

Introduction to PCORnet

Engelberg Center for Health Care Reform
The Brookings Institution • Washington, DC
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Launching PCORnet, the National Patient-Centered Clinical Research Network

PCORnet Kickoff Meeting

January 21st, 2014



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The National Patient-Centered Clinical Research Network

PCORnet: the National Patient-Centered Clinical Research Network



The goal of PCORI's National Patient-Centered Clinical Research Network Program is to **improve the nation's capacity to conduct CER efficiently, by creating a large, highly representative, national patient-centered clinical research network** for conducting clinical outcomes research.

The vision is to support a learning US healthcare system, which would allow for **large-scale research** to be conducted with **enhanced accuracy and efficiency**.



Overall objectives of PCORnet: achieving a single functional “network of networks”

- ❖ **Engagement** of patients, providers and health system leaders
- ❖ Support and conduct of **multi-network observational and interventional CER** studies
- ❖ **External data and research partners** participate with PCORI-funded networks
- ❖ **Researchers not directly affiliated** with PCORnet participate through collaborative arrangements.
- ❖ PCORnet partners will **use the resources created with PCORI’s support** for a range of activities supported by other organizations.



CDRN Highlights

- Networks of **academic medical centers**, hospitals and physician practices
- Networks of non-profit **integrated health systems**
- Networks of **low income clinics**
- Networks leveraging **AHRQ investments and NIH investments (CTSAs)**
- Inclusion of **Health Information Exchanges**
- Wide **geographical** spread
- Inclusion of **underserved** populations
- Range from **1M covered lives to 28M**



