



NIH Collaboratory

Health Care Systems Research Collaboratory

The NIH Collaboratory Distributed Research Network

Millions of people. Strong collaborations. Privacy first.

Steering Committee Meeting

February 24, 2014

A Vision For A National Patient-Centered Research Network

Francis S. Collins, M.D., Ph.D.

Director, National Institutes of Health

National Workshop to Advance the Use of Electronic Data in

Patient-Centered Outcomes Research

July 2, 2012



Imagine ...

A National Patient-Centered Research Network

- Bringing together **20–30 million covered lives**, with
 - Good representation of gender, geographic, ethnic, age, educational level, and socioeconomic diversity
 - Broad opt-in consents from 80 - 90% of participants
 - Longitudinal follow up over many years
- Offering a stable **research infrastructure**
 - Including trained personnel in each of the participating health services organizations
 - Making it possible to run protocols with low marginal cost



What Could We Do With a National Patient-Centered Research Network?

- Rapidly design and implement observational trials
 - At very low cost
- Quickly and affordably conduct randomized studies
 - Using individual or cluster design
 - In diverse populations and real-world practice settings
- Significantly reduce usual expenses associated with start-up and shut-down of clinical research studies



Why Now?

- For the first time in the U.S., health services organizations with EHRs have reached the point of making this network feasible on a large scale
- Scientific opportunities and the urgency of getting answers to clinical questions have never been greater
- If we are ever to engage a larger proportion of the American public in medical research, we need to come to them – in partnership
- General feasibility has been demonstrated through modest prior efforts (e.g. HMORN, eMERGE, etc.)
- **PCORI has arrived on the scene** – and successful establishment of this Network, potentially with NIH and AHRQ as partners, could be PCORI's most significant contribution and enduring legacy



pcornet

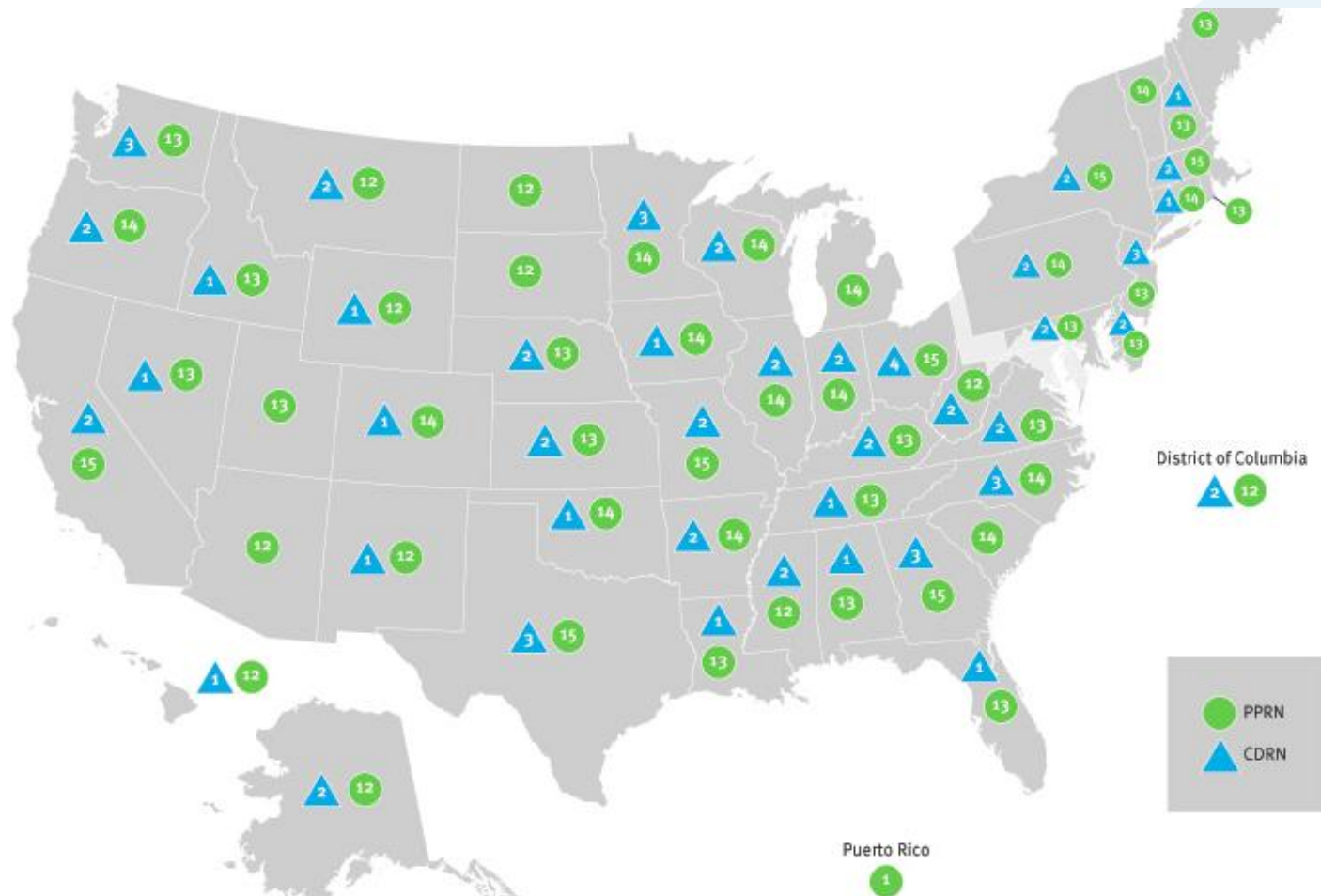
The National Patient-Centered Clinical Research Network

PCORnet: the National Patient-Centered Clinical Research Network



The goal: improve the nation's capacity to conduct rapid, efficient, economical comparative effectiveness research that is beyond existing capabilities

11 Clinical Data Research Networks and 18 Patient Powered Research Networks



11 Clinical Data Research Networks

CDRN Name	Lead Organization
ADVANCE	Oregon Community Health Information Network
CAPriCORN	The Chicago Community Trust
Great Plains Collaborative	University of Kansas Medical Center
Louisiana Clinical Data Research Network	Louisiana Public Health Institute
Mid-South CDRN	Vanderbilt University
NYC-CDRN	Weill Medical College of Cornell University
PEDSNet	The Children's Hospital of Philadelphia
PORTAL	Kaiser Foundation Research Ins
pSCANNER	University of California, San Diego
P2ATH	University of Pittsburgh
SCIHLS	Harvard University

Clinical Data Research Networks' 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

Patient Powered Research Networks

- Target size of **0.5% of U.S population** with condition:
> 50 patients for rarest diseases; 50,000 for most common
- **Patient-reported data** collected for at least 80% of cohort
- **Patients** involved in governance
- **Standardized data** suitable for sharing with other infrastructure members and successfully responds to queries

9 Patient Powered Research Networks *in rare conditions*

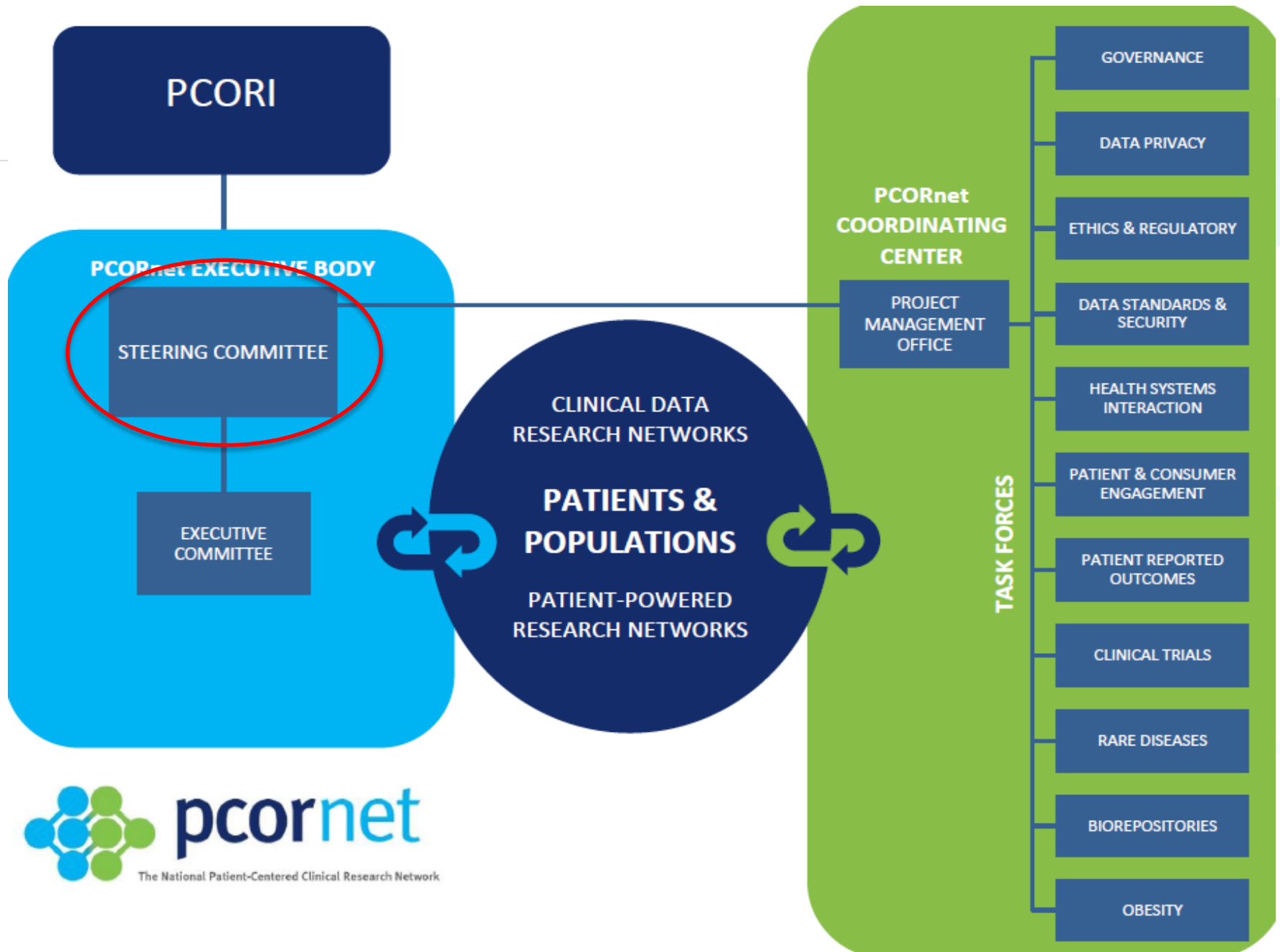
Organization	Condition	Proposed Pop
ALD Connect, Inc	Adrenoleukodystrophy	3,000
Arbor Research Collaborative for Health	Primary Nephrotic Syndrome (Focal Segmental Glomerulosclerosis), Minimal Change Disease, and Membranous Nephropathy, Multiple Sclerosis	1,250
Duke University	Juvenile Rheumatic Disease	9,000
Epilepsy Foundation	Aicardi Syndrome, Lennox-Gastaut Syndrome, Phelan-McDermid Syndrome, Hypothalamic Hamartoma, Dravet Syndrome, and Tuberous Sclerosis	1,500
Genetic Alliance, Inc	Alström syndrome , Dyskeratosis congenital, Gaucher disease, Hepatitis, Inflammatory breast cancer, Joubert syndrome, Klinefelter syndrome and associated conditions, Metachromatic leukodystrophy, Pseudoxanthoma elasticum (PXE), Psoriasis	50- 50,000
Immune Deficiency Foundation	Primary Immunodeficiency Diseases	1,250
Parent Project Muscular Dystrophy	Duchenne and Becker muscular dystrophy	4,000
Phelan-McDermid Syndrome Fndn	Phelan-McDermid Syndrome	737
University of Pennsylvania	Vasculitis	500

