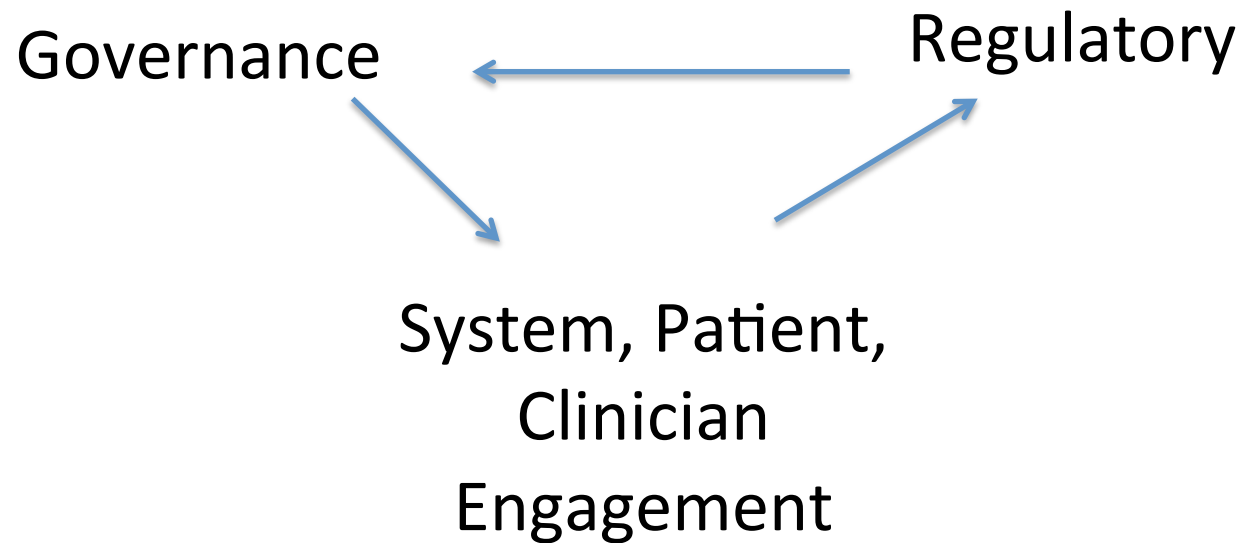
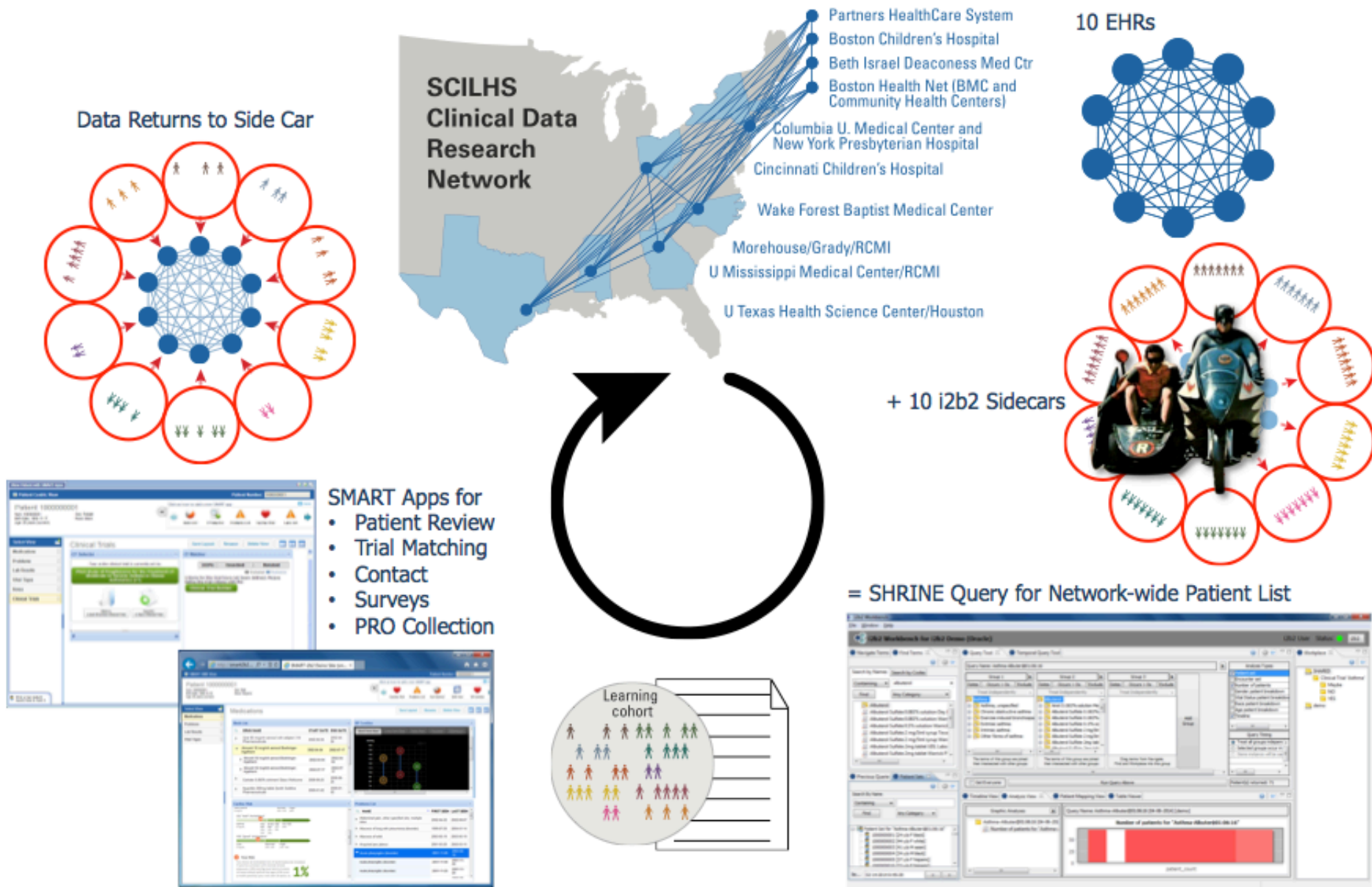


