U.S. Department of Health & Human Services • National Institutes of Health

National Center for Complementary and Integrative Health

Perspectives from the NIH Healthcare Systems Research Collaboratory

FDA/UMD CERSI Workshop - March 24, 2016
Developing a National Resource for Evidence Generation

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NIH Health Care Systems Research Collaboratory Common Fund Program

- **Goal: To strengthen the national capacity to implement cost-effective large-scale research studies that engage health care delivery organizations as research partners.**

- **Aim: To provide a framework of implementation methods and best practices that will enable the participation of many health care systems in clinical research. Research conducted in partnership with health care systems is essential to strengthen the relevance of research results to health practice.**

NIH Collaboratory Distributed Research Network

Millions of people. Strong collaborations. Privacy first.

The NIH Collaboratory Distributed Research Network (DRN) 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 pre-existing 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.

On this page

What does the NIH Collaboratory Distributed Research Network do?

How does the network operate?

Who can submit a query/data request?

How do I submit a query/data request?

What datasets are available in the NIH Collaboratory Distributed Research Network?

How can my organization/network become a data partner?

What software platform does the network use?

What are the confidentiality and nondisclosure rules for data partners and DRN Coordinating Center staff?

Drs. Jeff Brown and Lesley Curtis explain the NIH Collaboratory Distributed Research Network.

Documents

NIH Collaboratory Distributed Research Network User's Guide

NIH Collaboratory DRN Request Form

DRN Governance

Recent Presentations

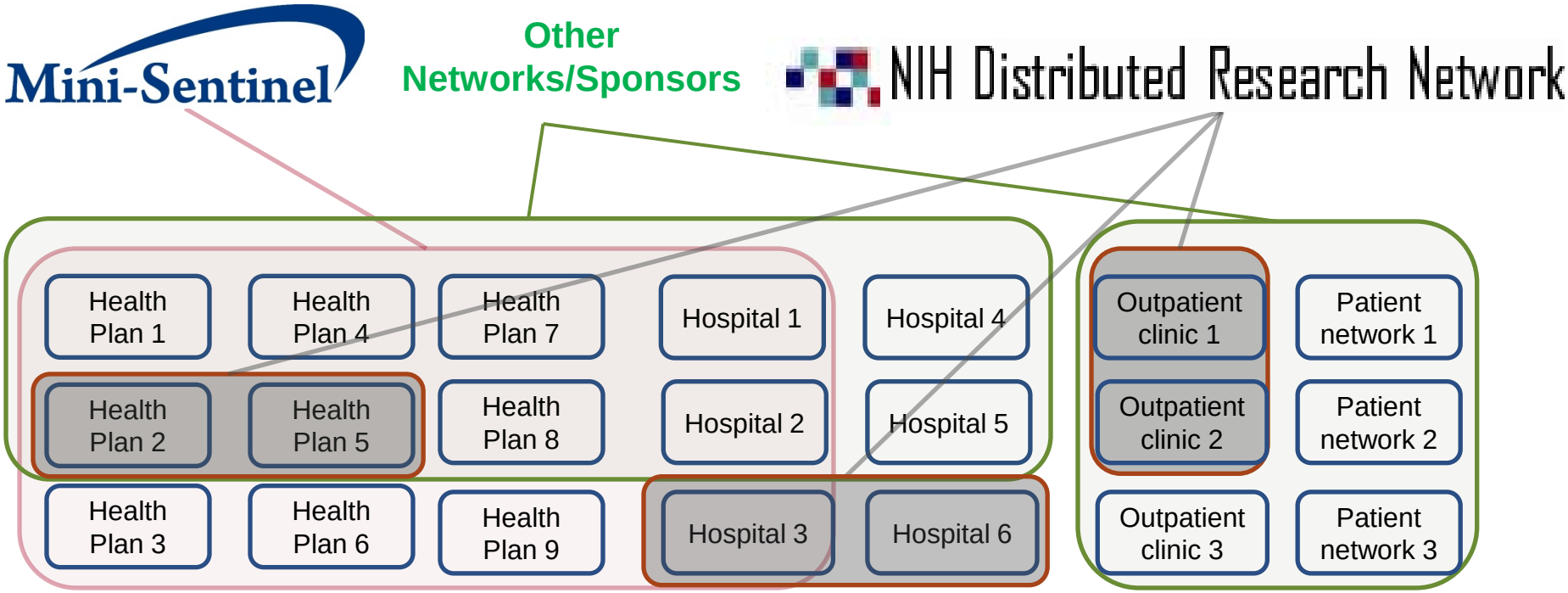
6/5/2015: Grand Rounds Presentation: NIH Collaboratory Distributed Research Network (Video; Slides)