9 Patient Powered Research Networks *in “non rare” conditions*

Organization	Condition	Proposed Population
Accelerated Cure Project for Multiple Sclerosis	Multiple Sclerosis	20,000
Amer Sleep Apnea Association	Sleep Apnea	50,000
Cincinnati Children's Hospital Medical Center	Pediatric Crohn's Disease and Ulcerative Colitis	15,000
COPD Foundation	Chronic Obstructive Pulmonary Disease	50,000
Crohn's and Colitis Foundation of America	Inflammatory Bowel Disease (Crohn's disease and ulcerative colitis)	30,000
Global Healthy Living Foundation	Arthritis (rheumatoid arthritis, spondyloarthritis), musculoskeletal disorders (osteoporosis), and inflammatory conditions (psoriasis)	50,000
Massachusetts General Hospital	Major Depressive Disorder (MDD) and Bipolar Disorder (BP)	50,000
Univ of California, San Francisco	Cardiovascular health	100,000
University of South Florida	Hereditary Breast and Ovarian Cancer (HBOC)	17,000

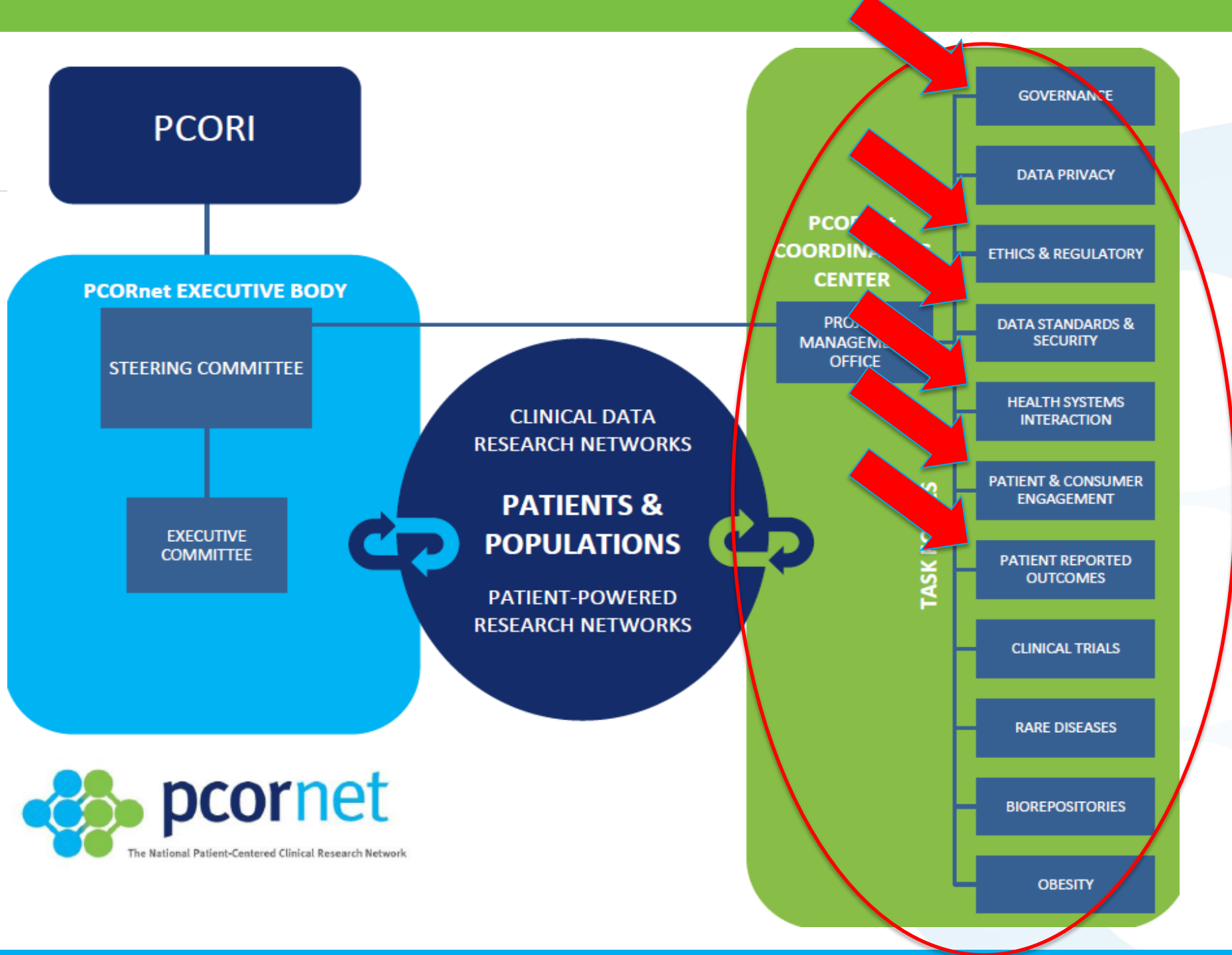
Patient Powered Research Networks' Highlights

- Variety of **stakeholders** in leadership: patients, advocacy groups, physician organizations, academic centers, PBRNs etc.
- Strong understanding of **patient engagement**
- Significant range of **conditions and diseases**
- Variety in **populations** represented (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**