# PCORNet and the Scalable Collaborative Infrastructure for a Learning Healthcare System

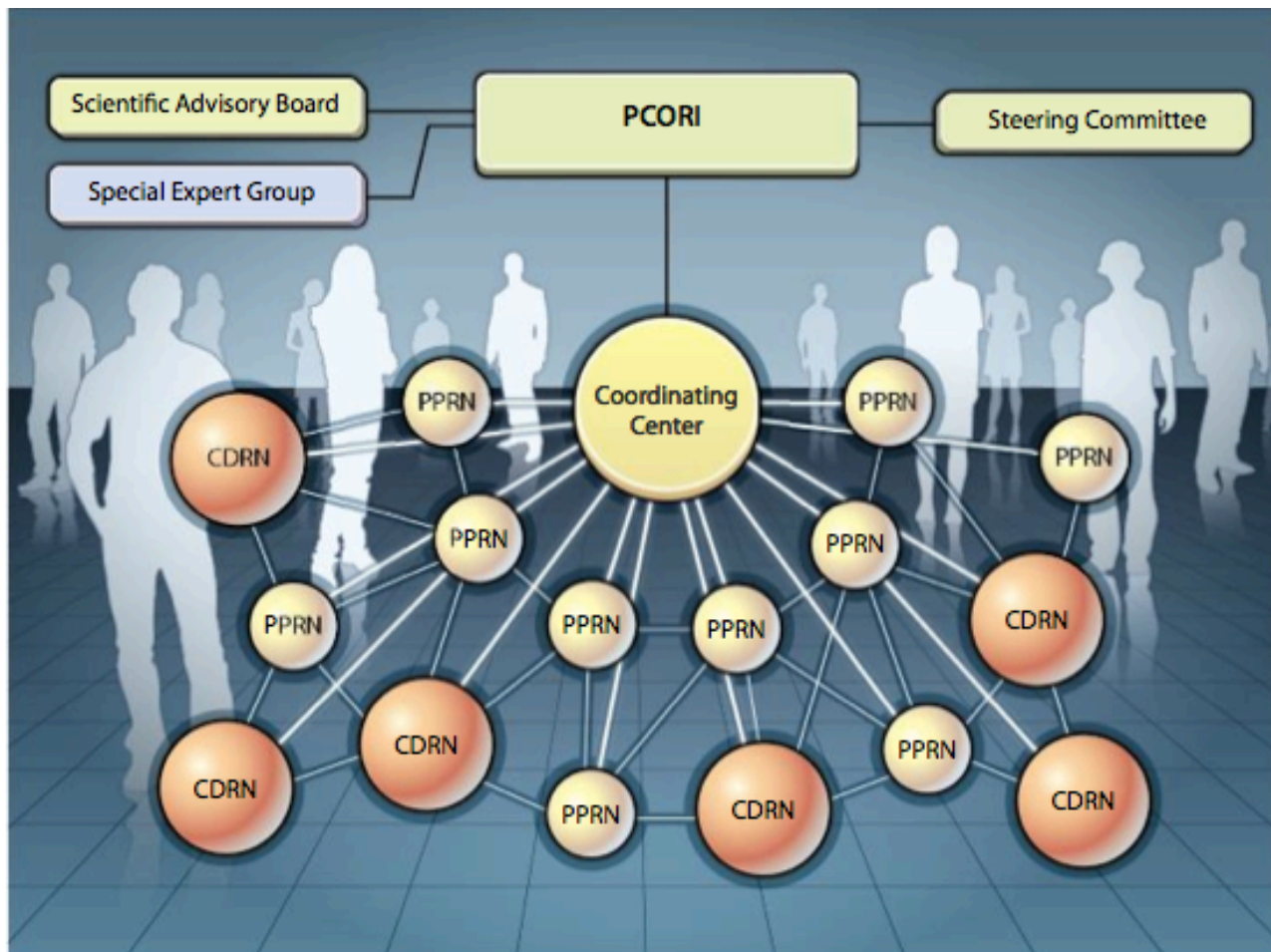
Kenneth D. Mandl, MD, MPH  
Professor, HMS

