

PCORnet: Managing EHR Phenotypes

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PCORI



pcornet

The National Patient-Centered Clinical Research Network

Outline

PCORnet Overview

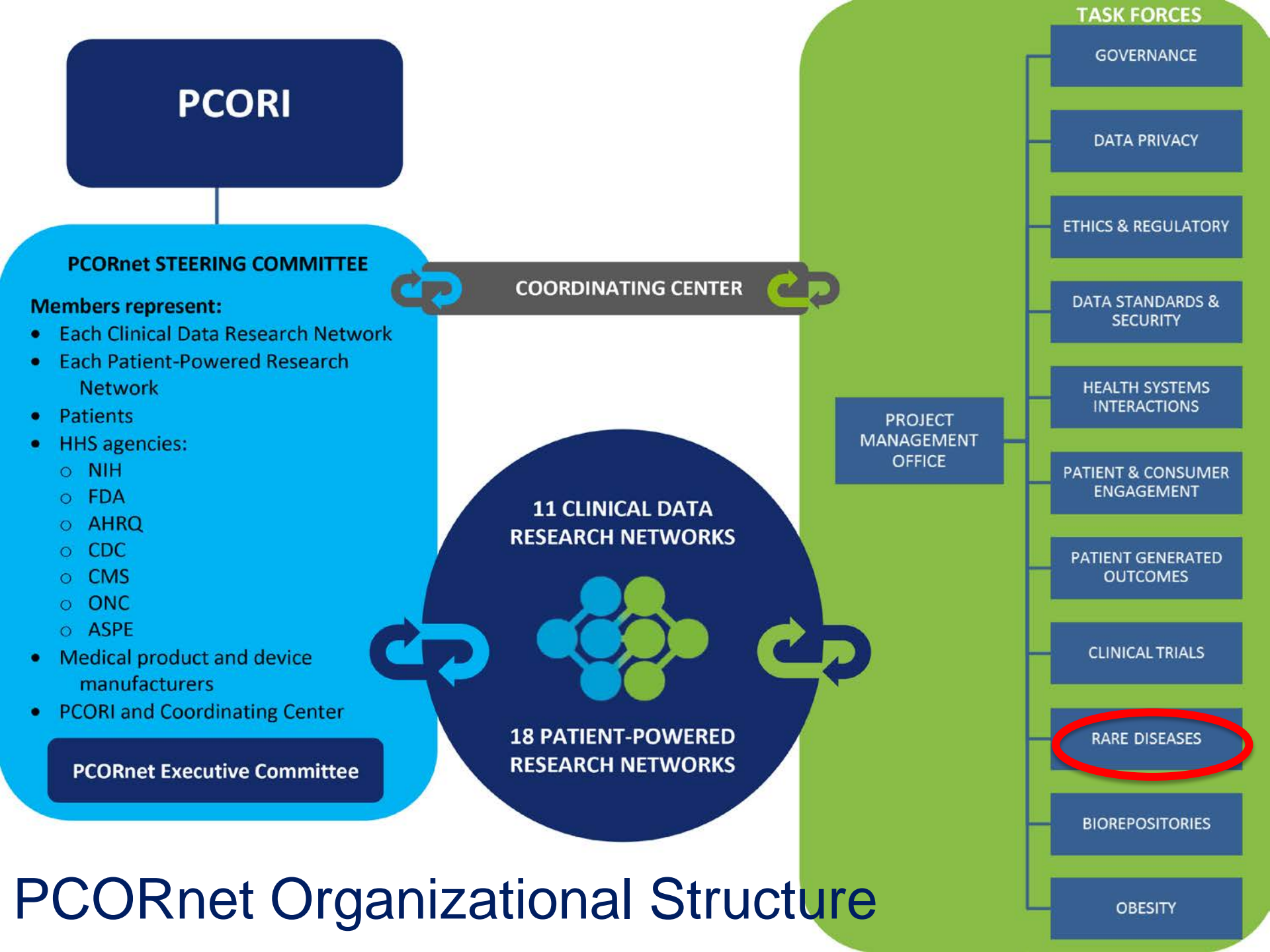
PCORnet Cohorts

PCORnet Computable Phenotypes

- Approaches/Procedures (*in progress*)
- Expectations (*by end of Phase I*)

PCORnet Overview: Purpose and Goals

- ❁ The Patient-Centered Outcomes Research Institute (PCORI) is authorized by Congress to conduct research to provide information about the best available evidence **to help patients and their healthcare providers make more informed decisions.**
- ❁ PCORI's goal is to improve the nation's capacity to conduct **rapid, efficient, and economical comparative effectiveness research**
- ❁ **PCORnet**, the National Patient-Centered Clinical Research Network, is an innovative initiative of PCORI.
 - **The goal of PCORnet is to improve the nation's capacity to conduct comparative effectiveness research efficiently by creating a large, highly representative network for conducting clinical outcomes research.**



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

COORDINATING CENTER

11 CLINICAL DATA RESEARCH NETWORKS

18 PATIENT-POWERED RESEARCH NETWORKS

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

PCORnet Organizational Structure

CDRNs: Disease cohorts

Organization	Common Disease Cohort	Rare Disease Cohort
ADVANCE	Diabetes	Alpha-1-antitrypsin deficiency
CAPriCORN	Anemia; asthma	Sickle cell disease; recurrent <i>C. difficile</i> colitis
Greater Plains Collaborative	Breast cancer	Amyotrophic lateral sclerosis
Louisiana Clinical Data Research Network	Diabetes	Sickle cell disease; rare cancers
NYC-CDRN	Diabetes	Cystic fibrosis
Mid-South CDRN	Coronary heart disease	Sickle cell disease
PEDSNet	Inflammatory bowel disease	Hypoplastic left heart syndrome
PORTAL	Colorectal cancer	Severe congenital heart disease
pSCANNER	Congestive heart failure	Kawasaki disease
P2ATH	Atrial fibrillation	Idiopathic pulmonary fibrosis
SCILHS	Osteoarthritis	Pulmonary arterial hypertension

PPRNs Represent a Number of Conditions...