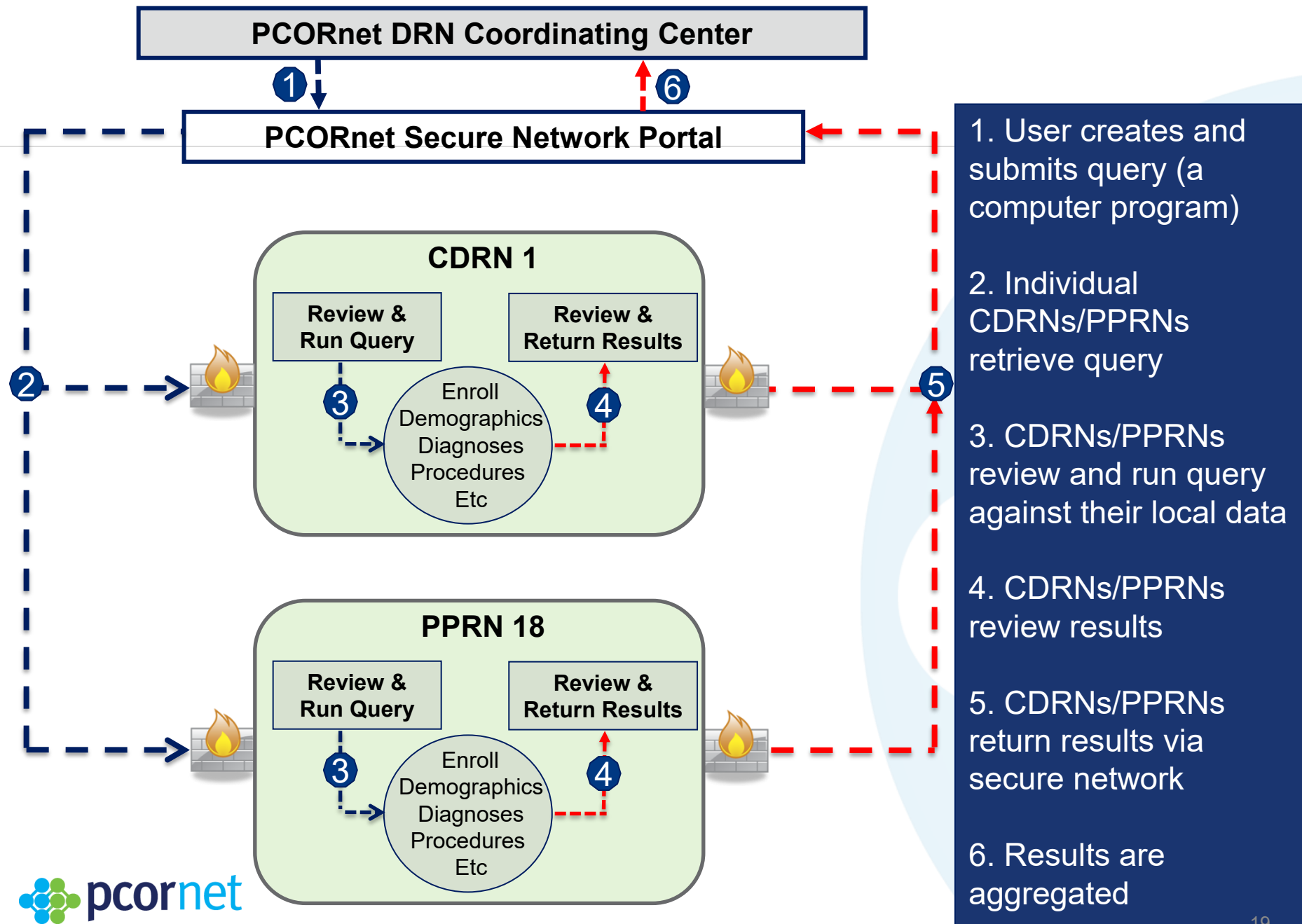
PCORnet Steering Committee

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



Distributed data / distributed analysis

- ⚙ Data partners keep and analyze their own data
- ⚙ Standardize the data using a common data model
- ⚙ Distribute code to partners for local execution
- ⚙ Provide results, not data, to requestor
- ⚙ All activities audited and secure



PCORnet DRN Operations Center

Reporting

Project
Management

Policies and
Procedures

Query
Fulfillment

ETC...

PCORnet DRN Secure Portal

Knowledge Management System

Cross project lessons learned, query tracking, meta-data capture, search functions, etc

Projects

Utilization trends

Observational studies

Pragmatic and clinical trials

Analytic Tools

Modular programs

Summary tables

Query interface

Menu-driven query

Data checking tools

Reporting tools

Administration

Security \ Access control

File \ Query repository

User administration

Workflow management

CDRN 1

CDRN 2

CDRN 11

PPRN 1

PPRN 2

PPRN 18

Other data
resources

Mini-Sentinel Operations Center

Reporting

Project
Management

Policies and
Procedures

Query Fulfillment

ETC...

Mini-Sentinel Secure Portal

Knowledge Management System

Cross project lessons learned, query tracking, meta-data capture, search functions, etc

Projects

Protocol based assessment

Response to regulation

Methods evaluation

Analytic Tools

Modular programs

Summary tables

Query interface

Menu-driven query

Data checking tools

Reporting tools

Administration

Security \ Access control

File \ Query repository

User administration

Workflow management

Mini-Sentinel
Site 1

Mini-Sentinel
Site 3

Mini-Sentinel
Site 5

Mini-Sentinel
Site 7

Mini-Sentinel
Site 9

...