# Explore Across This Mix



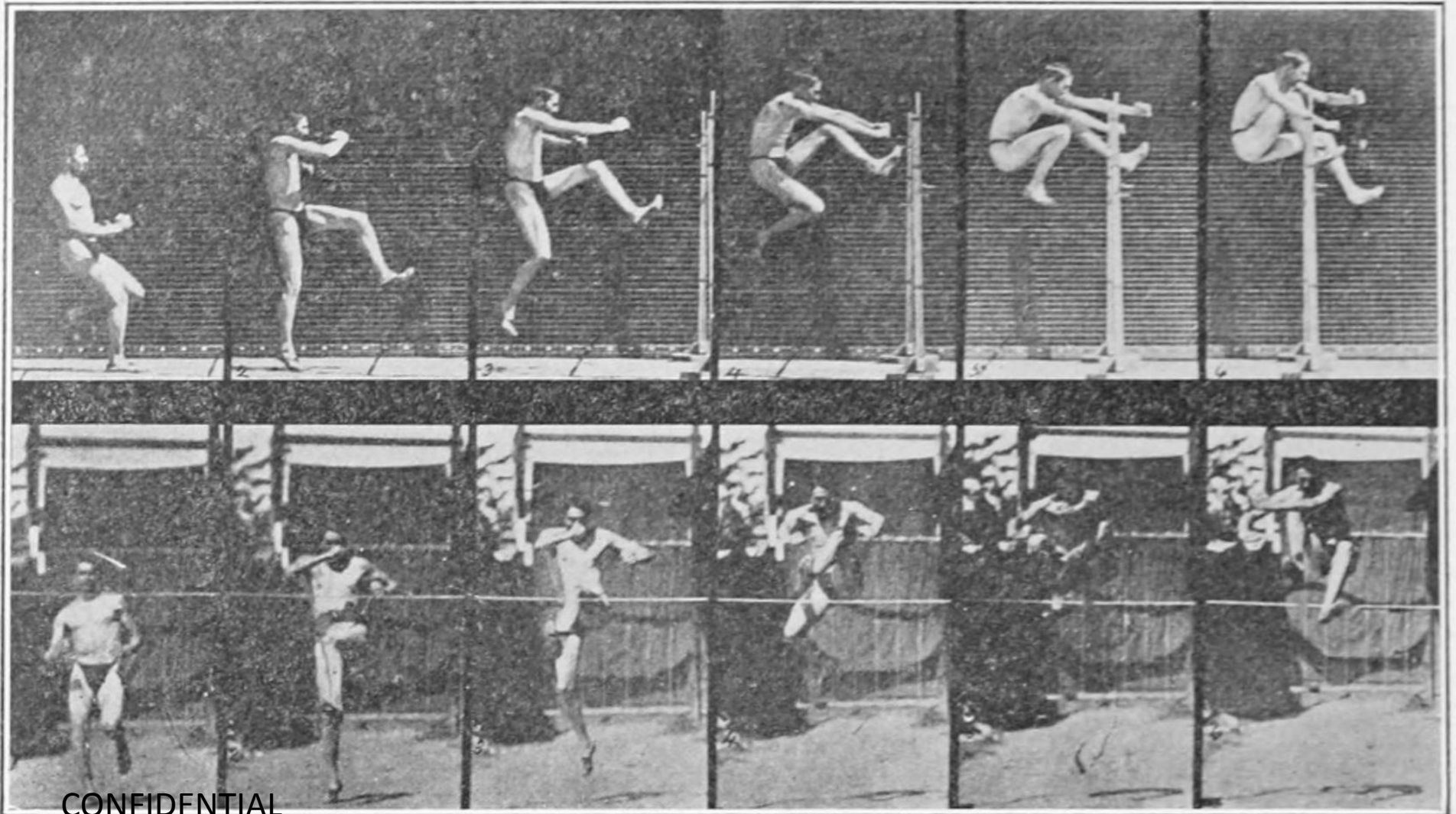


# The National Network of Networks



\$500M/yr

# 18 Month Work Period:





# The Plan

Common data platform **(i2b2)**

+

Federated queries across sites **(SHRINE)**

+

Point of care apps **(SMART)**

+

Patient-facing technologies **(RedCap, SMART, +)**



CDRN Name	Lead Organization	Principal Investigator
<b>ADVANCE</b>	Oregon Community Health Information Network	Jennifer DeVoe
<b>CAPriCORN</b>	The Chicago Community Trust	Terry Mazany
<b>Great Plains Collaborative</b>	University of Kansas Medical Center	Lemuel Waitman
<b>Louisiana Clinical Data Research Network</b>	Louisiana Public Health Institute	Anjum Khurshid
<b>Mid-South CDRN</b>	Vanderbilt University	Russell Rothman
<b>NYC-CDRN</b>	Weill Medical College of Cornell University	Rainu Kaushal
<b>PEDSNet</b>	The Children's Hospital of Philadelphia	Christopher Forrest
<b>PORTAL</b>	Kaiser Foundation Research Institute	Elizabeth McGlynn
<b>pSCANNER</b>	University of California, San Diego	Lucila Ohno-Machado
<b>P2ATH</b>	University of Pittsburgh	Rachel Hess
<b>SCIHLS</b>	Harvard University	Kenneth Mandl



## CDRNs: Disease Cohorts

Organization	Common Cohort	Rare Cohort
<b>ADVANCE</b>	Diabetes	HIV & Hepatitis C virus Co-infection
<b>CAPriCORN</b>	Anemia; Asthma	Sickle cell disease; Recurrent C. Difficile colitis
<b>Great Plains Collaborative</b>	Breast Cancer	Amyotrophic Lateral Sclerosis (ALS)
<b>Louisiana Clinical Data Research Network</b>	Diabetes	Sickle Cell Disease, Rare Cancers
<b>NYC-CDRN</b>	Diabetes	Cystic Fibrosis
<b>Mid-South CDRN</b>	Coronary Heart Disease	Sickle Cell Disease (SCD)
<b>PEDSNet</b>	Inflammatory bowel disease	Hypoplastic left heart syndrome
<b>PORTAL</b>	Colorectal Cancer	Severe Congenital Heart Disease
<b>pSCANNER</b>	Congestive Heart Failure	Kawasaki Disease
<b>P2ATH</b>	Atrial Fibrillation	Idiopathic Pulmonary Fibrosis
<b>SCIHLS</b>	Osteoarthritis	Pulmonary arterial hypertension

