



PBRN Pragmatic Research and Translation Working Group
Monday, January 5, 2015
Meeting Summary

Meeting Facilitators

- Rowena Dolor, Network Director, Duke Primary Care Research Consortium
- Jonathan Tobin, Network Director, Clinical Directors Network, Inc.
- Rebecca Roper, Director of the Practice-Based Research Network Initiative at the Agency for Healthcare Research and Quality (AHRQ)
- Milton Eder “Mickey”, Department of Family Medicine and Community Health, University of Minnesota
- Hazel Tapp, Department of Family Medicine, Carolinas HealthCare System

Attendees

- Jeanette Daly – IRENE
- Claudia Davidson
- Katrina Donahue – NC-FM-RN
- Chet Fox – UNYNET
- Rosa Hand – DPBRN
- Jewel Harden-Barrios – Ochsner-PCRN
- Mary Ann Kozak – Rx-SafeNet
- Susan LeBailly – REACH Network
- Aaron Leppin
- Paula Darby Lipman – Westat
- John Lynch – CCPC
- Donald Nease, Jr. – SNOCAP
- Eboni Price-Haywood – Ochsner-PCRN
- Margaret Spurlock – The National Dental PBRN
- Clare Sullivan – Meharry-Vanderbilt Community Research Network
- Camille Washington – ACORN
- Richard "Mort" Wasserman – PROS
- Martyn Whittingham
- Jeff Whittle – Southeast Wisconsin Alliance for Translating Research into Practice
- Litzy Wu

Patient Engagement in Research and the Role of PBRNs

- Patients should be engaged throughout the entire research process, beginning as early as possible.
- Focus groups and the incorporation of feedback during the research process will help to build trust.
- Patient engagement in patient-centered care often takes the form of shared decision making.
 - Evaluation methods for patient engagement include mapping of patient populations with a certain disease and other techniques.
 - An example of patient engagement in research is the PCORI-funded ADAPT-NC project (which works with 4 PBRNs); the project engages patients in research by inviting

patients to participate in focus group sessions. At the conclusion of the session, those patients interested in deeper involvement in the research are invited to participate in meetings to discuss interventions and/or to participate on the patient advisory board. Some patients have even been hired onto the project itself.

- Another way of engaging patients in research is by establishing a Community Advisory Board (CAB) (with representatives from schools, health departments, and advocacy organizations) and grounding the research in Community Based Participatory Research (CBPR) methods.

Considerations and Challenges in Pragmatic Research and Translation

- Considerations regarding the research design process and dissemination of pragmatic research results include ethical issues, such as the blurring of doctor/patient and investigator/subject-participant relationships, as well as logistical questions, such as how and who organizes recruitment and obtains informed consent.
- Challenges identified include understanding the difference between standard of care and an acceptable range of standard care. Research designs that randomize patients to one of these two intervention arms could result in different patient risk levels. It is important to keep this in mind as patients and practices are engaged in large-scale clinical designs.
- Another challenge raised relates to payment issues and how to respond to the challenge of engaging people with the time and financial imperative. Who is actually doing the work?
 - In FQHCs, people participating in projects were in the office and wanted to discuss project participation even if they weren't actively engaged in the research.
 - At some point, if we train patients and communities to develop and implement projects, at what point does the lay/patient perspective value get lost on research questions or cross some boundary that makes them part of the research team and changes their perspective on the whole research project?
- It is important to think about how to share preliminary results and how to translate findings for multiple audiences.
- It is reasonable to think about relationships, roles, and identities for Clinicians and Patients on a sliding scale (continuous rather than discrete relationships), but there may be ethical challenges in seeking to make sure clinicians clearly communicate research issues versus care issues for patients.

Randomization, Equipoise and Patient Preference Design

- There are challenges in explaining randomization and the concept of equipoise to patients.
- One option is to promise patients that they will receive the other intervention arm at the end of a certain time, equipping patients with knowledge of the choices offered, reminding them that clinicians do not always know which option is better. Also, when randomizing by practice, patients do not connect with each other, so they do not know whether they are receiving what might be thought of as an optimum intervention.
- Conveying the notion of equipoise while simultaneously eliciting preferences on behalf of a potential clinician or patient participant is a challenge for clinicians as research indicates that patients do not fully understand the notion of equipoise in medicine. This necessitates the use of decision-support tools and apps.

- Patient Preference Design describes a type of study in which patients' choice dictates randomization. Those who have no preference for a particular treatment are randomized, while those with a preference receive treatment according to their preference.
- There are patient-focused preference designs as well as clinician-focused preference designs, wherein the clinician's preferences dictate treatment or randomization for patients.
- Preference can almost be treated as a covariate, which might predict results, and sensitivity analyses can be run.

Patient versus Community Engagement

- Patient and community engagement can be considered closely linked and dependent on the particular project, study, or research question.
- Another perspective, based on CBPR, argues that defining patient versus community engagement is a matter of defining who the community comprises. The community level can be thought of as the organizational level and the patient level is those participating in the study.