Mini-Sentinel
Site 17

Mini-Sentinel
Site 2

Mini-Sentinel
Site 4

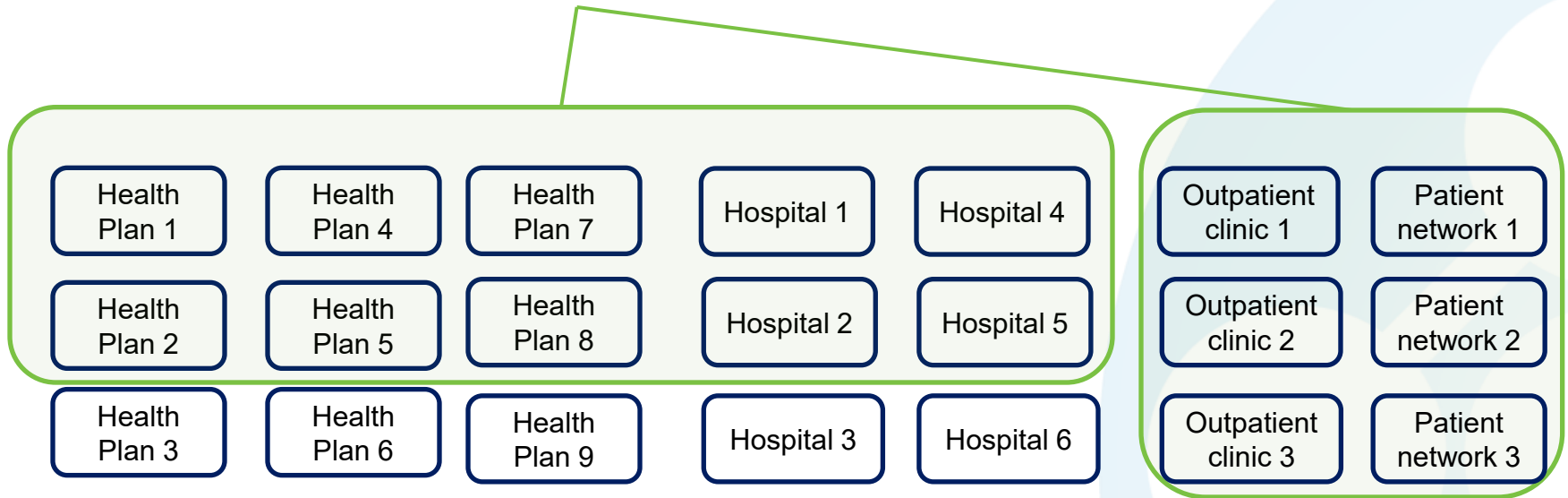
Mini-Sentinel
Site 6

Mini-Sentinel
Site 8

Mini-Sentinel
Site 10

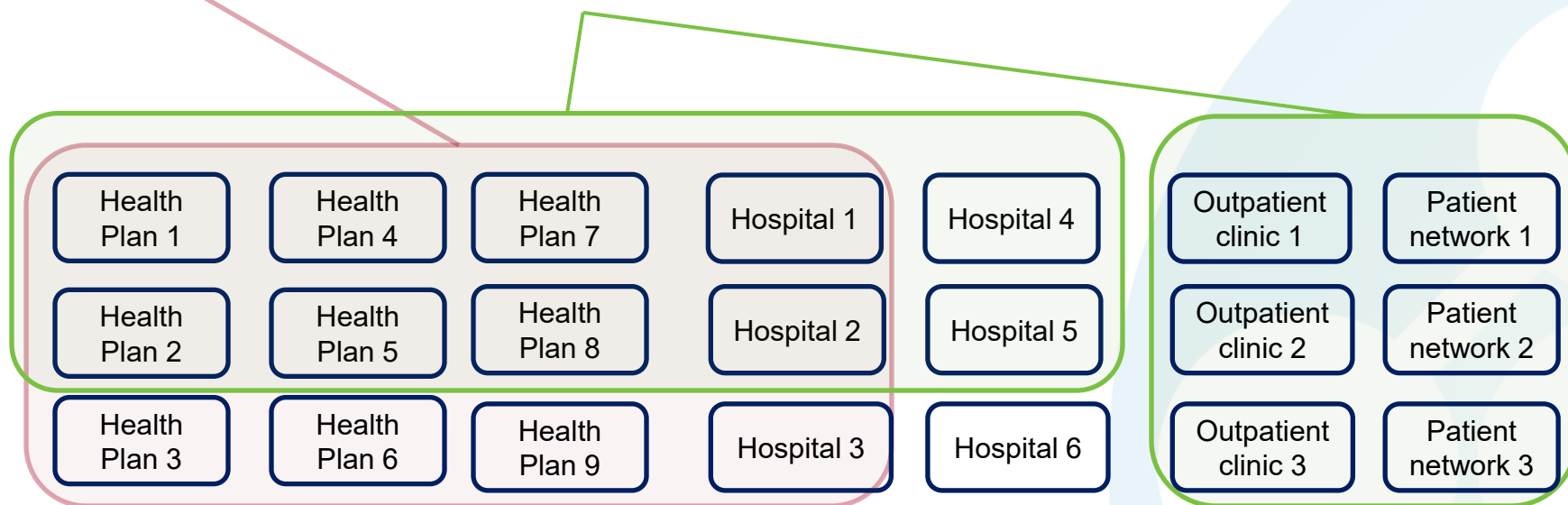
Mini-Sentinel
Site 18

Multiple Networks Sharing Infrastructure

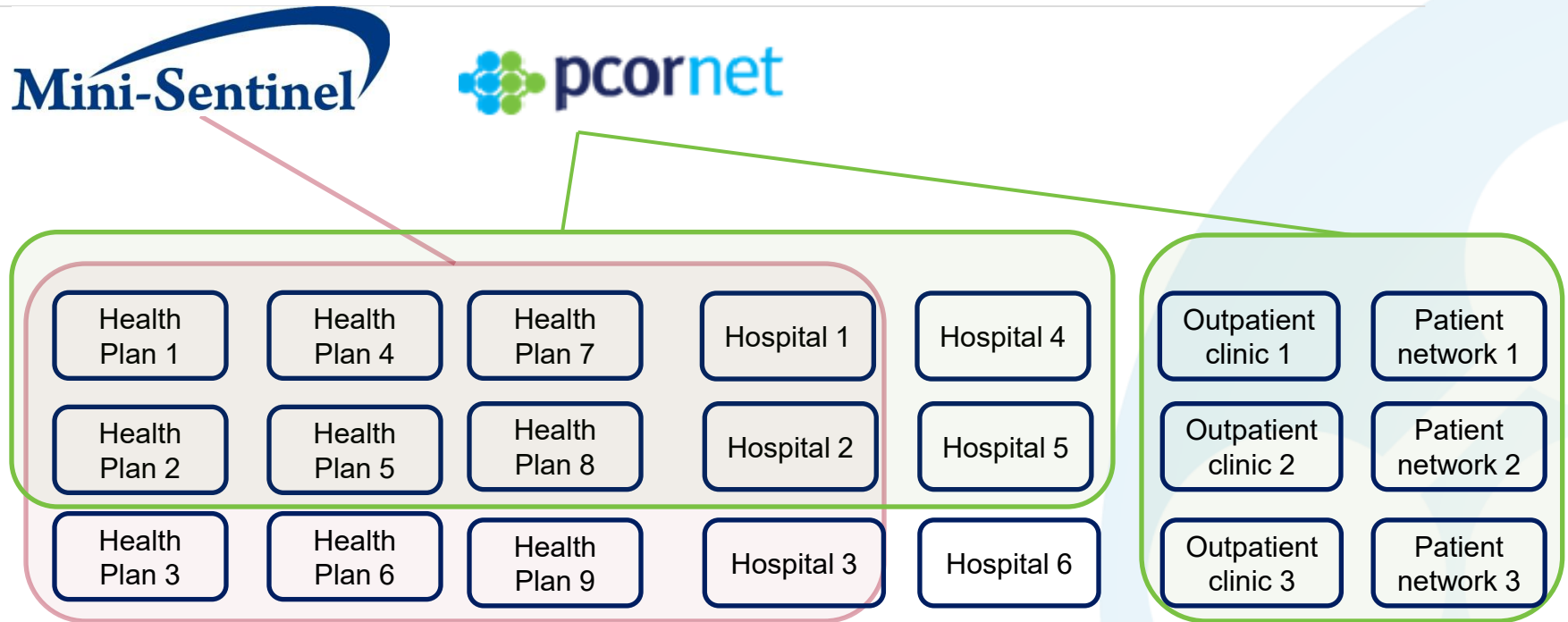


Multiple Networks Sharing Infrastructure

Mini-Sentinel



Multiple Networks Sharing Infrastructure



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



NIH Collaboratory

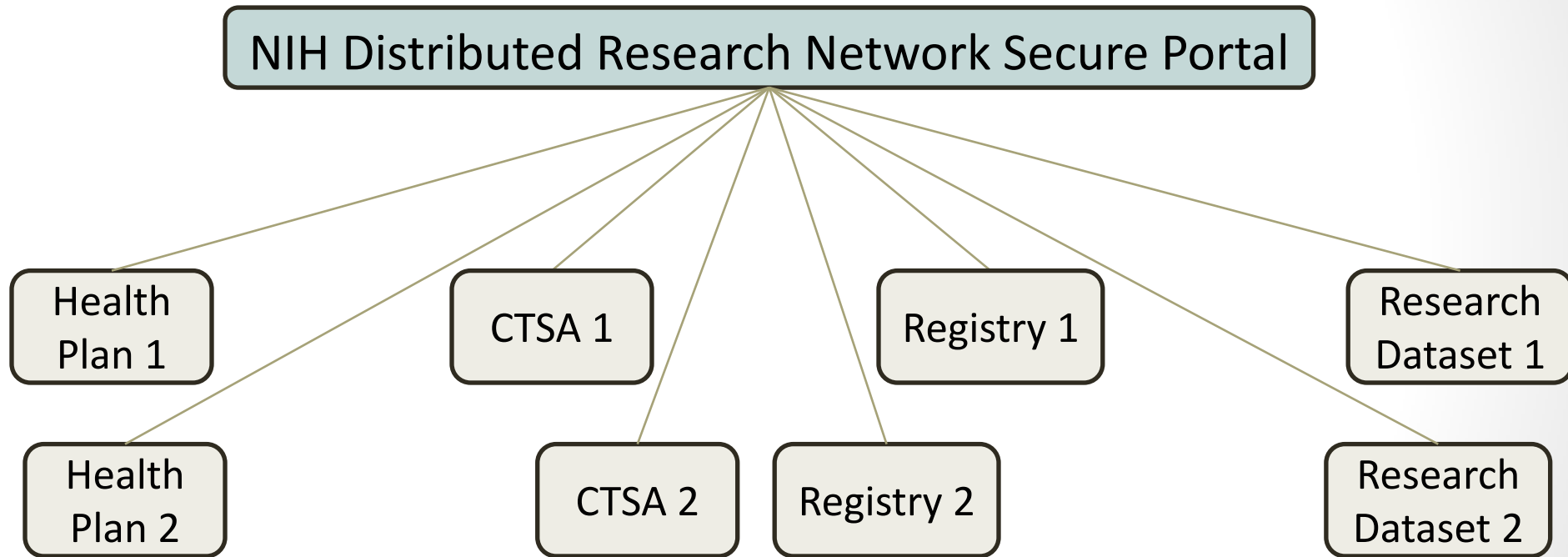
Health Care Systems Research Collaboratory

The NIH Collaboratory Distributed Research Network: Making NIH investigators PCORnet-ready

Millions of people. Strong collaborations. Privacy first.

Vision for the Network:

Many types of organizations and data



Not the goal



We will **not** create a new stand-alone network with its own research agenda or content experts



Investigators will **not** have access to data without data partners' active engagement

NIH Distributed Research Network Coordinating Center

Network
Management

Query
Support

Knowledge
Database

Project
Management

Consultation

Research
Support

Query Tool
Development

Software
Development

Data Models
& Standards

Health System
Expertise

NIH DRN Secure Portal

Knowledge Management System

Cross project lessons learned, query tracking, meta-data capture, search functions, etc