11/14/2014: Grand Rounds Presentation: Using the NIH

Collaboratory DRN Data Partners

- Aetna
- Group Health Research Institutes
- Harvard Pilgrim Health Care Institute
- HealthCore, Inc.
- HealthPartners Institute for Education and Research
- Humana: Comprehensive Health Insights, Inc.
- Meyers Primary Care Institute
- The MURDOCK Study
- OptumInsight, Inc.
- Ochsner Health Systems

Sharing of Infrastructure

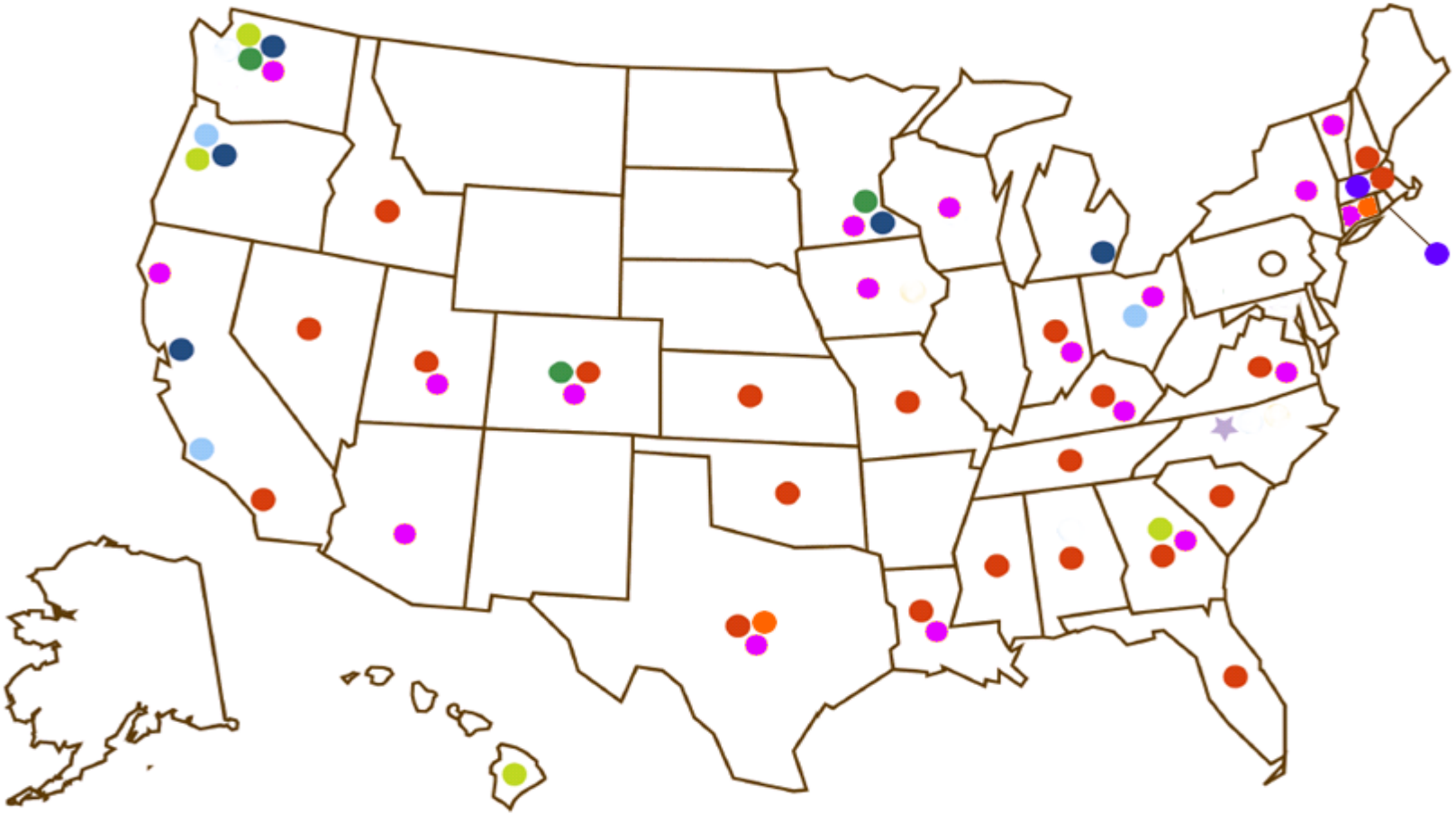


- Each organization can participate in multiple networks
- Each network controls its governance and coordination
- Networks share infrastructure, data curation, analytics, lessons, security, software development

NIH Collaboratory Coordinating Center (CCC)

- Provide national leadership and technical expertise in all aspects of research with health care systems
- Support the design and rapid execution of a set of high impact Pragmatic Trial Demonstration Projects conducted in partnerships with health care systems
- Make available data, tools and resources from these, and other, projects to facilitate a broadened base of research partnerships with health cares systems

NIH Health Care Systems Research Collaboratory



- Collaboratory Coordinating Center
- Suicide Prevention Outreach Trial (SPOT)
- Time to Reduce Mortality in End-Stage Renal Disease (TiME) (sites in dialysis units across the US)
- Trauma Survivors Outcomes & Support (TSOS)
- Lumbar Image Reporting and Epidemiology
- Strategies and Opportunities to Stop Colorectal Cancer (STOP CRC)
- Collaborative Care for Chronic Pain in Primary Care (PPACT)
- Active Bathing to Eliminate Infections (ABATE)
- Improving Chronic Disease Management with Pieces (ICD-Pieces)
- Pragmatic Trial of Video Education in Nursing Homes (PROVEN) (sites in nursing homes across the US)

NIH Collaboratory Demonstration Project HCS