# PPRNs represent a number of conditions...

Organization	PI	Condition	Population Size
<b>Accelerated Cure Project for Multiple Sclerosis</b>	Robert McBurney	Multiple Sclerosis	20,000
<b>American Sleep Apnea Association</b>	Susan Redline	Sleep Apnea	50,000
<b>Cincinnati Children's Hospital Medical Center</b>	Peter Margolis	Pediatric Crohn's Disease and Ulcerative Colitis	15,000
<b>COPD Foundation</b>	Richard Mularski	Chronic Obstructive Pulmonary Disease	50,000
<b>Crohn's and Colitis Foundation of America</b>	R. Balfour Sartor	Inflammatory Bowel Disease (Crohn's disease and ulcerative colitis)	30,000
<b>Global Healthy Living Foundation</b>	Seth Ginsberg	Arthritis (rheumatoid arthritis, spondyloarthritis), musculoskeletal disorders (osteoporosis), and inflammatory conditions (psoriasis)	50,000
<b>Massachusetts General Hospital</b>	Andrew Nierenberg	Major Depressive Disorder and Bipolar Disorder	50,000
<b>Univ of California, San Francisco</b>	Mark Pletcher	Cardiovascular health	100,000
<b>University of South Florida</b>	Rebecca Sutphen	Hereditary Breast & Ovarian Cancer	17,000

## including rare diseases

Organization	PI	Condition	Population Size
<b>ALD Connect, Inc</b>	Florian Eichler	Adrenoleukodystrophy	3,000
<b>Arbor Research Collaborative for Health</b>	Bruce Robinson	Primary Nephrotic Syndrome, Focal Segmental Glomerulosclerosis, Minimal Change Disease, and Membranous Nephropathy Multiple Sclerosis	1,250
<b>Duke University</b>	Laura Schanberg	Juvenile Rheumatic Disease	9,000
<b>Epilepsy Foundation</b>	Janice Beulow	Aicardi Syndrome, Lennox-Gastaut Syndrome, Phelan-McDermid Syndrome, Hypothalamic Hamartoma, Dravet Syndrome, Tuberous Sclerosis	1,500
<b>Genetic Alliance, Inc</b>	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
<b>Immune Deficiency Foundation</b>	Kathleen Sullivan	Primary Immunodeficiency Diseases	1,250
<b>Parent Project Muscular Dystrophy</b>	Holly Peay	Duchenne and Becker muscular dystrophy	4,000
<b>Phelan-McDermid Syndrome Foundation</b>	Megan O'Boyle	Phelan-McDermid Syndrome	737
<b>University of Pennsylvania</b>	Peter Merkel	Vasculitis	500

# PCORnet: A Complex Equation

11 CDRN lead sites (x  $\approx$  100 partner organizations)

+ 18 PPRN lead sites (x  $\approx$  50 partner organizations)

