

Citizen Science and PCORnet: Early Insights from Governance in Research Networks

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NIH ELSI & Citizen Science Workshop January 13-14, 2015*



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The National Patient-Centered Clinical Research Network

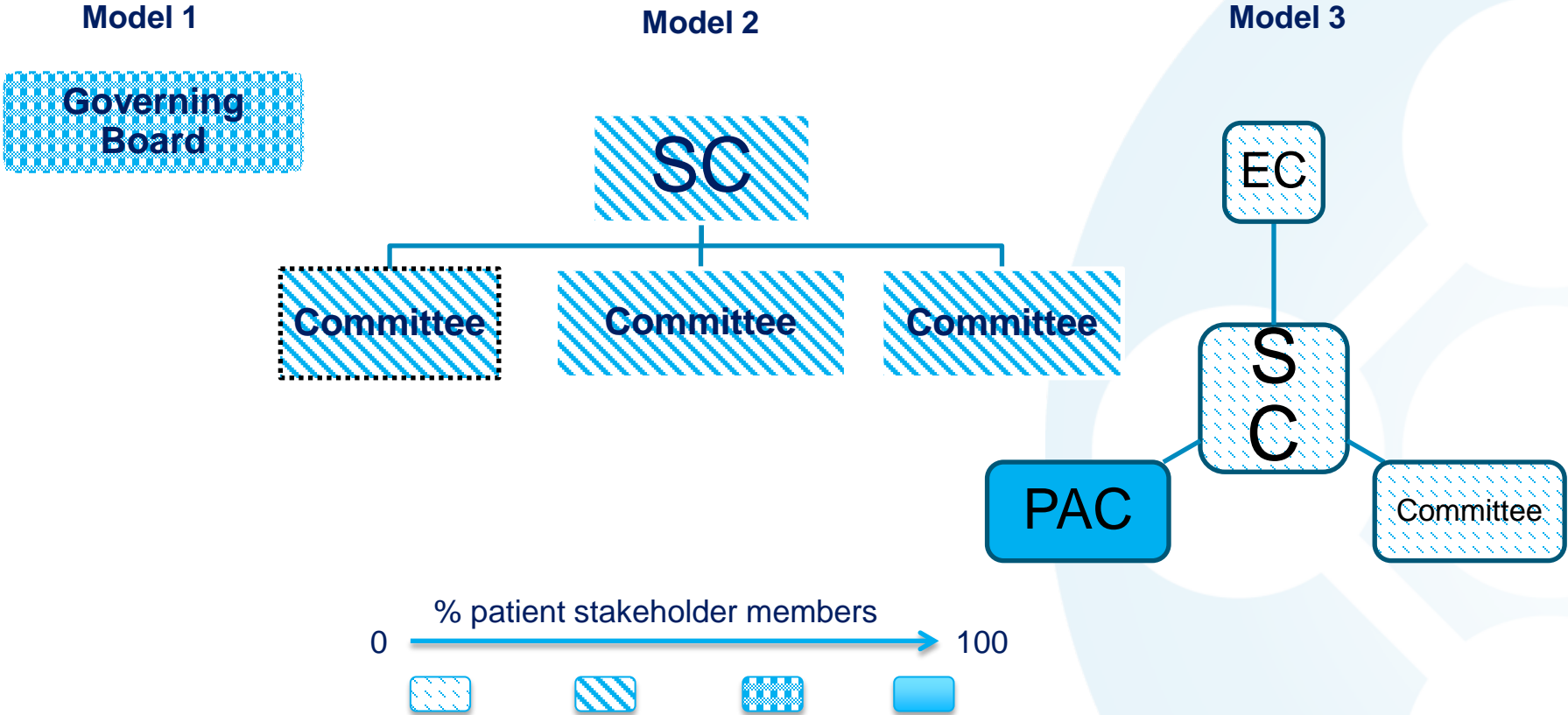
PCORnet as a backdrop

- PCORnet is an infrastructure development initiative funded by the Patient-Centered Outcomes Research Institute (PCORI)
- At its heart, PCORnet is designed to blend the capabilities of healthcare systems and patient-driven organizations in support of a retooled national ecosystem for research that is much more efficient than our current system, and much more patient-centered
- There are many research networks in existence today which have made both incremental and monumental differences—and we need both types of changes...
- PCORnet's objective is to harness the potential of patient engagement and blend it with the data-driven movement we're enjoying right now

Current State

- Currently, PCORI has funded 29 networks to be a part of Phase I of PCORnet
- 11 Clinical Data Research Networks and 18 Patient-Powered Research Networks. These reflect those complementary capabilities: blend of patients' passions & healthcare systems' vast data resources
- Up and running for about a year, and already are awaiting applicants for Phase II, which will run from October 2015-2018
- Networks were asked to bring in patient cohorts of their choosing
- The current networks include 151 different organizations, and are creating cohorts to study everything from rare genetic disorders to very common conditions like breast cancer and diabetes

Governance Structures as Natural Experiments



Partnering with Patient Leaders in Networks

Internal drivers, advisors, and informants

PI or co-PI

Key advisors

Advisory council or governing board members

Task Force Liaisons

External ambassadors

Key Connectors to disease advocacy orgs & hard-to-reach communities

Communication specialists to help raise awareness



Engagement
Retention
Interaction
Collaboration

Citizen Science & Patient Engagement: Sides of the Same Coin?

- ❁ Befitting PCORI-funded projects, participating networks are obliged to involve patients in governance activities, from setting policies to deciding on high priority research questions
- ❁ Yet PCORnet is pretty far upstream—building infrastructure at present, vs. developing a passel of research questions
- ❁ Only a paucity of patients/would-be participants are attuned to the shortcomings of the current system of research which is still saddled with inefficiencies and bureaucracy
- ❁ So first and foremost, there's typically a learning curve to address with the interested participants

“Challenge-tunities” when patients are co-creators in research context

- Do they “become” researchers, and what kind of training should be provided?
- In what ways should researchers change?
- How do we (i.e., this entire community) address issues of power asymmetry and information asymmetry?
- How can we create a lingua franca and enable good communication?
- Challenge: “Don’t want to bother patients with these details”
- Opportunity: Up-voting – letting patients weigh in on research ideas, crowd-source whether they are viable (of interest to a patient community, and methodologically viable)

Additional Questions & Considerations

- Who should “govern?” Who owns research data?
- Nothing about me without me – should Berwick’s plea apply to research as well as health care?
- Ideas for engaging folks in the upstream/opaque arcana of research?
- Data and data privacy
- Suitability of focusing on depth of engagement with a few patients rather than lower level of engagement with more patients
- How can we change the rebalance the scales such that the Individual benefit and societal good inherent in research are equalized?

Thank you!

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