



Promising Practices of Meaningful Engagement in the Conduct of Research

September 19, 2013
Webinar/Teleconference

Patient-Centered Outcomes Research Institute

Agenda

1:00-1:10 pm Welcome and Introductions



1:10 - 1:25 pm PCORI Research Team Presentation:
Ken Wells, UCLA, and patient partners
Loretta Jones and Pluscedia Williams



1:25 – 1:40 pm PCORI Research Team Presentation:
David Loring, Emory University, and
patient partner Brandy Parker



1:40 – 2:00 pm Live Q&A



Webinar Learning Objectives

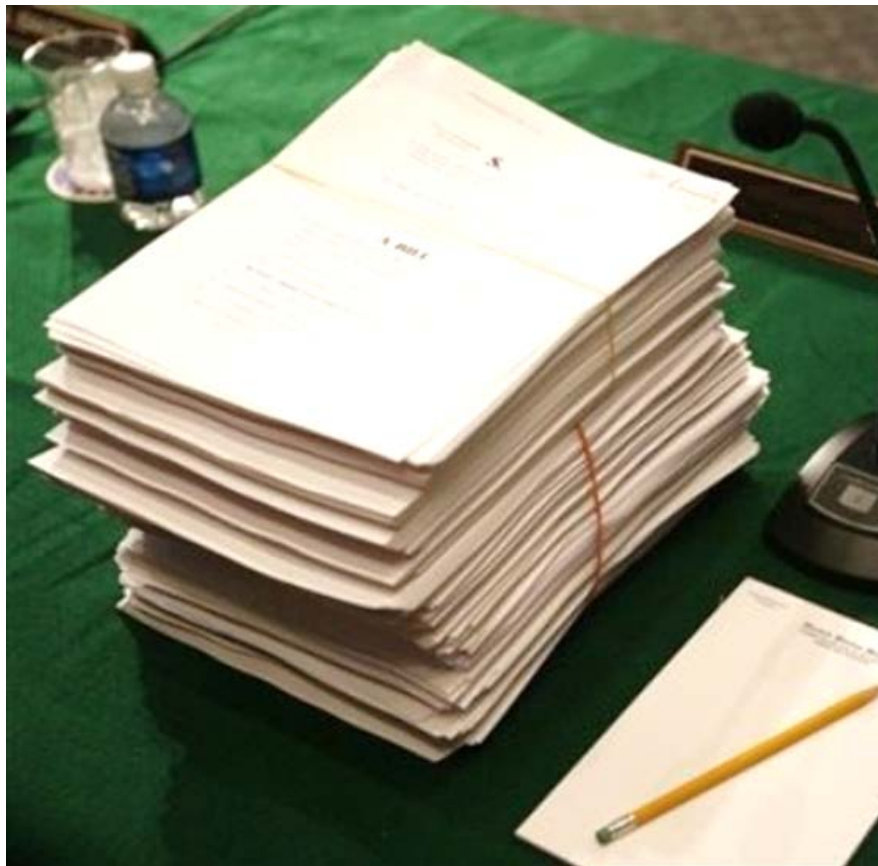
- To learn from PCORI funded research teams about successful practices of patient and stakeholder engagement in all stages of the research process;
- To address major concerns and barriers to engaging patients and stakeholders in research; and
- To inform the public on ways to get involved with PCORI and our work.

Why PCORI?



- Research has not answered many questions patients face
- People want to know which treatment is right for them
- Patients need information they can understand and use

About PCORI



“The purpose of the Institute is to **assist patients, clinicians, purchasers, and policy-makers in making informed health decisions** by advancing the quality and relevance of evidence concerning the manner in which diseases, disorders, and other health conditions can effectively and appropriately be prevented, diagnosed, treated, monitored, and managed **through research and evidence synthesis** that considers variations in patient subpopulations, and the dissemination of research findings with respect to the relative health outcomes, clinical effectiveness, and appropriateness of the medical treatments...”

“The Institute shall establish a standing methodology committee to...develop and improve the science and methods of comparative clinical effectiveness research”

Our Mission

PCORI helps people make informed health care decisions, and improves health care delivery and outcomes, by producing and promoting high integrity, evidence-based information that comes from research guided by patients, caregivers and the broader health care community.



Our Focus

Comparative Clinical Effectiveness Research



- Patient-centered
- Answering questions that matter to patients and other clinical decision makers
- Comparisons of outcomes that matter to patients

We Use Engagement as a Path to Rigorous Research



What Does Patient and Stakeholder Engagement in Research Look Like?

- What are some challenges you encountered in integrating and practicing engagement in research?
- How exactly do you engage? How did you initiate this partnership?
- What does engagement mean to you? How does it impact your research?
- What are the three main pieces of advice you would give to researchers and patient/community partners interested in getting involved in PCOR?