+ 11 Task Forces ( $\approx$  minimum 25 people/

**Sizable Communication & Coordination Effort!**

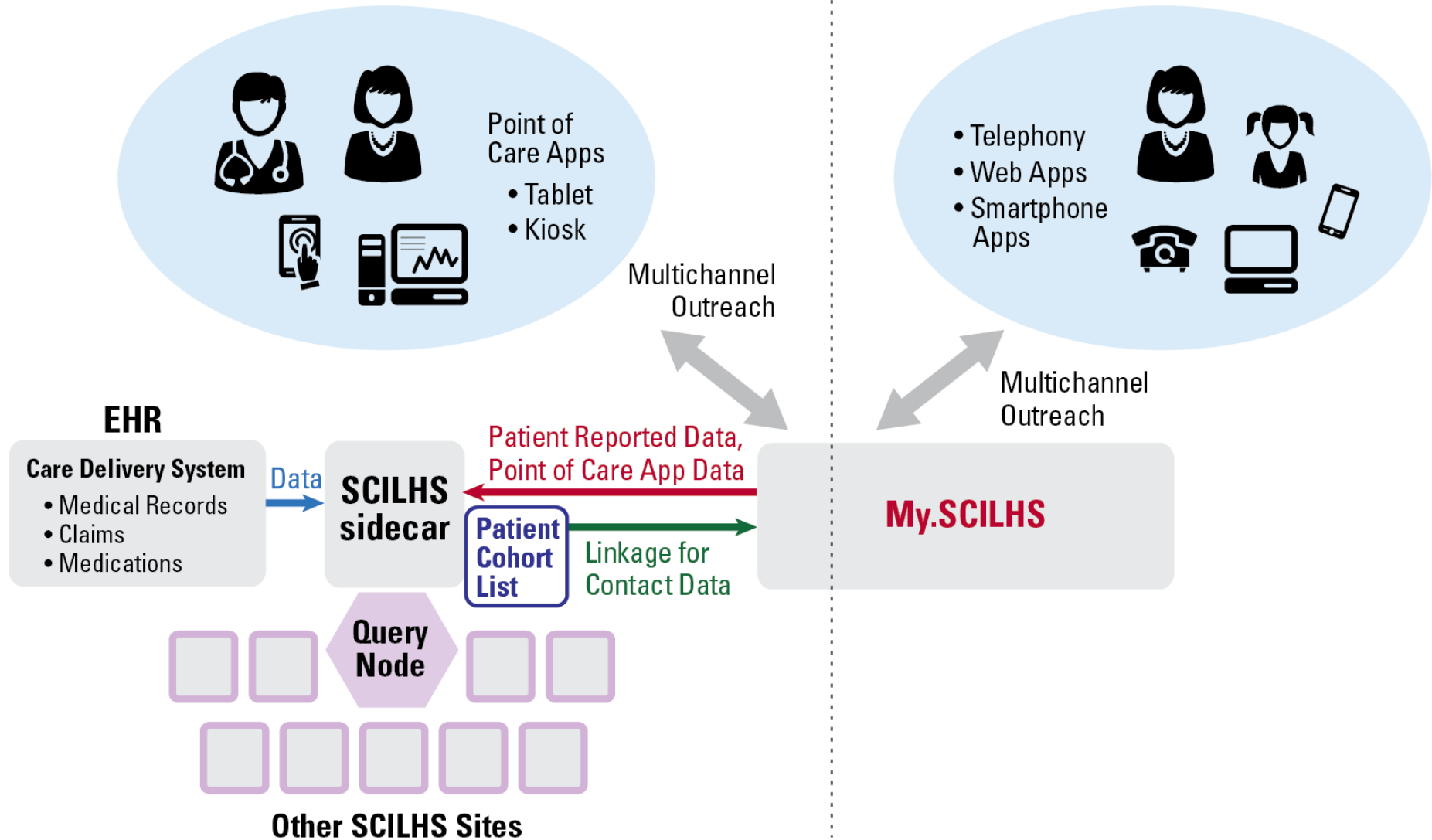
+ Coordinating Center (n  $\approx$  15 staff)

+ PCORI Program Office (n = 7)

