What Are We Looking For?

Building a National Infrastructure for Conducting PCOR

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pcori

PCORI Mission and Vision

PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

PCORI Vision

Patients and the public have information they can use to make decisions that reflect their desired health outcomes.

PCORI Mission

The Patient-Centered Outcomes Research Institute (PCORI) helps people make informed health care decisions, and improves health care delivery and outcomes by producing and promoting high integrity, evidence-based information that comes from research guided by patients, caregivers and the broader health care community.

Addressing PCORI's Strategic Imperatives

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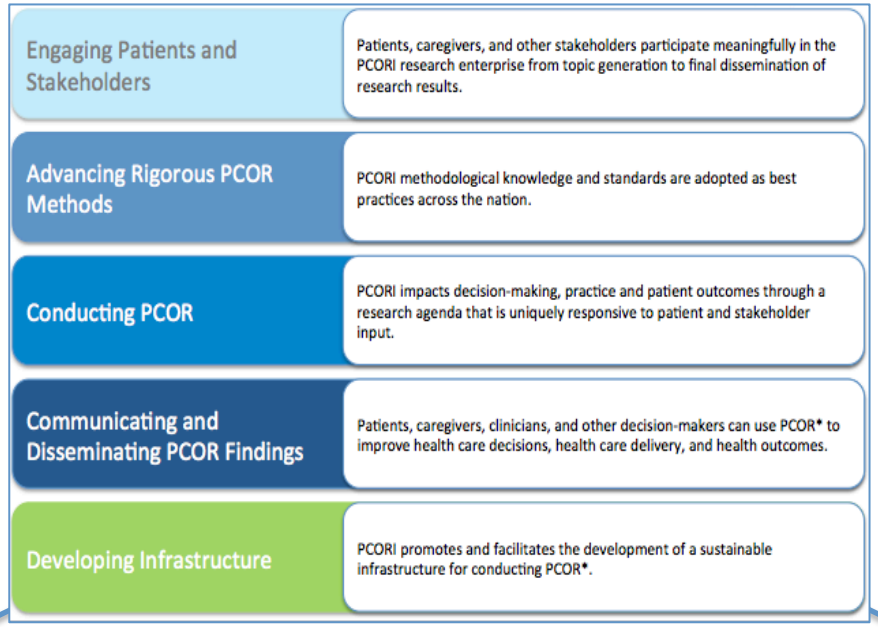
Advancing Use of Electronic Data Supports Imperative to Develop Infrastructure to Conduct PCOR*



Developing Infrastructure

PCORI promotes and facilitates the development of a sustainable infrastructure for conducting PCOR*.

