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Oral Paper

Barriers and Solutions to Working with Patients as Research Partners

Friday, November 14

10:40 AM - 12:40 PM

Room: Clearwater/Orlando

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The Patient-Centered Outcomes Research Institute (PCORI), a new organization, has approved 279 awards totaling more than \$464.4 million to fund patient-centered comparative clinical effectiveness research projects (Mullins, 2012), and many employ a little known vehicle—patient advisory boards (PAB). The community-based participatory research (CBPR) literature is helpful in overcoming the challenges psychiatrists will encounter in these investigations (Jones, 2007). This presentation describes the research paradigm, barriers, and proposed solutions to using PAB.

A PCORI project to improve communication with high-mortality hemodialysis patients in New England and New Mexico created two PAB and encountered a number of problems. A mutually acceptable time for the inaugural conference call of the New England board was carefully arranged; however, only 2/7 patients called at the agreed upon time. Patients and staff were interviewed and the CBPR literature was reviewed to similarly identify problems and recommendations. Changes were then instituted to the PAB.

Challenge	Example	Potential Solutions	Action Plan
Patient motivation may differ from that of the research teams.	Patient primary goal is to help other patients, not to develop research design and question.	Elicit personal motivation at the beginning; discuss meeting personal goals while achieving study needs.	Develop a worksheet that can be used early in process of partnership development.
Power differential between seasoned researchers and patients.	Dialysis patients lack confidence in their “place at the table.”	Acknowledge the relationship shift; discuss mechanisms to address conflicts.	Face-to-face time with patients-academic team and training.
Necessity for conference calls.	Patients unaccustomed to conference calls.	Group leader tutors patients individually.	Patients are to be called and feedback obtained following calls.

Appropriate compensation.	Risk of losing benefits due to increased income.	Formal contract outlining responsibilities and flexible compensation.	Individualized compensation agreement.
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Challenges exist to meaningfully involving patients in comparative effectiveness research. Although recommendations for overcoming obstacles exist, the practicalities of developing academic-patient partnerships remain difficult to navigate. In this project where a consultation psychiatrist is the principal investigator, dialysis patients represent the community for whom knowledge gained will have the most value. The CBPR and PCORI models for developing and sustaining patient engagement are especially germane.

Psychiatry has long been considered the specialty most attuned to listening to patients, and it is well positioned to respond to medicine's new paradigm of patient-centered care and research.

Practicalities of clinician-academic-patient collaborations are difficult to navigate, few investigators have experience with PAB, and there are useful lessons that can be gleaned from the CBPR literature. PCORI is a new funding source that is available to psychiatrists.

1. Mullins CD, Abdulhalim AM, Lavalley DC. Continuous patient engagement in comparative effectiveness research. *JAMA* 2012; 307(15):1587-1588.

2. Jones L, Wells K. Strategies for academic and clinician engagement in community-participatory partnered research. *JAMA* 2007; 297(4):407-410.

Learning Objectives:

- The learner will be able to explain how patient-centered research represents a paradigm shift.
- The learner will be able to contrast the mandate of NIMH and PCORI.