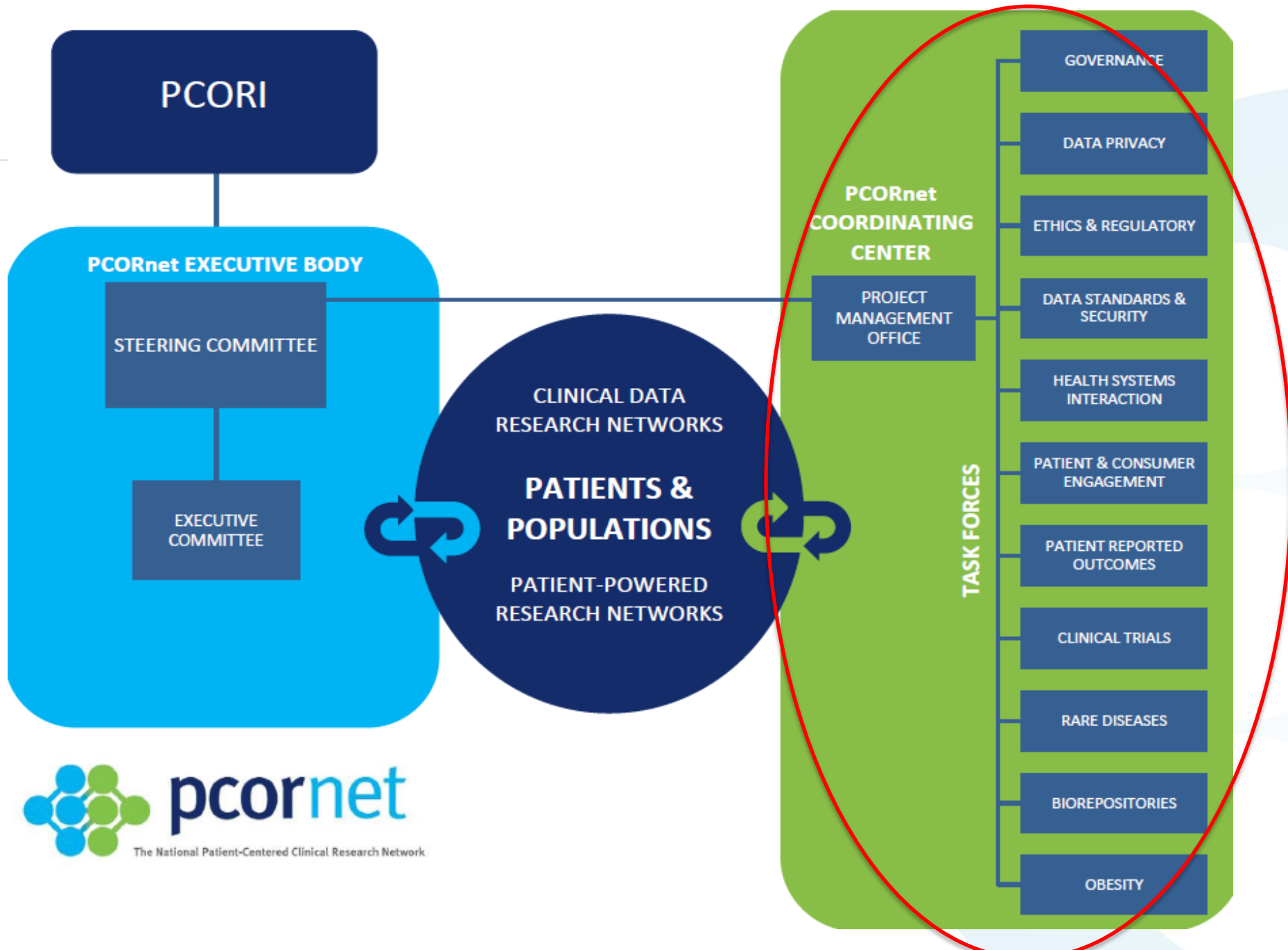
PPRN Highlights

- Variety of **stakeholders** in participating organizations and in leadership team: patients, advocacy groups, physician organizations, academic centers, PBRNs etc.
- Strong understanding of **patient engagement**
- Significant range of **conditions and diseases**
- Variety in **populations** represented (including pediatrics, underserved populations etc.)
- **50% rare diseases**
- Significant range in the **maturity** of the group in terms of data available
- Several have capacity to work with **biospecimens**

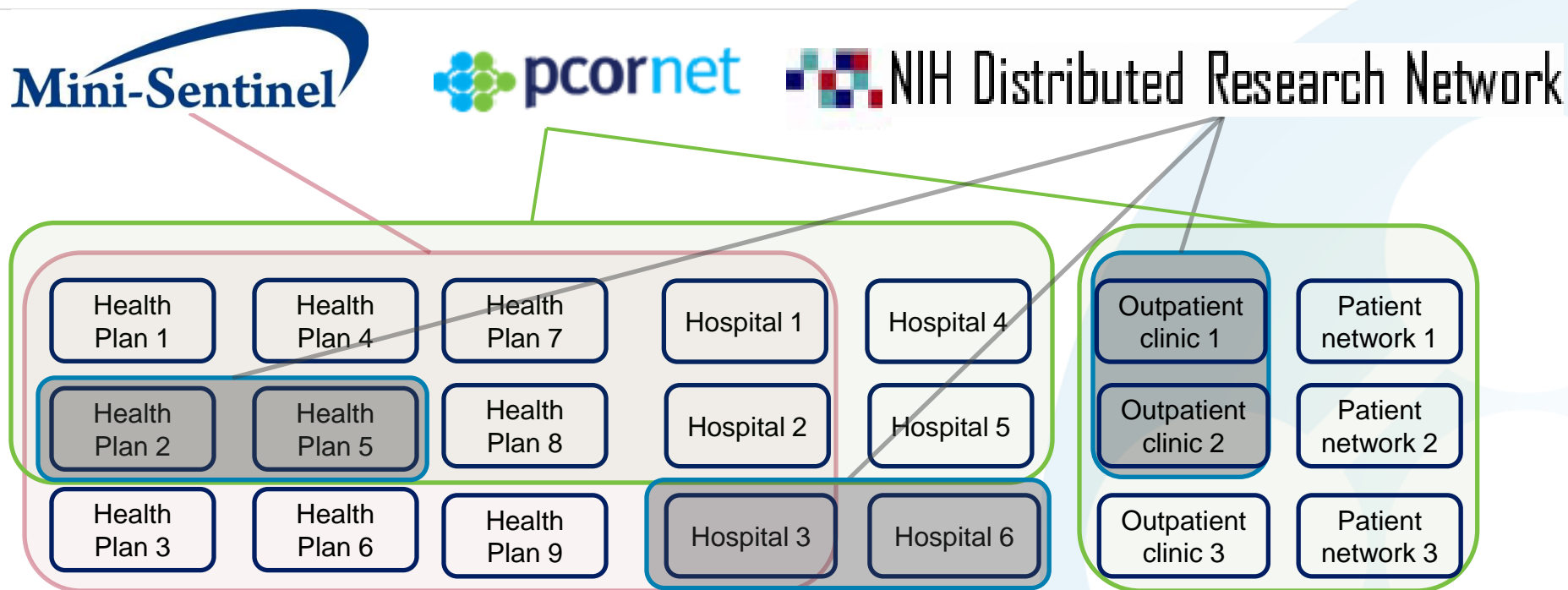


PCORnet Steering Committee

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



Multiple Networks Sharing Infrastructure



- Each organization can participate in multiple networks
- Each network controls its governance and coordination
- Networks share infrastructure, data curation, analytics, lessons, security, software development

Bray Patrick-Lake
Patient Representative,
Executive Leadership Committee,
PCORnet Coordinating Center



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The National Patient-Centered Clinical Research Network

Patients need relevant, high quality information for informed decision making



- Complex navigation of risk/benefit tradeoffs
- Dependent on where patients are in trajectory of the disease
- Delicate balance of co-morbidities
- Long term consequences vs. short term benefit
- Quality vs. quantity of life
- Respectful of cultural preferences

Based on my personal characteristics, what can I expect my outcome to be? **WE DON'T KNOW**

- Therapies reach market after study in cleanest population possible
- Smallest number of patients, shortest amount of time possible
- Results often an average; some receive benefit, others harm
- Subgroup analysis on single variables
- Things patients care about most are absent - QOL and PROs



The current system is broken; patients are over it.