Desirable Characteristics for Data Infrastructure to Support PCOR

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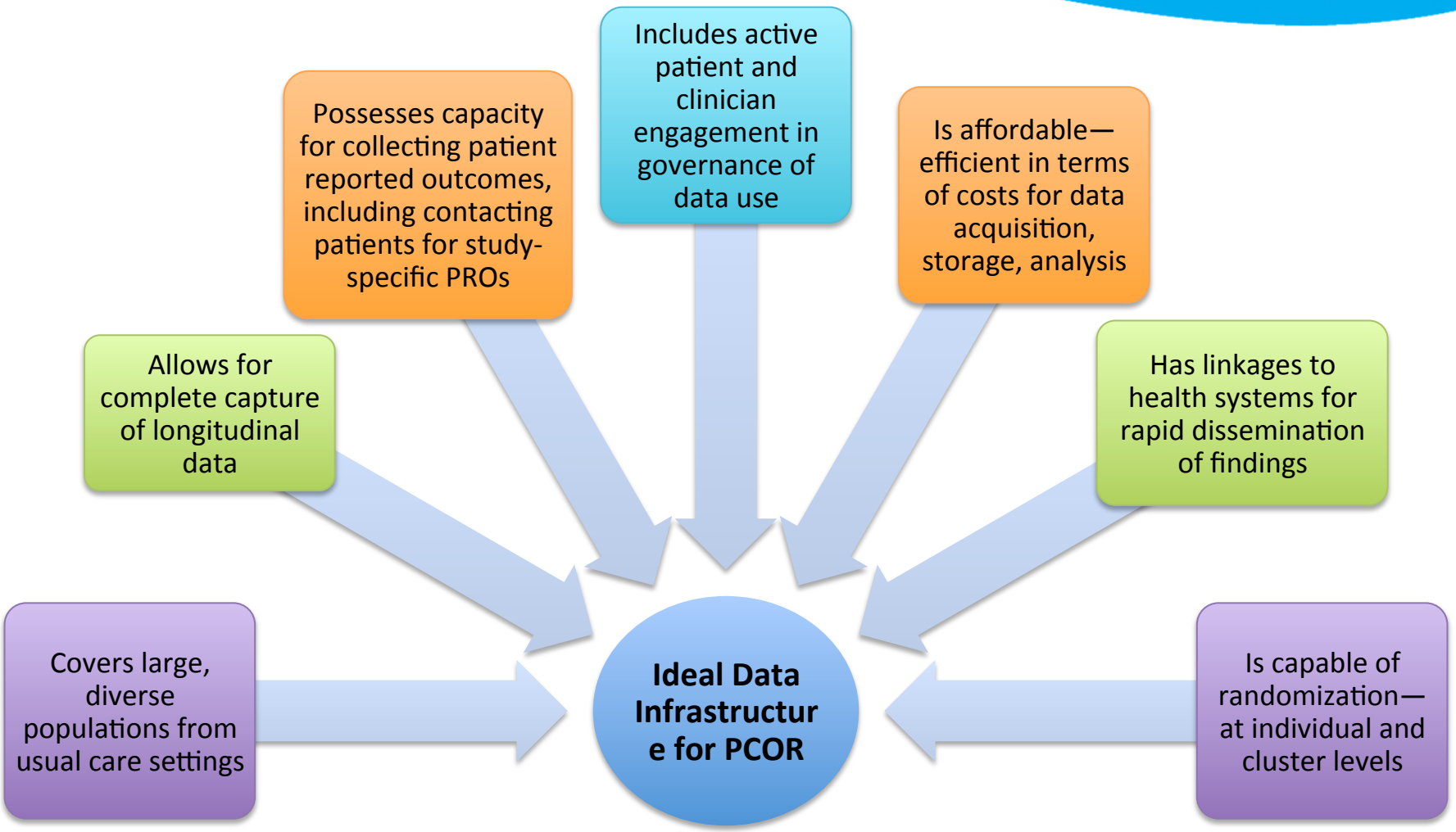

Funders, Models, and Opportunities

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ONC

- Meaningful Use
- EHR Certification programs
- Standards & Interoperability Framework
- SHARP Program
- BEACON Communities

FDA

- Sentinel
- OMOP

AHRQ

- DRNs
- PBRNs
- Registries
- SPAN
- PROSPECT
- EDM Forum

NIH

- CTSA
- Collaboratory
- CRN, CVRN
- ClinicalTrials.gov
- eMERGE Network
- PROMIS/ NIH - Snomed-CT, LOINC

VA

- VistA
- iEHR (2017)

IOM

2011 Report: *Digital Infrastructure for the Learning Health System: The Foundation for Continuous Improvement in Health and Health Care*