PROJECTS

Feasibility

LIRE

Other projects

Query Tools

Modular Programs

Summary Tables

Query Interface

SAS, SQL,
menu-driven

Analytic Tools

Reporting Tools

Administration

Security & Access Control

File & Query Repository

User Administration

Workflow Management

Mini-Sentinel A

CTSA 1

Registry 1

Medical Practice 1

Medical Practice 2

Research dataset 1

Mini-Sentinel B

CTSA 2

Registry 2

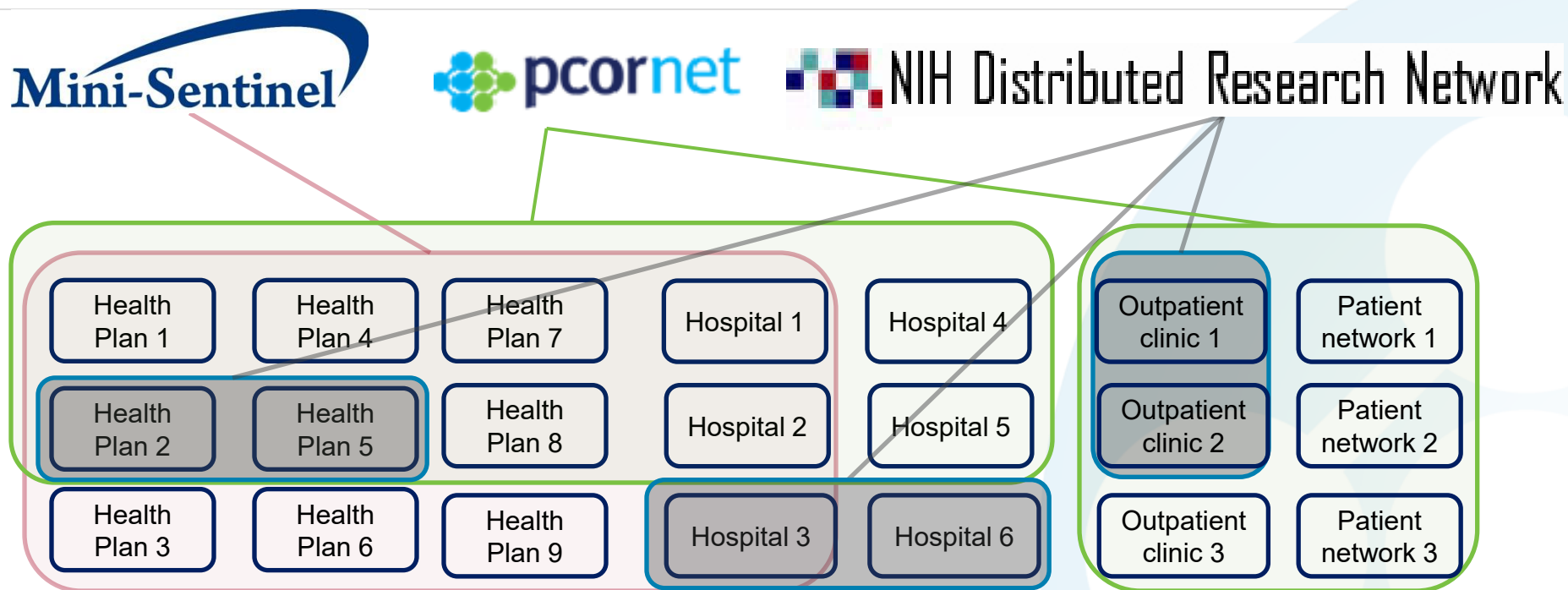
Hospital 1

Hospital 1

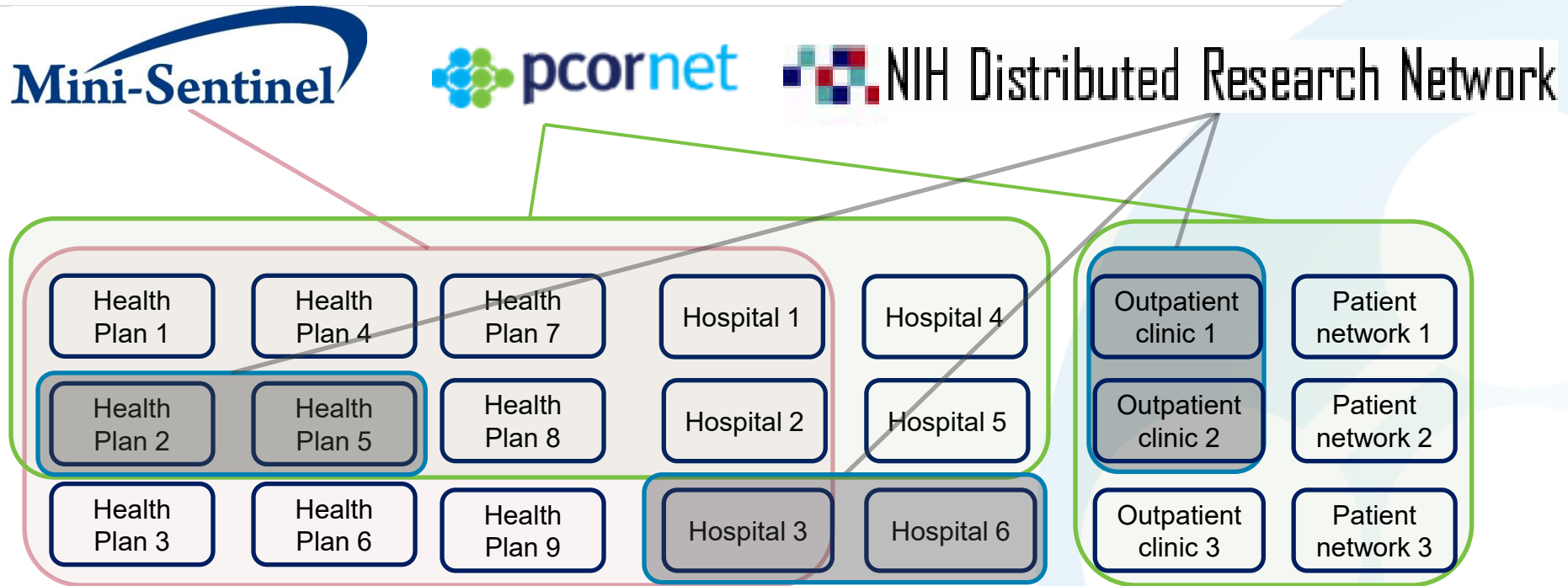
Research dataset 2



Multiple Networks Sharing Infrastructure



Multiple Networks Sharing Infrastructure



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

NIH Distributed Research Network

Millions of people. Strong collaborations. Privacy first.

The NIH Distributed Research Network enables investigators to collaborate with each other in the use of electronic health data, while also safeguarding protected health information and proprietary data. It supports both single- and multisite research programs.

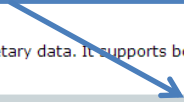
The Network's querying capabilities reduce the need to share confidential or proprietary data by enabling authorized researchers to send queries to collaborators holding data (i.e., data partners). In some cases, queries can take the form of computer programs that a data partner can execute on a preexisting dataset. The data partner can return the query result, typically aggregated (count) data, rather than the data itself. This form of remote querying reduces legal, regulatory, privacy, proprietary, and technical barriers associated with data sharing for research.

The network seeks to build strong and trusted collaborations to support the research that will lead to improved health for millions of people around the world.

What does the NIH Distributed Research Network do?

- Provides infrastructure and mechanisms to facilitate multicenter studies using electronic clinical, administrative, and research data
- Allows searchable discovery of available data resources, health systems, researchers, and re-usable analytic tools
- Enables authorized investigators to identify clinical, administrative, and research datasets of interest
- Facilitates multisite distributed querying of data resources, while allowing the data to remain in the control of the data owners
- Serves as a repository of tools to leverage EHRs to support clinical research across multiple health systems

“DRN Governance Document”



[DRN Governance Document, v1.0](#)

To learn more about the NIH Distributed Research Network

info@NIHquery.org



The goal

Facilitate multi-site research collaborations between investigators and data partners by creating secure networking capabilities and analysis tools for electronic health data

Use cases

- Assess disease burden/outcomes
- Pragmatic clinical trial design
- Single study private network
- Pragmatic clinical trial follow up
- Reuse of research data

Use case: Assess disease burden/outcomes

- A program officer wants to characterize the use bisphosphonates and the occurrence of fractures
- The Collaboratory networking center uses pre-existing (“canned”) programs to query electronic data from millions of people to assess:
 - Frequency of use
 - Characteristics of the users (age, sex, prior treatment history)
 - Frequency of selected outcomes before and after initiation of use

Use case: Pragmatic clinical trial design

- Investigators planning a multi-center pragmatic trial of bisphosphonate therapy want to assess the feasibility of embedding a clinical trial in care settings
- The Collaboratory networking center queries electronic health data to :
 - Assess baseline hospitalization rate fractures, and the rate of fractures among those patients, stratified by risk factors of interest.
 - If the trial involves two regimens already in use, create propensity score matched estimates of the outcomes of the two regimens.
 - Identify organizations with enough potential study participants
 - Identify potential study participants and their providers – all identifiable information stays with the host organization

Use case: Pragmatic clinical trial follow up

- Investigators conducting a multi-center pragmatic trial of bisphosphonate treatment want to simplify follow up
- The Collaboratory networking center supports clinical organizations' periodic scans of their electronic data covering study participants to identify
 - Dispensing of prescription medications, including dates, names, and amounts dispensed
 - All inpatient and ambulatory medical encounters, with dates and diagnoses and procedures

Use case: Reuse of research data

- A clinically rich research dataset of patients with incident hypertension contains longitudinal records of all blood pressure measurements, BMI, medical utilization, diagnoses, treatments, and laboratory test results
- The data steward uses the Collaboratory's networking capability to allow an investigator at another organization to submit analytic programs
- The output does not contain direct identifiers

Use case: Single study private network

- A multi-center pragmatic trial team wants to create a pooled final analysis data file
- The Collaboratory networking center establishes a private distributed network
 - To distribute programs that create separate analysis files at each site
 - To securely transfer the analysis files to the analyst

Current partners

- Aetna
- Group Health Research Institute
- Harvard Pilgrim Health Care
- HealthCore
- Humana
- Optum
- HealthPartners Institute for Education and Research
- MURDOCK Study Registry and Biorepository

Approximately 40 million current members



[Home](#) | [JOIN NOW!](#) | [About the Study](#) | [Current Studies](#) | [Services and Capabilities](#) | [Events](#) | [Volunteer](#) | [Meet the Team](#) | [Resources & News](#)

FACES OF THE MURDOCK STUDY



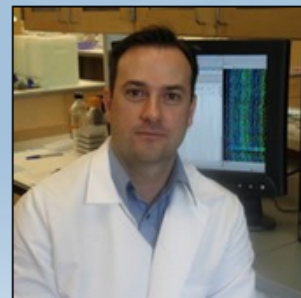
Join us in improving the health of our community. More than 10,000 residents of Kannapolis, Cabarrus County and the surrounding region are already involved!

Tony Nunes, avid supporter and participant of the MURDOCK Study, pictured above. [Learn more about his experience with the MURDOCK Study...](#)

[Click here to learn more!](#)

Greetings! Welcome to the MURDOCK Study website!

We are excited to announce our extension of recruitment efforts for the **MURDOCK Study Multiple Sclerosis Cohort** to individuals with Primary Progressive Multiple Sclerosis (PPMS). PPMS is a subtype of MS that accounts for about 10% of MS diagnoses. Unlike other MS disease subtypes, known as Relapsing Remitting MS (RRMS) or Secondary Progressive MS (SPMS), individuals with PPMS are affected by disability from the onset of their MS with no or minor remissions or improvement in symptoms. Unfortunately, no treatment has proven successful yet for PPMS patients. [Read more...](#)



Announcements

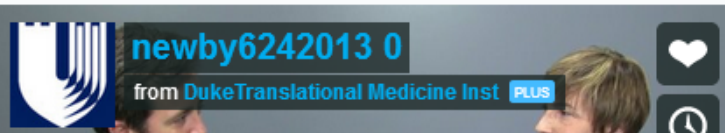
Now Hiring!

The MURDOCK Study is interested in hiring a data technician to be based in the Duke-Kannapolis office. [Please click here to read the job description.](#)

Physical Performance Study (PPS) Expands Its Eligibility

Dr. Newby discusses MURDOCK recruitment


MURDOCK Study Looking for a Few Good Men!