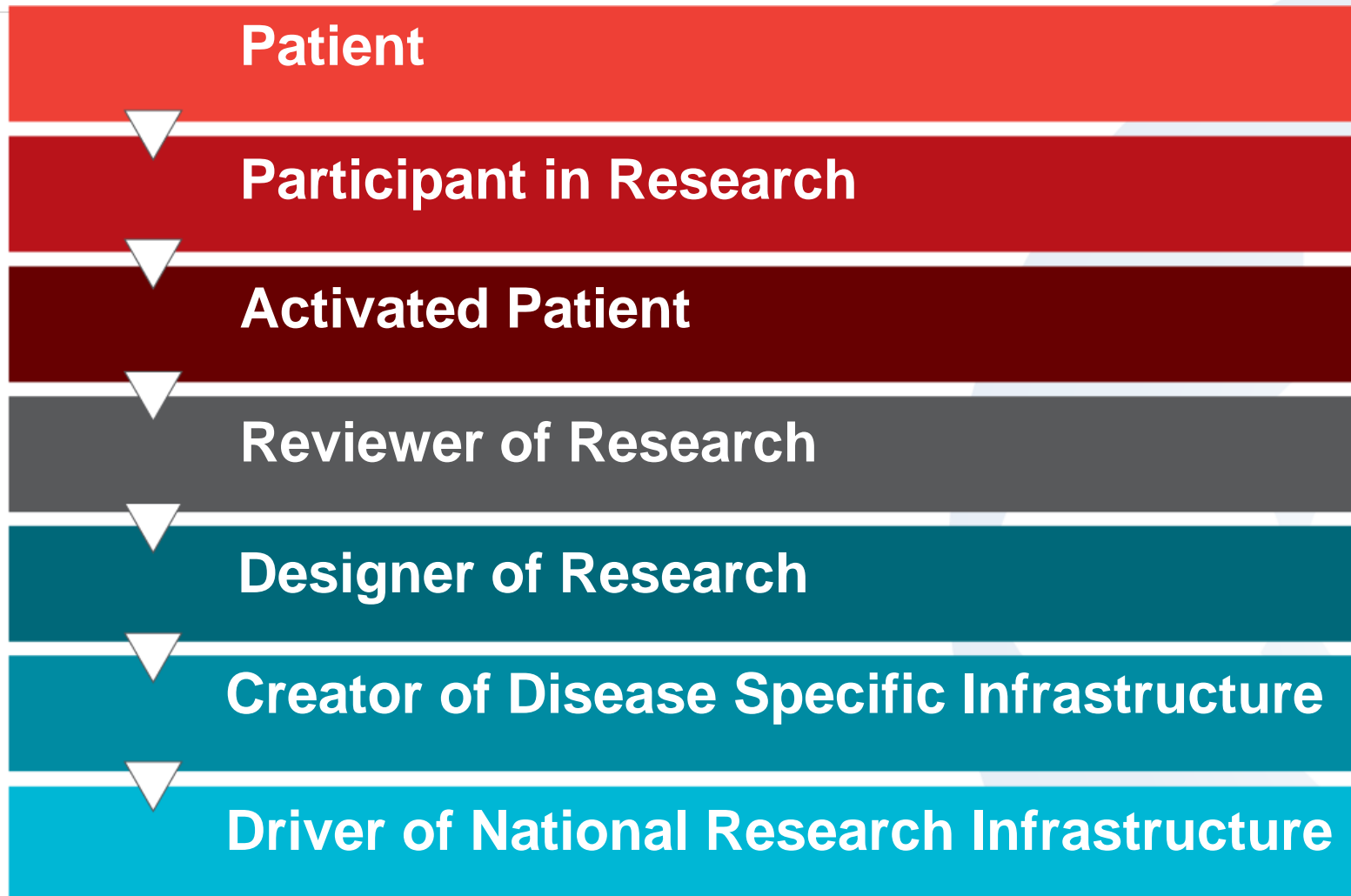
- ❖ Incredible waste of resources on repetitive activities
- ❖ Unnecessary delays due to bureaucracy
- ❖ Recruitment and retention failures rampant
- ❖ Data that could help patients remains inaccessible
- ❖ Research results don't get disseminated to patients or translated into decision support tools

Patients dream of ...

A high quality clinical research system that is patient-centered and evidence-based prevention & treatment options that are responsive to patients' individual needs

Maybe we should ask patients how to achieve this ...

Evolution of patient engagement in research: PCORnet's history in the making



PCORnet and its partners make the dream a reality

- ⊕ Dream team of research and patient experts working on PCORnet
- ⊕ Historic amount of patient engagement in research
- ⊕ Unprecedented opportunities for collaboration, knowledge sharing, and community building
- ⊕ **Together we will make a difference in the lives of millions of patients**

(and change our nation's clinical research system forever!)

Thank You!

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