Community-Partnered Participatory Research: The What, How, and Why of Community Engagement to Reduce Depression Disparities

Kenneth Wells, Loretta Jones, and Pluscedia Williams
CPIC Council, September 19, 2013

Challenges of Client Engagement in Mental Health Disparities Research

- Historical legacy of research abuses of minority populations
- Distrust of government programs and health services
- Social stigma and discrimination based on mental health diagnosis and treatment
- Research leadership offers opportunities to contribute, but potential public exposure; clients may be unprepared
- Community-based participatory research is recommended to build trust in research and services

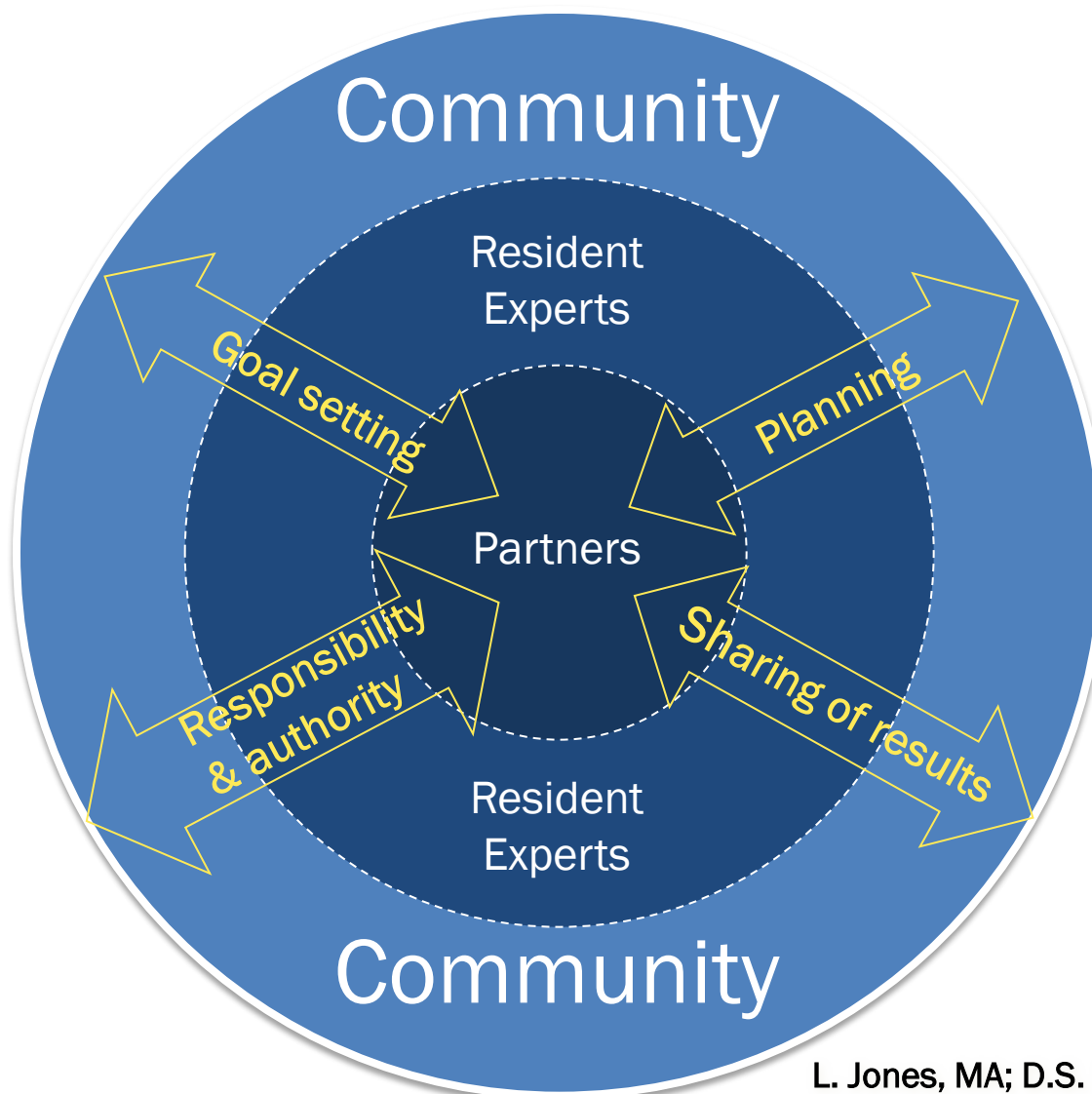
Community-Partnered Participatory Research (CPPR)

CPPR Principles:

- Transparency
- Respect
- Power sharing
- Co-leadership
- Two-way knowledge exchange



Stakeholder Engagement: Circle of Influence Model[©] 2002





New Vision Church of Jesus Christ



COMMUNITY PARTNERS IN CARE
Compañeros Comunitarios en la Salud



DEPARTMENT
OF
MENTAL
HEALTH



**Working together in an *equal* partnership
to learn how to improve depression care
and build community strength**



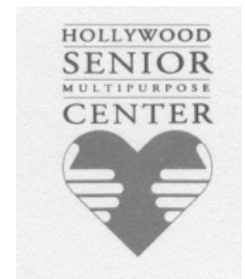
A family
of services.
A family
that serves.