## Clinic

Firewall

## Home





# Coordinating Center Use Case

- Dabigitran

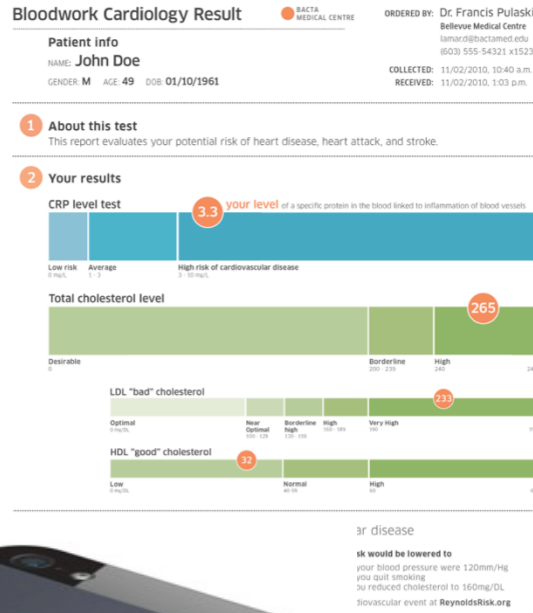
# Study Designs to Support

- Prep to Research Study
- Observational Cohort Study
- Pragmatic Randomized Trial

# Designing the App Store for Health



SMART



The NEW ENGLAND  
JOURNAL of MEDICINE

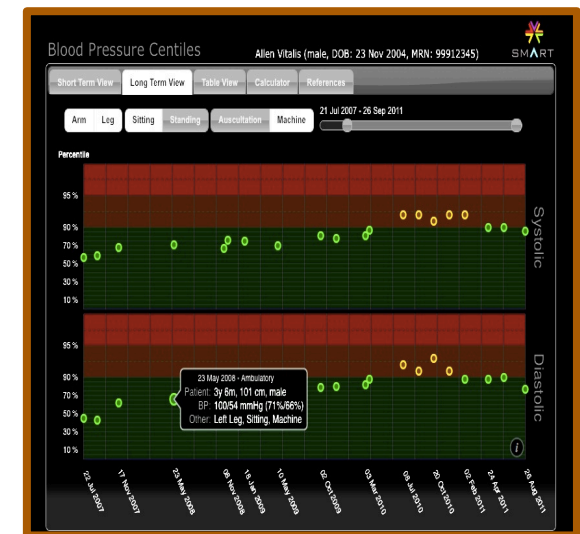
## No Small Change for the Health Information Economy

Kenneth D. Mandl, M.D., M.P.H., and Isaac S. Kohane, M.D., Ph.D.