Payers

hmo research network

OPTUMInsight™

Special Societies

Industry

Medtronic

Mainspring Data Express

Innovators and Entrepreneurs

C3N

patientslikeme

CANCERCOMMONS

Where We Need Your Help

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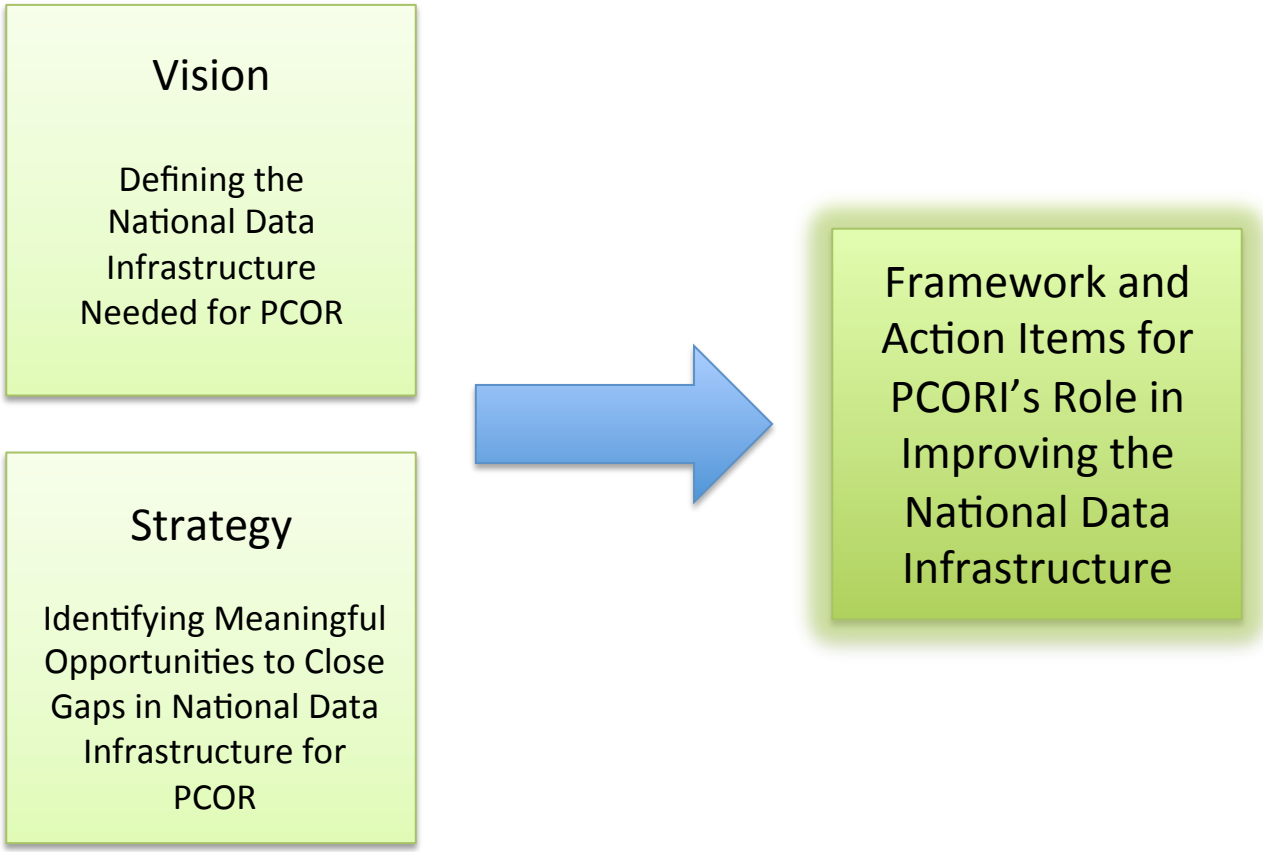

In the PCORI Quiver

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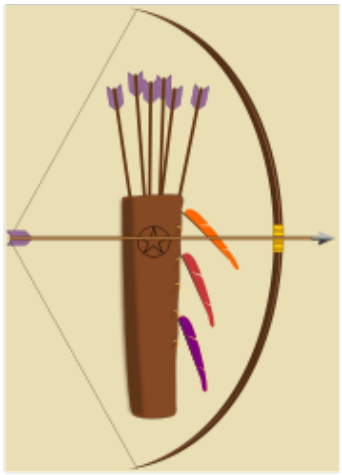

- Funding Research in Priority Areas
- Establishing Standards for PCOR
- Convening Relevant Stakeholder Groups
- Engagement of Patients and Other Stakeholders
- Strategic Investments and Partnerships

Challenges Ahead

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Breakout Groups to Address Large Areas for Improvement of the Electronic Health Infrastructure for PCOR

Need Identified	To Be Addressed
Governance	Which models of governance best address the challenges of data ownership and availability, protect intellectual property, and actively engage patients and clinicians in overseeing data use?
Data Standards and Interoperability	What must be done to assure that data collected across multiple sites holds common definition and can be aggregated reliably for analytic purposes?
Architecture and Data Exchange	What network design best address desires for both local control of native data and researchers need for cross-site data access? How do advancements like cloud computing affect network design?
Privacy, and Ethical Issues	What must be done to preserve patient privacy while allowing data to flow between patients, clinicians, and researchers for the conduct of PCOR?
Methods	What methods can be used to overcome the limitations of imperfect data?
Incorporating Patient-Reported Outcomes	What must be done to assure that systems support the collection and analysis of data that are most meaningful to patients?
"Unconventional" Approaches	How can we expand on innovations such as activated online patient communities and those from other industries to increase the capacity to conduct PCOR as well as support its implementation and use?

How Will We Do This?

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Vision	Discovery	Ideation	Prioritization	Action
Defining our goal	Surveying the landscape	Identifying opportunities	Deciding where to start	Identifying next steps

July 2
Morning

- Survey of the landscape
- Lessons from the field
- Case Studies
- Panelist Responses

July 2
Afternoon

- Breakout Groups
- Poster Sessions

July 3

- Recap of Poster Session
- Exploring Top Ten Poster Session Proposals
- Reflections