NAMI URBAN LOS ANGELES
The Community's Voice on Mental Illness



Watts Counseling and Learning Center



Methodology Standards Associated with Patient-Centeredness (Current)

- PC-1 Engage people representing the population of interest and other relevant stakeholders in ways that are appropriate and necessary in a given research context. Stakeholders can be engaged in the processes of:
 - o Formulating research questions;
 - o Defining essential characteristics of study participants, comparators, and outcomes;
 - o Identifying and selecting outcomes that the population of interest notices and cares about (e.g., survival, function, symptoms, health-related quality of life) and that inform decision making relevant to the research topic;
 - o Monitoring study conduct and progress; and
 - o Designing/suggesting plans for dissemination and implementation activities.

Example: Community Input, Randomization

- Two-way knowledge exchange (“book club”) format
 - Randomization, validity
 - Community trust/Tuskegee legacy
- Council community leaders explicitly used experience to improve program matching for randomization
- Community leaders selected seed numbers to initiate randomization
- Academic & community co-presenters of design
 - Community conferences
 - American Statistical Association

CPIC Intervention Results and PCORI Research Questions

- **Community Engagement and Planning Relative to Resources for Services (6-month outcomes)**
 - o **Increased** staff participation in trainings
 - o **Improved** mental health, quality of life, and physical activity
 - o **Reduced** homelessness risk factors
 - o **Reduced** behavioral health hospitalizations
 - o **Shifted** outpatient depression services away from specialty medication visits and towards primary care, faith-based, and park services for depression
- *Do client outcome benefits persist over 3 years?*
- *How do clients make trade-offs among such diverse outcomes?*
- *How can systems respond to clients' values for outcomes?*

PCORI Client Engagement Activities

- CPIC Council directs all research activities:
- DMH stakeholder coalition supports CPIC Council
- Partnered workgroups review surveys, train interviewers, participate in analysis:
- “Book club” for group review of client and provider narratives
- Client Survey Participant Input Opportunities
- For Engagement manual see: www.communitytrials.org

Thank you to Partners and Funders!



Funders: Patient Centered Outcomes Research Institute (PCORI);
National Institute of Mental Health (NIMH); National Library of Medicine (NLM);
Robert Wood Johnson Foundation; California Community Foundation;
UCLA Clinical and Translational Science Institute

Cognitive Outcomes in Pediatric Localization Related Epilepsy (COPE)

PCORI Research Priority: Assessment of Prevention, Diagnosis and Treatment Options

David W. Loring, Ph.D.
Departments of Neurology and Pediatrics
Emory University

Brandy Parker
My Epilepsy Story

PCORI Webinar
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AED Selection – How to Choose?

- Stop seizures!
- Other factors
 - Cost
 - Ease of dosing/administration
 - Side-effect profile
 - Cognition and attention
 - Mood and irritability
 - Long-term effects on school and employment



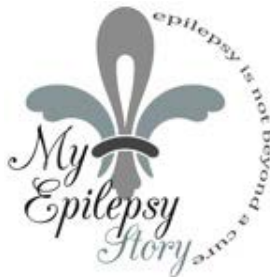
Multiple Stakeholders

- Children (and families) with LRE
- Physicians and Healthcare Professionals
- Epilepsy Advocacy Groups



Epilepsy Partnership

- Epilepsy Foundation
 - Provide web-based resources for education
 - Participate in Public Policy Institute with parents and teens given yearly in Spring
- www.MyEpilepsyStory.org (Ms. Parker)



we **ADVOCATING**
RESEARCHING
EDUCATING

for Women & Children
living with epilepsy.

COPE Executive Committee

- Clinical Core
 - David Loring, PhD
 - Kimford Meador, MD
- Patient Stakeholder Representative
 - Brandy Parker
- Clinical Site Representative
 - Tracy Glauser, MD
- Coordinating Center
 - Avital Cnaan, PhD
 - Catherine Gillespie, PhD
- Medical Monitor
 - William Gaillard, MD
- Consultant
 - Shlomo Shinnar, MD

COPE Summary

- Will establish if one AED maximally preserves cognition
- Will establish behavior side effect risk
- Characterizes child's perspective on multiple measures
- Information dissemination on partner websites will empower children and families to guide clinical treatment

Share your thoughts on engagement in research!

- Submit your comments and questions on PCORI's [website](#) until September 20 at 5:00 p.m. ET. We will make an effort to answer your questions during the allotted public comment period of the webinar, as well as post the answers online after the event.
- Join the conversation on Twitter during the meeting using the hashtag #PCORI.
- Share your comments and questions during the public comment period of the webinar from 1:40 - 2:00 p.m. ET.

Question and Answer Session

Thank you for joining us!

- Please complete the [brief survey](http://bit.ly/1ePKb92) about the webinar. Your feedback is important to us and we look forward to refining our efforts based on your experience.

<http://bit.ly/1ePKb92>