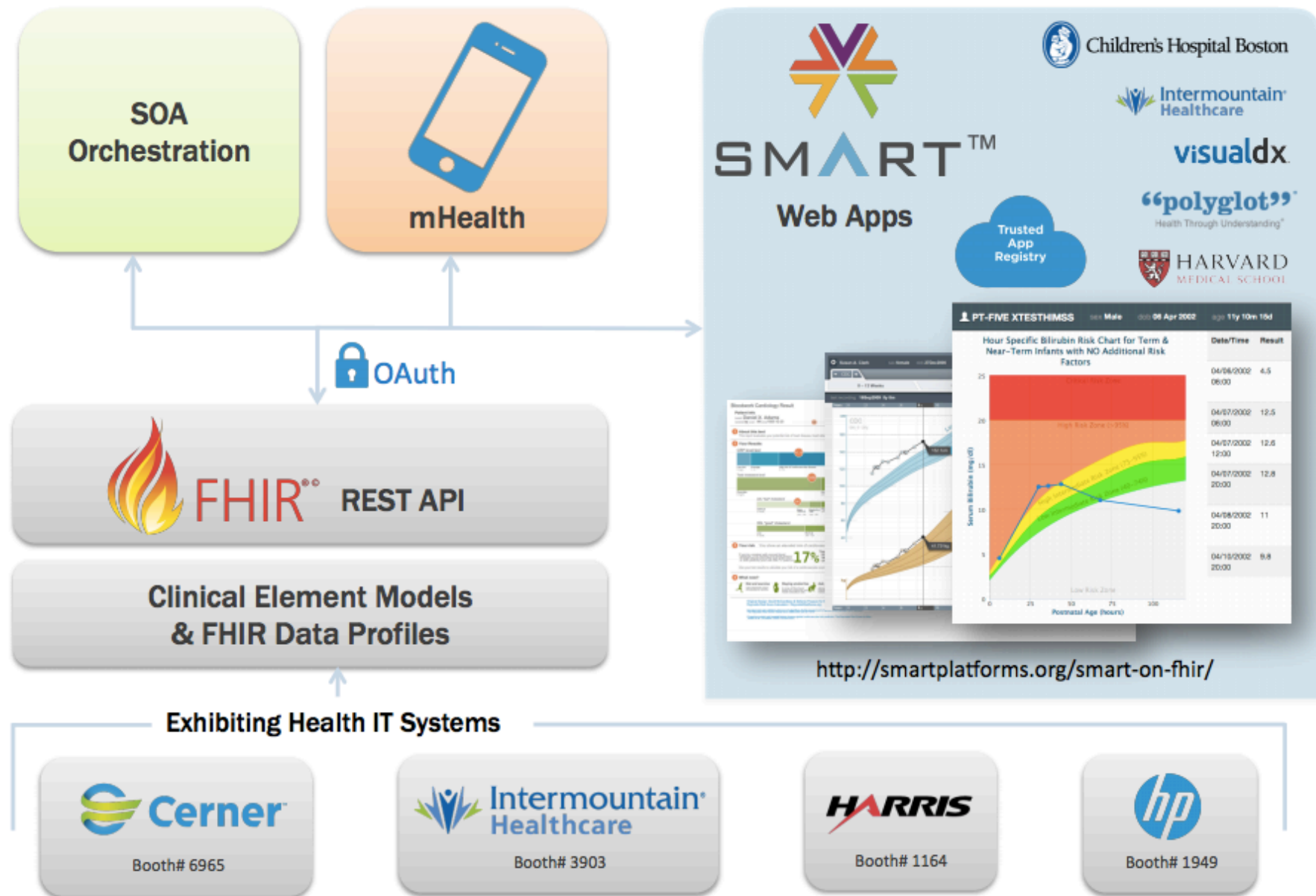
The economic stimulus package signed by President Barack Obama on February 17 included a \$19 billion investment in health information technology. How can we best take advantage of this unprecedented opportunity to computerize health care and stimulate the health information economy while also stimulating the U.S. economy? A health care system adapting to the effects of an aging population, growing expenditures, and a diminishing primary care workforce needs the support