- Group Health Cooperative
- Kaiser Permanente
- Mayo Clinic
- Henry Ford Health System
- HealthPartners Institute
- Parkland Heath System
- Texas Health Resources
- ProHealth CT
- Fresenius and DaVita Dialysis Corporations
- Hospital Corporation of America
- US Level 1 Trauma Care Centers
- Genesis Healthcare
- UHS Pruitt Corporation
- Oregon Community Health Information Network (FQHCs)
- North Texas VA

NIH Collaboratory
Demonstration Project Interventions

- Organizational change to patient care (e.g. dialysis time or new bathing protocol)
- Enhancing information available to providers in EHR to change care delivery
- Direct to patient screening kits, video education, or online intervention
- Enhanced coordination of care delivered to complex patients

Pragmatic Trial Demonstration Projects

- **Time to Reduce Mortality in End-Stage Renal Disease Trial - NIDDK**
- **Laura Dember, University of Pennsylvania**
  - **Fresenius Medical Care North America**
  - **DaVita**
- **CRT – 402 HD units, ~6,400 patients**

Pragmatic Trial Demonstration Projects

- **A Pragmatic Trial of Lumbar Image Reporting with Epidemiology – NIAMS & NCCIH**
- **Jeffrey Jarvik, University of Washington**
  - **Kaiser Permanente of Northern California**
  - **Group Health Cooperative, Seattle, WA**
  - **Mayo Clinic, Rochester, MN**
  - **Henry Ford Health System, Detroit, MI**
- **CRT (stepped wedge design) – 100 sites, practitioners, ~270,000 patients**
- **Began April 2014 (currently with 98 sites/150,000 patients)**

Pragmatic Trial Demonstration Projects

- **Strategies and Opportunities to Stop Colon Cancer in Priority Populations - NCI**
- **Gloria Coronado, Kaiser Foundation Hospitals**
- **Oregon Community Health Information Network (OCHIN)**
  - **Federally Qualified Health Center Clinics in OR & CA**
- **CRT – 26 clinics, ~32,000 patients**