Current status

- Functional secure network with distributed querying capabilities
- Approved governance document
- Completed pilot project for querying i2b2 data repositories
- Actively adding new HMORN partners
- Developing cost estimates to establish ongoing querying capability for NIH institutes
- Enhanced meta-data capture and querying to enable “match-making” searches

Institutional Metadata



NIH Health Care System Collaboratory Distributed Research Network

Welcome, jbrown

HomeRequestsProfileResourcesReportsNetworkContact UsLogoff

NetworkOrganizationsHPHC

Organization Information

Name	Acronym	Parent	
Harvard Pilgrim Health Care	HPHC	<none> [x]	
Contact First Name	Contact Last Name	Contact Phone	Contact Email
Jeffrey	Brown	617 509 9986	jeff_brown@hphc.org

Health Plan/Health System Description

Harvard Pilgrim is a full-service health benefits company serving members throughout Massachusetts, New Hampshire, Maine and beyond. Our mission is to improve the quality and value of health care for the people and communities we serve. Harvard Pilgrim's provider network is extensive and includes physicians who practice in a variety of settings, including individual practices, small medical groups and large multi-specialty groups. Harvard Pilgrim has a growing network of over 135 hospitals and 28,000 doctors and clinicians.

Collaboration Requirements and Additional Information

HPHC is open to collaboration on observational and prospective research. All research must include an HPHC Institute (HPHCI) Department of Population Medicine (DPM) research collaborator. HPHC does not sell data. HPHC has a research data warehouse that can be augmented with state registry data and linked to EHR data.

Research Capabilities

Research is conducted by the HPHC Institute (HPHCI) Department of Population Medicine (DPM). DPM is a Harvard Medical School department affiliated with the HPHCI. We have expertise across a range of clinical areas and topics, including medical product safety surveillance, public health surveillance, drug policy, child health studies, and obesity prevention. We manage several distributed health data networks, include FDA Mini-Sentinel, NIH Health Care Systems Research Collaboratory DRN, MDPHnet, and the PCORnet. We also are a member of the HMO Research Network. More info here: www.populationmedicine.org

Institutional Metadata 2

Willing to participate in:		
<input checked="" type="checkbox"/> Observational Research	<input type="checkbox"/> Prospective Trials	
Type of Data Collected		
<input type="checkbox"/> None	<input checked="" type="checkbox"/> Enrollment	<input checked="" type="checkbox"/> Other
<input checked="" type="checkbox"/> Inpatient	<input checked="" type="checkbox"/> Demographics	<input type="text" value="Cancer registry"/>
<input checked="" type="checkbox"/> Outpatient	<input type="checkbox"/> Laboratory Results	
<input checked="" type="checkbox"/> Pharmacy	<input type="checkbox"/> Vital Signs	
Electronic Health Records System Used		
Inpatient	Outpatient	
<input type="text" value="None"/>	<input type="text" value="None"/>	
Data Models		
<input checked="" type="checkbox"/> MSCDM	<input type="checkbox"/> ESP	<input type="checkbox"/> Other
<input checked="" type="checkbox"/> HMORN VDW	<input type="checkbox"/> i2b2	

Current data and functionality

- Routinely updated and quality-checked data
- Over 90 million covered lives
 - Complete data capture for defined intervals
 - Inpatient and outpatient encounters, diagnoses, procedures
 - Outpatient pharmacy dispensings
 - Demographics
- Mini-Sentinel common data model
- Functionality includes
 - Simple queries of pre-compiled frequencies
 - Standardized queries of person-level data

The Network is Research Ready

- For observational studies – including studies requiring full text records



The NEW ENGLAND JOURNAL of MEDICINE

ORIGINAL ARTICLE

Intussusception Risk after Rotavirus Vaccination in U.S. Infants

W. Katherine Yih, Ph.D., M.P.H., Tracy A. Lieu, M.D., M.P.H., Martin Kulldorff, Ph.D.,
David Martin, M.D., M.P.H., Cheryl N. McMahon-Walraven, M.S.W., Ph.D.,
Richard Platt, M.D., Nandini Selvam, Ph.D., M.P.H., Mano Selvan, Ph.D.,
Grace M. Lee, M.D., M.P.H., and Michael Nguyen, M.D.

Epub: January 14, 2014

The Network is Research Ready

- For observational studies – including studies requiring full text records
- For interventional studies – both individually and cluster randomized



Potential Next Steps

- NIH Institutes can use the existing resources to:
 - Plan program announcements
 - Develop research partnerships
- NIH Investigators can use the existing resources to:
 - Perform prepratory-to-research analyses for observational and intervention studies
 - Conduct full observational analyses



Three use cases from Mini-Sentinel/CTTI

- IMPACT Atrial Fibrillation Cluster Randomized Trial
 - Primary Aim: Determine whether a multilevel educational intervention will increase the rate of initiation of oral anticoagulants among patients with atrial fibrillation
 - Cluster randomized trial of 2,800 patients
- The Torsemide Risk Reduction versus Furosemide In Cardiac Insufficiency Trial (TERRIFIC)
 - Primary Aim: Compare the treatment strategy of torsemide versus furosemide on clinical outcomes in HF patients at high risk for clinical events
 - Cluster randomized trial of 6,200 patients
- Effectiveness of Discontinuing Bisphosphonates (EDGE)
 - Primary Aim: Evaluate the impact of a continuation versus discontinuation of alendronate on non-vertebral fracture.
 - Individually randomized trial of 8,500 patients



Effectiveness of Discontinuing bisphosphonates (EDGE)*

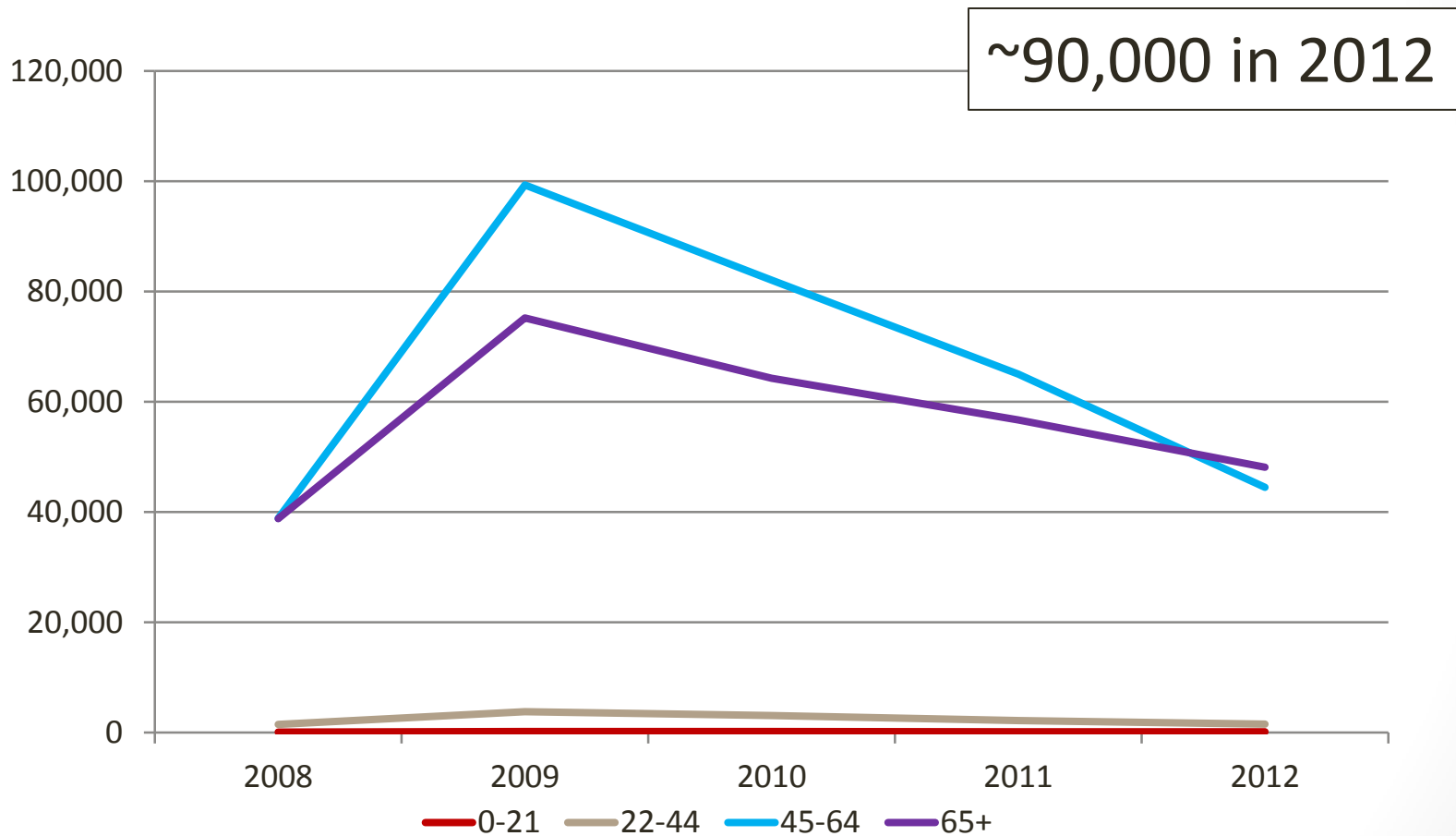
- Rationale: Benefits may decline and risks may increase over time
- Objectives: Assess outcome of longer vs shorter duration treatment
- Intervention: Discontinuation of treatment
- Eligible population: Women taking alendronate for 3-5 years
- Primary outcome: Non-vertebral fracture within 3 years of randomization
- Secondary outcomes: hip fracture, osteonecrosis of the jaw, atypical femoral fracture, esophageal cancer
- Design: Individual RCT with informed consent