Organization	Principal Investigator	Condition	Population Size
Accelerated Cure Project for Multiple Sclerosis	Robert McBurney	Multiple sclerosis	20,000
American Sleep Apnea Association	Susan Redline	Sleep apnea	50,000
Cincinnati Children's Hospital Medical Center	Peter Margolis	Pediatric Crohn's disease and ulcerative colitis	15,000
COPD Foundation	Richard Mularski	Chronic obstructive pulmonary disease	50,000
Crohn's and Colitis Foundation of America	R. Balfour Sartor	Inflammatory bowel disease (Crohn's disease and ulcerative colitis)	30,000
Global Healthy Living Foundation	Seth Ginsberg	Arthritis (rheumatoid arthritis; spondyloarthritis), musculoskeletal disorders (osteoporosis), and inflammatory conditions (psoriasis)	50,000
Massachusetts General Hospital	Andrew Nierenberg	Major depressive disorder and bipolar disorder	50,000
University of California, San Francisco	Mark Pletcher	Cardiovascular health	100,000
University of South Florida	Rebecca Sutphen	Hereditary breast & ovarian cancer	17,000

....Including Rare Diseases

Organization	Principal Investigator	Condition	Population Size
ALD Connect, Inc.	Florian Eichler	Adrenoleukodystrophy	3,000
Arbor Research Collaborative for Health	Bruce Robinson	Primary nephrotic syndrome; focal segmental glomerulosclerosis; minimal change disease; and membranous nephropathy multiple sclerosis	1,250
Duke University	Laura Schanberg	Juvenile rheumatic disease	9,000
Epilepsy Foundation	Janice Beulow	Aicardi syndrome; Lennox-Gastaut syndrome; Phelan-McDermid syndrome; hypothalamic hamartoma; Dravet syndrome, tuberous sclerosis	1,500
Genetic Alliance, Inc.	Sharon Terry	Alström syndrome; dyskeratosis congenital; Gaucher disease; hepatitis; inflammatory breast cancer; Joubert syndrome; Klinefelter syndrome & associated conditions; psoriasis; metachromatic leukodystrophy; pseudoxanthoma elasticum	50- 50,000
Immune Deficiency Foundation	Kathleen Sullivan	Primary immunodeficiency diseases	1,250
Parent Project Muscular Dystrophy	Holly Peay	Duchenne and Becker muscular dystrophy	4,000
Phelan-McDermid Syndrome Foundation	Megan O'Boyle	Phelan-McDermid syndrome	737
University of Pennsylvania	Peter Merkel	Vasculitis	500

Approaches/Procedures (*in progress*)

Basic Steps:

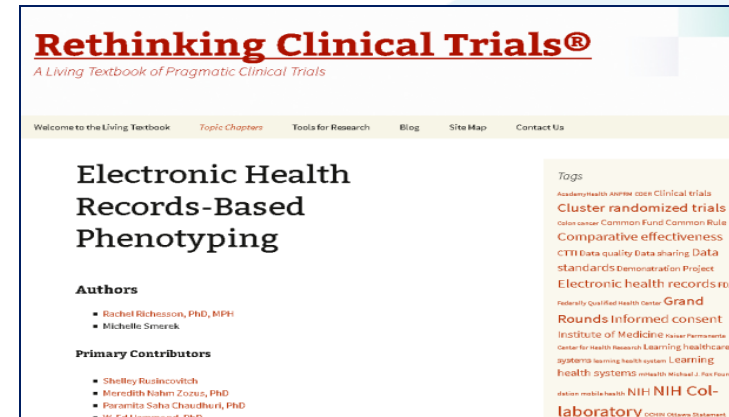
- Define research population
 - Study and study objectives
 - Define target population
 - Identify setting & strategy for EHR data
- Define EHR-based Condition Definition (Computable Phenotype)
 - Either “borrow or build”
 - Assess/report performance or validation
- Implement
- **Share data fields, logic, justification, and validation experience with PCORnet**

Approaches/Procedures (*in progress*)

Guidance

- Living Textbook for Pragmatic Trials
- Instructions
- Template

Repository for access



<http://sites.duke.edu/rethinkingclinicaltrials/ehr-phenotyping/>

Expectations (*by the end of Phase I*)

Definitions should support:

- Development and conduct of new multi-site studies (interventional and observational)
- Comparability of EHR-derived data sets
- Comparison of study results and aggregation of evidence
- Reporting of data sets or results (e.g., ClinicalTrials.gov)
- Better practices for describing research populations in publication submissions to medical journals

Expectations (*by the end of Phase I*)

Present Philosophy:

- Minimize burden for sharing phenotypes
- Encourage and support but not mandate standards
- All sites use high-quality validated phenotypes
- Appropriate for purpose
- Reduce variation
 - ideally all PCORnet researchers will use same definition