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- Support the design and rapid execution of a set of high impact Pragmatic Trial Demonstration Projects conducted in partnerships with health care systems
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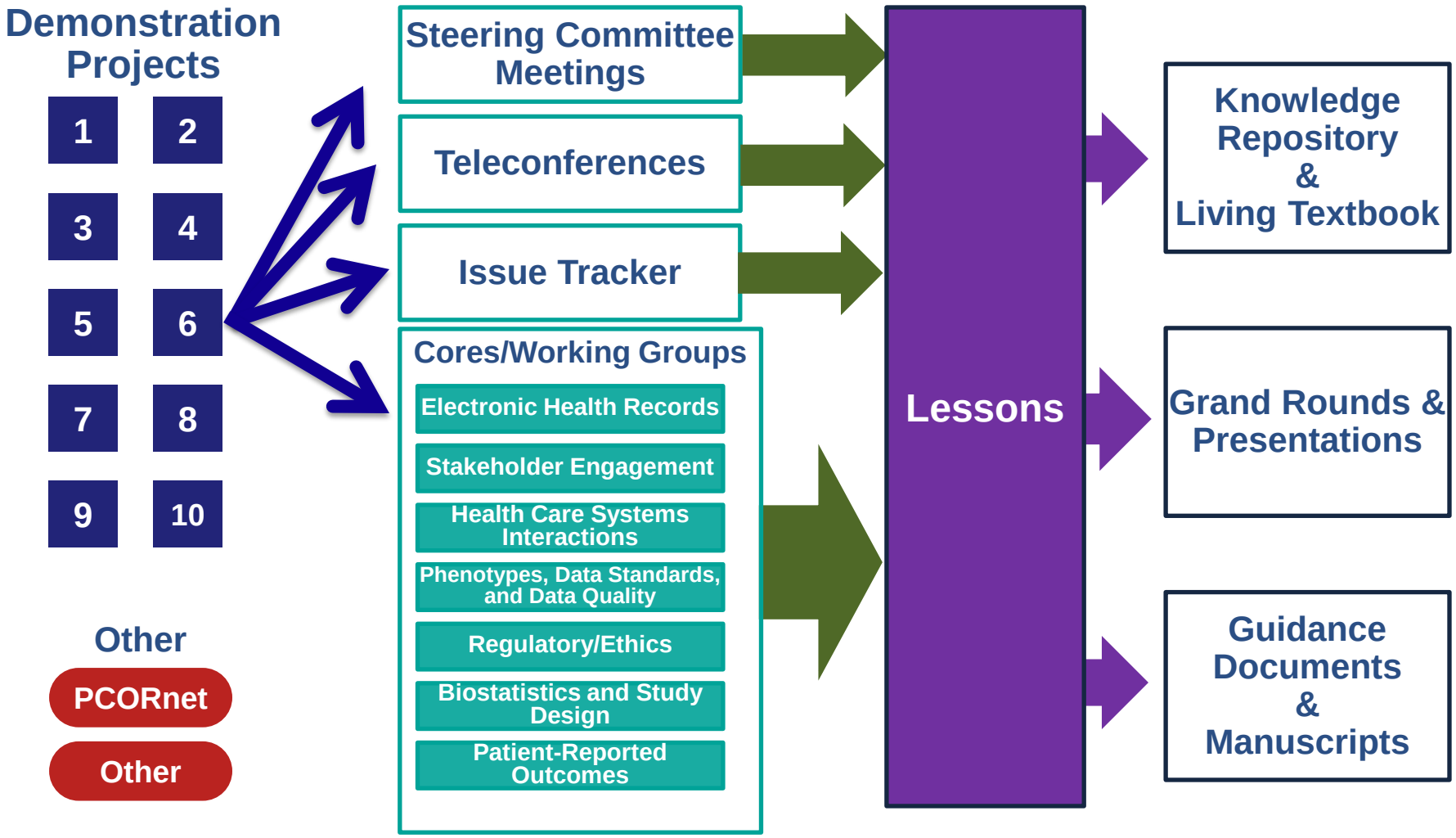
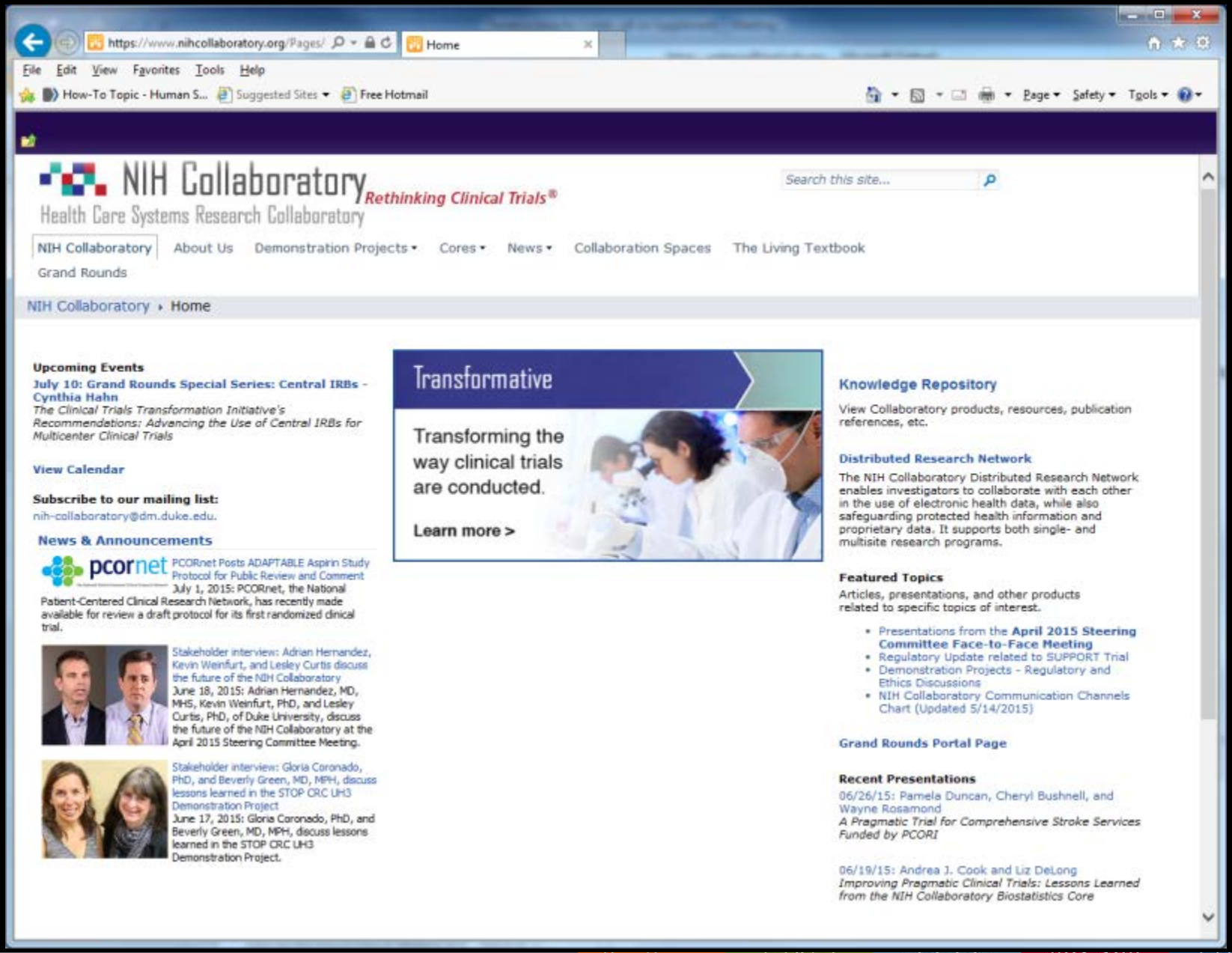
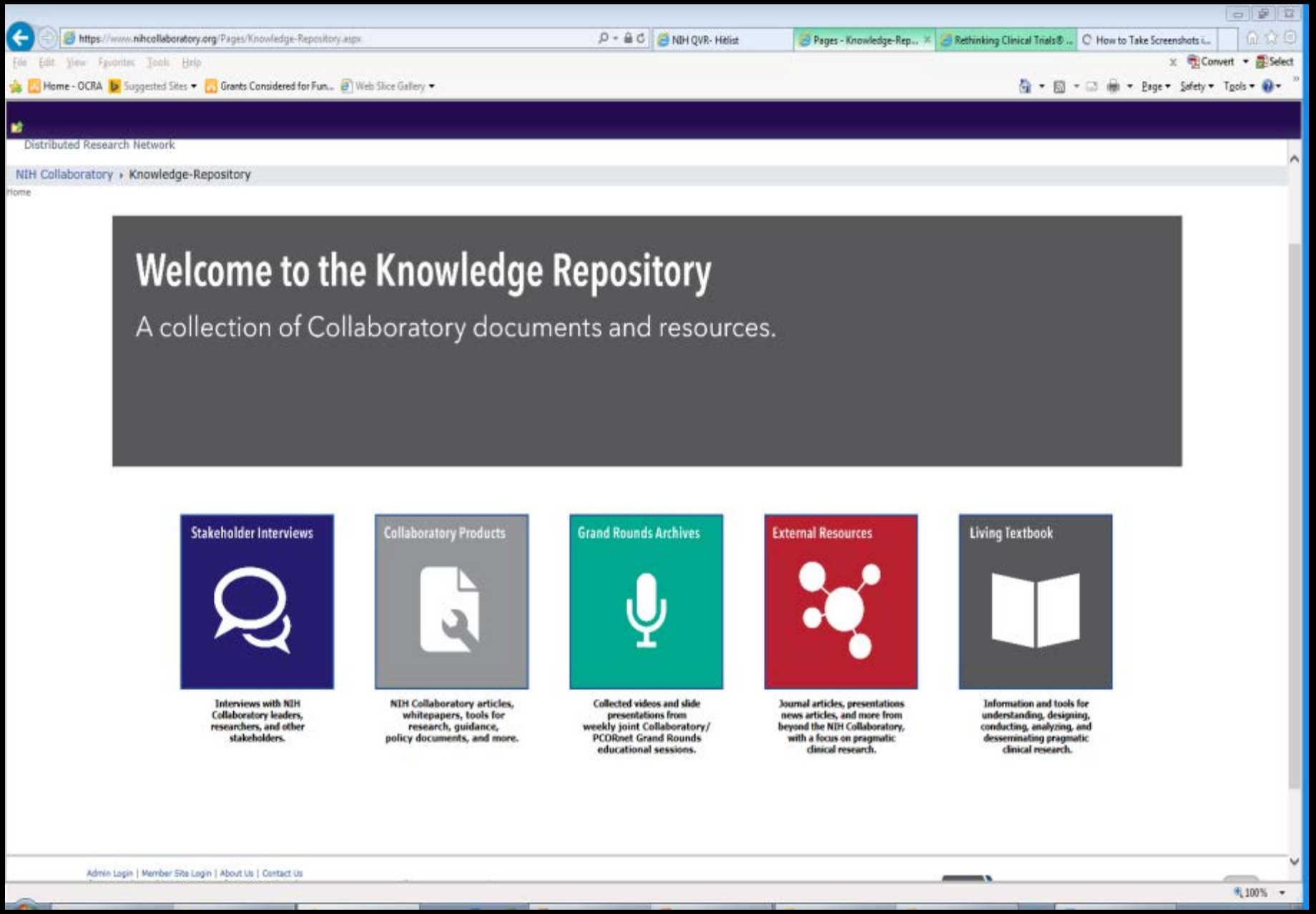
Collaboratory Overview of Activities



https://www.nihcollaboratory.org

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NIH QVR- Hitlist
Pages - Knowledge-Rep...
Rethinking Clinical Trials® ...
How to Take Screenshots i...
Home - OCRA
Suggested Sites
Grants Considered for Fun...
Web Slice Gallery
Distributed Research Network
NIH Collaboratory › Knowledge-Repository
Home
Welcome to the Knowledge Repository
A collection of Collaboratory documents and resources.
Stakeholder Interviews
Interviews with NIH Collaboratory leaders, researchers, and other stakeholders.
Collaboratory Products
NIH Collaboratory articles, whitepapers, tools for research, guidance, policy documents, and more.
Grand Rounds Archives
Collected videos and slide presentations from weekly joint Collaboratory/ PCORnet Grand Rounds educational sessions.
External Resources
Journal articles, presentations news articles, and more from beyond the NIH Collaboratory, with a focus on pragmatic clinical research.
Living Textbook
Information and tools for understanding, designing, conducting, analyzing, and disseminating pragmatic clinical research.
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