Rationale:	Optimal duration of bisphosphonate treatment for osteoporosis is unknown. Prolonged treatment may increase risks that exceed benefits.
Primary Objective:	Assess impact on major non-traumatic fractures of continuation vs discontinuation of bisphosphonate therapy among women treated for at least 3 years.
Secondary Objectives	Compare bisphosphonate associated adverse event rates among those who continue vs those who discontinue.
Study Design:	Individual RCT with informed consent
Intervention	Randomization to continuation or discontinuation
Primary Endpoint:	The rate of hospitalization for any major non-traumatic bone fracture
Secondary Endpoints:	All-cause mortality, Minor fractures, Adverse events
Key Inclusion Criteria:	1.Age ≥ 18 , 2.Prior history of osteoporosis 3.Currently treated with alendronate for 3-5 years
Key Exclusion Criteria:	1.None
Abbreviated Study Flow:	1. Patients meeting eligibility criteria will be randomized to withdrawal of bisphosphonate or continuation 2. Follow-up per routine clinical care
Sample size:	8,500

Use case: Assess disease burden/outcomes

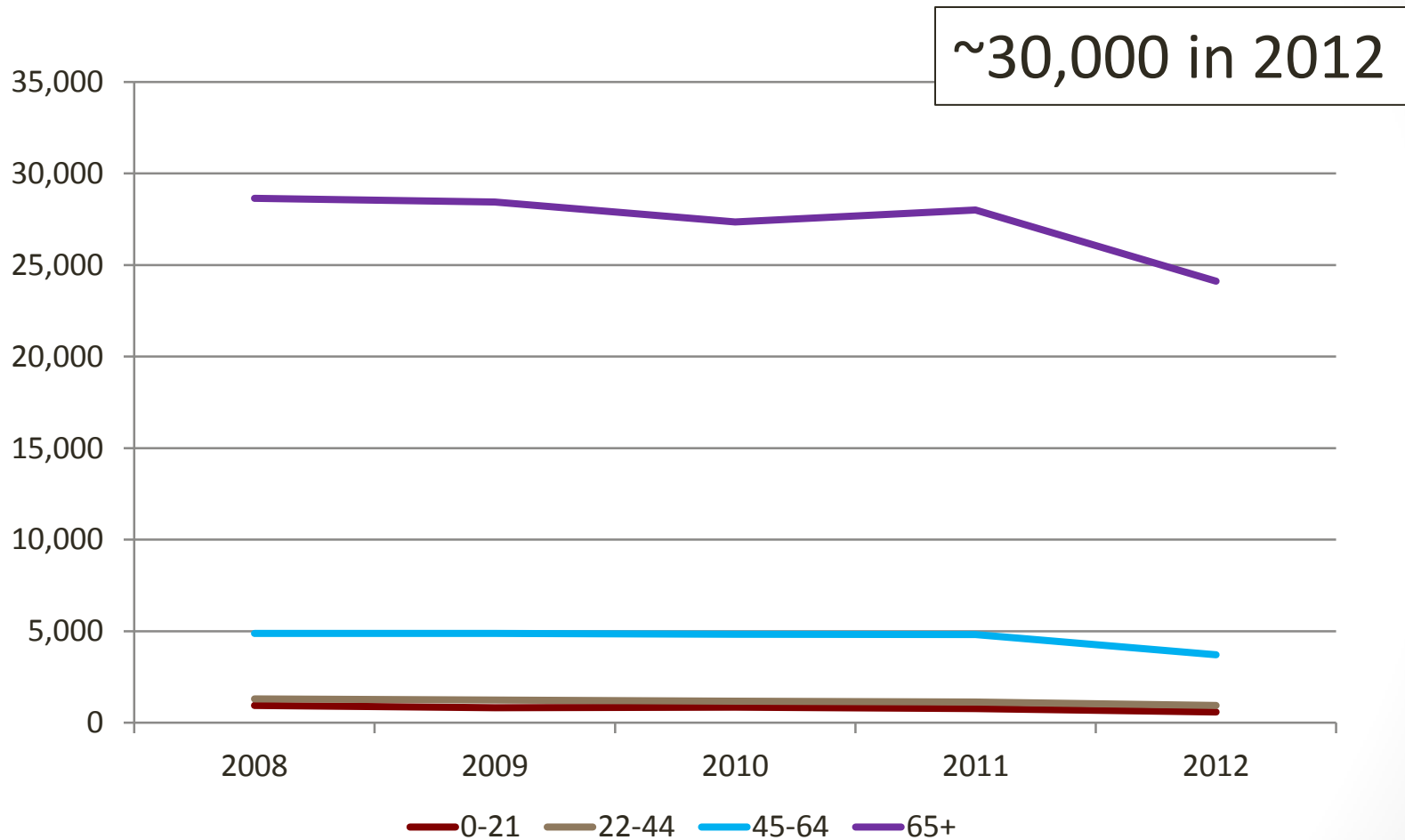
- A program officer wants to characterize the use bisphosphonates and the occurrence of fractures
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 - Frequency of use
 - Characteristics of the users (age, sex, prior treatment history)
 - Frequency of selected outcomes before and after initiation of use

Alendronate users by year and age group*



* Incident users based on a 90-day wash-out period

Hip fracture*



*Prevalence

Use case: Pragmatic clinical trial design

- Investigators planning a multi-center pragmatic trial of bisphosphonate therapy want to assess the feasibility of embedding a clinical trial in care settings
- The Collaboratory networking center queries electronic health data to :
 - Assess baseline hospitalization rate fractures, and the rate of fractures among those patients, stratified by risk factors of interest.
 - If the trial involves two regimens already in use, create propensity score matched estimates of the outcomes of the two regimens.
 - Identify organizations with enough potential study participants
 - Identify potential study participants and their providers – all identifiable information stays with the host organization

Standardized query of patient-level data

Validated SAS programs with flexible inputs for exposure, outcome, and other settings

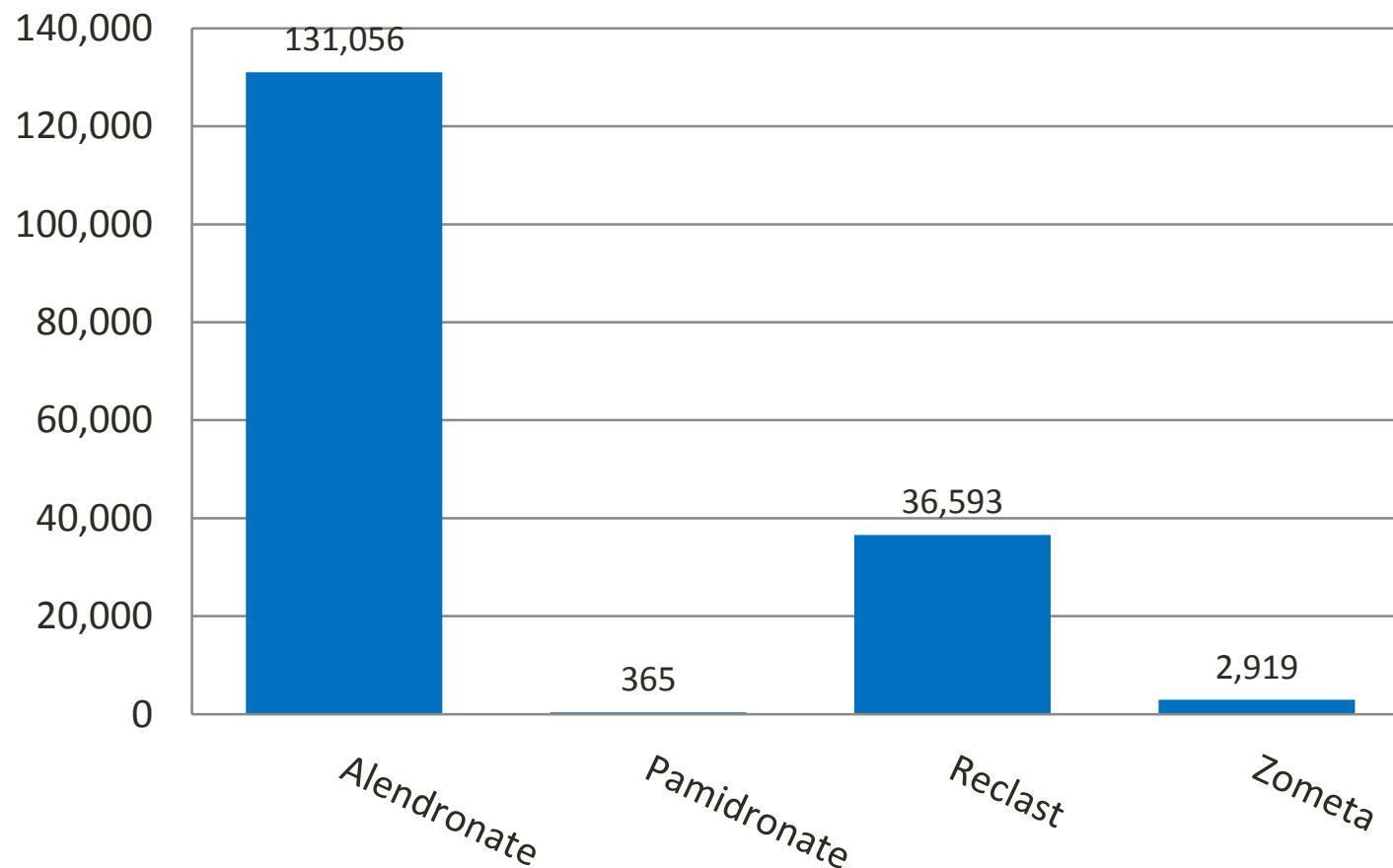
Key specifications of standardized query

- Define cohort
- Define incident user
- Define incident events
- Query period
- Age range
- Continuous enrollment gap
- Coverage (medical and drug) requirements

