



Health Care Systems Research Collaboratory

# The NIH Healthcare Systems Research Coordinating Center: What have we learned and where are we going?

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# Big Picture

- 5 of 7 UH2s going forward to UH3s
- 1 of 7 dropped but going back in through normal NHLBI mechanism
- 1 of 7 working on pilot with full support
- New RFAs from NIH IC's in the "Collaboratory template"
- PCORnet startup is direct derivative of the Collaboratory work
- Unprecedented collaboration across agencies to change the clinical research landscape
- Choice of Working Groups validated by PCORnet Task Forces

# The Work

- There have been some hard and overwhelming times
- But the teamwork and willingness to support the effort has been uplifting: NIH, UH2's, CC personnel at multiple institutions
- And people have been willing to give direct feedback
- We're now in the "Production Phase"
  - Getting the UH3s done (the best way to build confidence in research is to get results: "reliable answers to questions that matter")
  - Onboarding the new UH2s
  - Dissemination

# Dominant Issue: Ethics and Regulatory

- Initial involvement of OHRP in individual projects
- SUPPORT Trial controversy
- End result: large amount of energy and resources went into dealing with mix of NIH, OHRP, IOM and others concerned about the direction of the SUPPORT Trial discussion
- Some other deliverables slipped

# PCORnet

- When “PFA” came out it appeared to be modeled after learnings from the Collaboratory (along with many others)
- CC is virtual and includes the Collaboratory cast plus additional groups (Brookings, Academy Health, AHIP)
- Substantial momentum to change the landscape

# Lesson: “The Big 5 Issues”

- **Data**—finding a way to create a data platform that frees researchers to use the data rather than spending their time and money creating the data in a parallel universe from clinical care
- **Reaching the spectrum of “health system” players**-- CEO’s, providers, administrators, patients– crossing the “tipping point” in which all elements contribute to Learning Health Systems
- **Patients and their advocates**– harnessing their energy, insight and focus on getting answers through research
- **Ethics and regulatory**—protecting research participants/subjects without becoming the limiting factor in answering questions that will save lives and reduce disability
- **Communication**—effectively sending messages that galvanize work and listening to create efficient feedback system

# Work in Progress

- Some deliverables from working groups
- Finding the “sweet spot” for the composite of NIH Collaboratory DRN, Sentinel and PCORnet
- Knowledge repository
- Living textbook
- Reaching out to constituencies: NIH, FDA, CMS, professional societies
- Writing and publishing in traditional medical journals



# The Challenge

We can increase the rate of reliably answering questions that are important to patients by ten fold if we succeed in all arenas