  ○  Lurie Children’s Hospital  ○  Next Step/Strive  ○  Office of Health Information Technology  ○  Respiratory Health Association  ○  Sickle Cell Disease Association of Illinois  ○  The Peggy Lillis Memorial Foundation
The CAPriCORN team and elected officials kicking off the award. Elected officials: Senator Dick Durbin, Congressman Danny K. Davis, State Senator Antonio Munoz, County Commissioner Robert Steele
## Steering Committee Members

<table>
<thead>
<tr>
<th>Organization</th>
<th>Members</th>
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<tbody>
<tr>
<td>Cook County Health and Hospital System</td>
<td>Bill Trick</td>
</tr>
<tr>
<td>Hines Veterans Affairs</td>
<td>Brian Schmitt</td>
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<tr>
<td>Jesse Brown Veterans Affairs Medical Center</td>
<td>Wendy Brown</td>
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<tr>
<td>Loyola Medicine</td>
<td>Fran Weaver</td>
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<tr>
<td>NorthShore University HealthSystem</td>
<td>Jonathan Silverstein</td>
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<tr>
<td>Northwestern University</td>
<td>Abel Kho</td>
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<tr>
<td>Rush University Medical Center</td>
<td>Raj Shah</td>
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<tr>
<td>The University of Chicago Medicine</td>
<td>David Meltzer</td>
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<tr>
<td>University of Illinois Hospital and Health Sciences System</td>
<td>Jerry Krishnan</td>
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<tr>
<td>Alliance of Chicago Community Health Services (FQHC)</td>
<td>Fred Rachman</td>
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<tr>
<td>External Research Partner</td>
<td>Tom Concannon</td>
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<tr>
<td>PCAC</td>
<td>Madeleine Shalowitz</td>
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<tr>
<td>CAPriCORN PI (The Chicago Community Trust)</td>
<td>Terry Mazany</td>
</tr>
<tr>
<td>CAPriCORN Admin (Illinois Medical District Commission)</td>
<td>John Collins</td>
</tr>
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Clinical Data Research Networks (CDRNs)

2. Mid-South CDRN (Vanderbilt)
3. Patient-oriented Scalable National Network for Effectiveness Research (UCSD)
4. Greater Plains Collaborative (Univ. Kansas Medical Center)
5. Kaiser Permanente & Strategic Partners Patient Outcomes Research To Advance Learning Network (Kaiser Foundation Research Institute)
6. Louisiana CDRN (Louisiana Public Health Institute)
7. National Pediatric Learning Health System (Children’s Hospital of Philadelphia)
8. New York City Clinical Data Research Network (NYC-CDRN)
9. Chicago Area Patient Centered Outcomes Research Network (CAPriCORN; Chicago Community Trust)
10. Accelerating Data Value Across a National Community Health Center Network (Oregon Community Health Information Network)
11. Towards a Learning Health System in the Mid-Atlantic Region (Univ. Pittsburgh)
18 Patient Powered Research Networks (PPRNs)

- Teams of patients, advocacy groups, clinicians, academic centers, practice-based research networks
- Strong understanding of patient engagement
- Significant range of conditions and diseases
- Variety of populations represented (including pediatrics, under-served)
- 50% focused on rare diseases
- Varying capabilities with respect to developing research data
- Several PPRNs have capacity to work with biospecimens
PCORI

PCORnet STEERING COMMITTEE

Members represent:
- Each Clinical Data Research Network
- Each Patient-Powered Research Network
- Patients
- HHS agencies:
  - NIH
  - FDA
  - AHRQ
  - CDC
  - CMS
  - ONC
  - ASPE
- Medical product and device manufacturers
- PCORI and Coordinating Center

PCORnet Executive Committee

11 CLINICAL DATA RESEARCH NETWORKS

18 PATIENT-POWERED RESEARCH NETWORKS

COORDINATING CENTER

PROJECT MANAGEMENT OFFICE

TASK FORCES
- GOVERNANCE
- DATA PRIVACY
- ETHICS & REGULATORY
- DATA STANDARDS & SECURITY
- HEALTH SYSTEMS INTERACTIONS
- PATIENT & CONSUMER ENGAGEMENT
- PATIENT GENERATED OUTCOMES
- CLINICAL TRIALS
- RARE DISEASES
- BIOREPOSITORIES
- OBESITY
Goals

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What is CAPriCORN expected to do in 18 mos?

- Establish procedures for clinical data standardization and interoperability across CDRNs and PPRNs
- Capture detailed longitudinal information on >1 million patients (~50% non-white)
- Operationalize a central IRB
What? (continued)

- Recruit and characterize 5 cohorts (asthma, anemia, sickle cell disease, obesity, and recurrent Clostridium difficile)

- Develop capacity to conduct comparative effectiveness research (CER) trials and observational studies
  - Engage patients, clinicians & health system leaders throughout research cycle from idea generation to implementation
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Comments from C-suite (some)

- Opportunities
  - Information from clinical practice to drive the cycle of continuous performance improvement
  - Path towards becoming a “learning health care system”

- Challenges
  - Distracts health systems from an already full agenda
  - Data privacy / HIPAA
  - Indemnification
Health System Leadership Meeting
June 20, 2014; Washington, D.C.

Topic
Health System Leaders Working Towards High Value Care
Through Integration of Research and Practice

Location
The National Academies of Sciences Building
2101 Constitution Ave NW
Washington, DC

Goals
1. Value proposition for integrating practice and research
2. Practical agenda and infrastructure alignment
3. Advancing progress
Discussion

Next steps
18 Month Organizational Goal