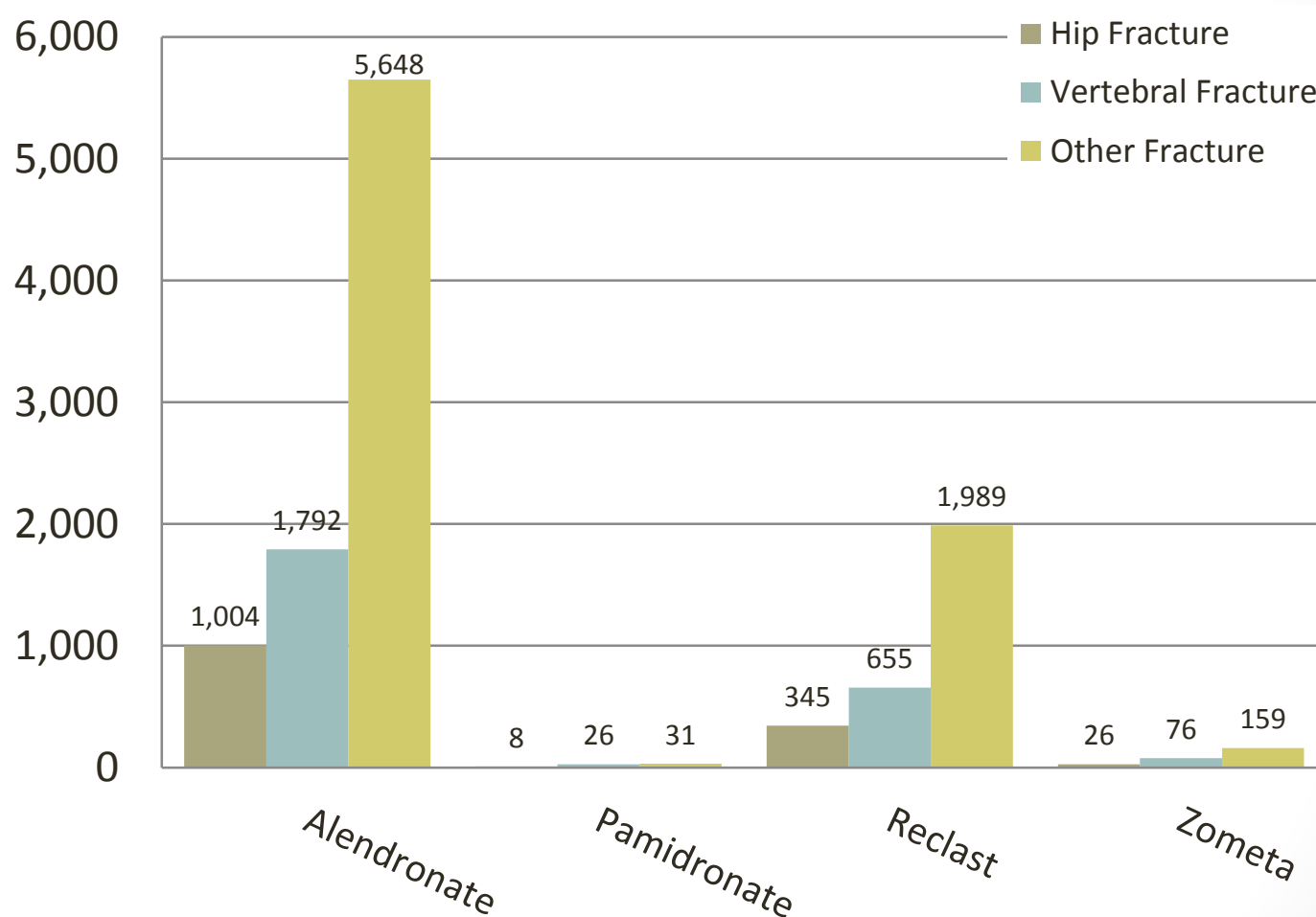
Specifications for bisphosphonate request

- **Cohort:** Members 40+ years old with an osteoporosis diagnosis and no fractures in the 365 days before new use
- **Incident exposure:** New users of ANY of the 4 bisphosphonates based on a 365 day wash-out period
- **At risk period:** 365 days after incident exposure
- **Incident outcome:** Observed fracture (hip, vertebral, non-hip/non-vertebral) in any care setting among new users
- **Query period:** January 1, 2008 - December 31, 2012
- **Age groups:** 40-54, 55-64, 65+ years
- **Continuous enrollment gap:** 45 days

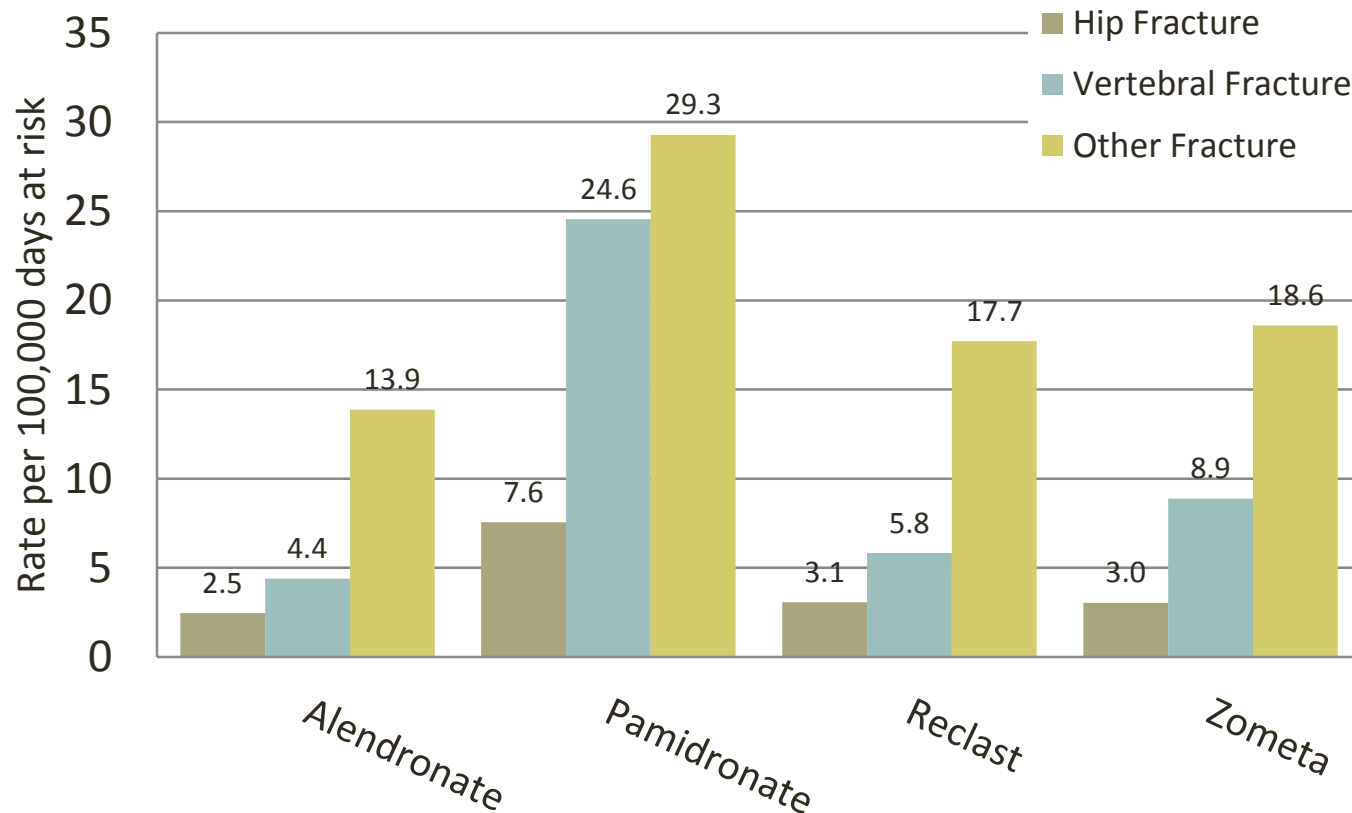
Incident users



Fractures among incident users



Fracture rate among incident users (per 100,000 days at risk)*



*Unadjusted

Caveats

- Data intended as an example of network capability
- Standard limitations of electronic health data
 - Use of diagnosis codes to identify osteoporosis and fractures
 - Codes not validated
 - Treatment indication not available
 - Privately insured population with stable enrollment
- Rates not adjusted

Clinical trials and complex observational studies

- Standardized programs inform development of full study protocols
- NIH DRN can support any analysis
- NIH DRN facilitates creation and use of pooled analytic datasets

Next steps

- Add most Kaiser Permanente and HMO Research Network plans
- Develop new querying and networking functionality
- Potential to expand to other data models
 - i2b2 networks
 - ESP networks
 - CTSAs
 - Registries
 - Others

The DRN is ready for NIH investigators to use

- Assess disease burden/outcomes
- Pragmatic clinical trial design
- Single study private network
- Pragmatic clinical trial follow up
- Reuse of research data

Thank You

For more information

- nihcollaboratory.org/Pages/distributed-research-network.aspx
- PopMedNet.org
- info@nihquery.org
- Jeff_brown@harvardpilgrim.org

Prior Grand Rounds

September 20, 2013

<https://www.nihcollaboratory.org/Pages/Grand-Rounds-09-20-13.aspx>

June 28, 2013

<https://www.nihcollaboratory.org/Pages/Grand-Rounds-06-28-13.aspx>

March 15, 2013

<https://www.nihcollaboratory.org/Pages/Grand-Rounds-03-15-13.aspx>