What is patient-centered research?

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What is patient-centered research?

- “In many underserved communities, “research” is a loaded word that sets expectations of being examined or exploited. This is more likely when data are published but not otherwise shared, such as in a community forum. Research, whether it intends to or not, may disadvantage groups by highlighting problems rather than assets….In community-partnered participatory research (CPPR), partners are valued equally and collaborate jointly in research development, implementation, and dissemination. Those involved learn to appreciate that knowledge comes in many forms, including data, experience, history, and perception.

Community-partnered participatory research in New Orleans


- (2007 - 2010) Community-partnered, research-informed agenda drives improvement in healthcare services delivery (Springgate et al. 2011)
  - Quality improvement program of 70 organizations and 400 health care providers of mental health services in primary care, specialty care, and community settings
  - More than 110,000 mental health services delivered
What is patient-centered research?

- Shares a number of similarities with CPPR in terms of opportunities and challenges

- PCORI faces a number of concurrent opportunities and challenges
  - Limitations of information use
  - Building trust
  - Sustained and equitable engagement
  - Results that are actionable, understandable, responsive to needs
  - Accountability in desire for input and feedback
  - Who do we mean?
What is patient-centered research?

- **PCORI** – multiple statutory *limitations* on use of its evidence and findings, as well as on measures that can be considered;

- Whether at the patient level, or at a provider level, health and health care decision-making, or engagement and research, optimally is not conducted in environments that operate with a priori limitations on how materially relevant information and products of research can be used.
What is patient-centered research?

- **PCORI**: Seeks to “produce information that patients and their health care providers can trust”

- Partnered approaches to research may foster trust and advance rigor
  - UCLA/RAND NIMH Partnered Research Center for Quality Care offers an excellent prototype for high quality, partnered research

- Emphasis on practical information and transparent products of research may also enhance trust
What is patient-centered research?

- **PCORI:** Patients “tell us what health care outcomes they value”

- Opportunity to hear about patients’ values may require committed engagement with particular attention to:
  - Times, locations, language, and resources that permit sustained participation of diverse groups of patients and stakeholders;
  - Equitable division of research program and infrastructure funding;
  - Use of systems that reliably exchange information with large numbers of patients, such as modified Delphi methods or social media applications (Dalal et al 2011; Goodman et al 2011)
What is patient-centered research?

- **PCORI:** “Results of research are provided to patients and clinicians in ways that are responsive to their needs and interests and easy to understand”

- Responsive and understandable products of research – should this be an requirement for research proposals to be funded?

- Would it be useful for researcher teams have to identify in advance which end-users (e.g. patient advocacy groups, physician groups, or hospital systems) agree to use the products of the research in daily practice?
What is patient-centered research?

- **PCORI:** “Obtain public input and feedback prior to adoption of priorities, agendas, methodological standards, peer review processes or dissemination strategies”

- Is such “input and feedback” sufficiently patient-centered to be meaningful? Will it occur at critical decision-making junctures at the highest levels of PCORI itself?

- Should patients have real (veto) authority on patient-led or co-led institutional review boards and research teams for every PCORI-funded project? On every PCORI review committee?
What is patient-centered research?

- **PCORI**:
  - “Given my personal characteristics, conditions and preferences, what should I expect will happen to me?”
  - “What are my options and what are the benefits and harms of those options?”
  - “What can I do to improve the outcomes that are most important to me?”
  - “How can the health care system improve my chances of achieving the outcomes I prefer?”

- WHO does PCORI mean? How convinced are THEY that you mean it?
References

Thank you. Please enjoy New Orleans.

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