of a flexible information infrastructure that facilitates innovation in wellness, health care, and public health. Flexibility is critical, since the system will have to function under new policies and in the service of new health care delivery mechanisms, and it will need to incorporate emerging information technologies on an ongoing basis. As we seek to design a system that will constantly evolve and encourage innovation, we can glean lessons from large-scale information-

technology successes in other fields. An essential first lesson is that ideally, system components should be not only interoperable but also substitutable. The Apple iPhone, for example, uses a software platform with a published interface that allows software developers outside Apple to create applications; there are now nearly 10,000 applications that consumers can download and use with the common phone interface. The platform separates the system from the functional-



# SMART on FHIR® – Open Platform Architecture





Nicole Fisher  
Contributor

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health policy expert  
covering health  
innovation, outcomes &  
justice  
full bio →

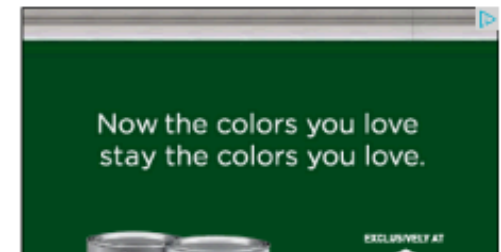
PHARMA & HEALTHCARE

5/29/2014 @ 4:43AM | 3,417 views

## Who's Who Of Health Care Join Forces For SMART Technology

+ Comment Now + Follow Comments

In the new app-driven health economy, ease of use of IT for providers and patients is a must. Equally important is a sound technical approach and business plan for application creators looking for success, sustainability, and a large market for their innovations. Under the leadership of Boston Children's Hospital's Drs. Kenneth Mandl, Isaac Kohane, Joshua Mandel and an advisory



- Clayton Christensen, HBS
- Susanna Fox, Pew
- The Advisory Board Company
- AARP
- BMJ
- Canadian Institutes of Health Research
- Centers for Medicare and Medicaid Services
- Hospital Corporation of America
- Eli Lilly MyHealthBook
- Polyglot Systems
- Surescripts
- UK National Health Service