

Title:

Rare Epilepsy Network: A PCORnet Study to Engage Patients in Research

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Session Title:

Conducting Patient-Centered Comparative Effectiveness Research: Exemplars From the Field

Slot:

G 19: Monday, 30 October 2017: 1:15 PM-2:30 PM

Scheduled Time:

1:55 PM

Keywords:

PCORnet, Patient Engagement and Rare Epilepsy

References:

Dyment, D.A., Tetreault, M., Beaulieu, C.L. et. al. (2015) Whole-exome sequencing broadens the phenotypic spectrum of rare pediatric epilepsy: a retrospective study. *Clinical Genetics*, 88: 34-40.

PCORnet PPRN Consortium, Saugherty SE, Wahba S, Fleurence R. (2014) Patient powered research networks: building capacity for conducting patient-centered clinical outcomes research. *Journal of American Medical Association*. 21: 583-586. PMID: PMC4078295

Abstract Summary:

The Rare Epilepsy Network is a data base built for and by people/families with a rare epilepsy. It is part of PCORnet and is designed to provide a place for patients and researchers to design studies important to those with the diagnosis of a rare epilepsy.

Learning Activity:

LEARNING OBJECTIVES	EXPANDED CONTENT OUTLINE
Participants will learn how patient/patient representatives were involved with the development of the Rare Epilepsy Network	1. Review the development of the research award "Rare Epilepsy Network" and how patient/patient partners were included. 2. Discuss the governance structure Rare Epilepsy Network

Participants will learn skills regarding patient engagement in research.

1. Present and discuss methods of patient engagement as they applied to the Rare Epilepsy Network

Abstract Text:

The Rare Epilepsy Network (REN), is a collaboration of rare epilepsy patient advocacy organizations, the Epilepsy Foundation, RTI International, and Columbia University. The REN, funded by the Patient-Centered Outcomes Research Institute (PCORI), is a registry of medical and quality of life self-reported data from rare epilepsy patients or their caregivers. REN is part of a much larger consortium of data bases also funded by PCORI and designed to work together to improve research outcomes for patients. The consortium is Patient-Centered Research Networks and consists of 13 Clinical Data Research Networks (CDRN), and 20 Patient Powered Research Networks (PPRN). The CDRNs are large research networks that work across large systems and generally rely on electronic health records. The PPRNs are patient-based networks of which REN is one. The primary purpose of REN is to recruit and enable persons with a rare epilepsy to be eligible for research. This is the first effort to provide an interactive program for patients and researchers to work together to promote research that is patient centric and that studies outcomes for people with a rare epilepsy. Our main goal is to enroll eligible participants in REN at <https://ren.rti.org/Enroll>. Here, we describe our strategies to engage rare epilepsy patients and their families in REN's research efforts.

The development of REN was driven by small rare epilepsy patient advocacy organizations who were desperate for research but did not have the capacity to do the work on their own. After receiving the PCORI award, researchers and patient representatives built the governance and structure of REN. The REN Steering Committee (SC), comprised of one patient representative from each of the participating rare epilepsy organizations, and the three Co-PI. The Steering Committee is REN's decision-making body. The Executive Committee, comprised of the three Co-PIs and an elected member representing patients/patient representatives from the SC, is the liaison between PCORnet and REN. Our patient partners are involved in all aspects of REN's work, including participation in the SC meetings, workgroups, and PCORI Task Forces. Patients and patient representatives are also identified from outside of the steering committee to be actively involved in patient engagement activities both within REN and also as representatives to PCORnet. Each rare epilepsy organizations identifies patient/patient representatives to be involved with recruitment and retention strategies, patient centered methodology, and patient centered research questions. Because of patient/patient representative input we have developed an active social media campaign on Facebook and You Tube. To address professional, medical and research issues, physicians and researchers with an interest in rare epilepsy were invited to a professional advisory board. This year we brought together patients/patient representatives and researchers to inform our research and next salient steps. The Institutional Review Board of RTI International approved all protocols

To date, we have 21 active rare epilepsy advocacy organizations who are actively participating in all aspects of the REN operation and research efforts. Currently, 1100 patient/patient representatives have entered in the REN data base. This is the largest active and ongoing repository for patient centric data that is focusing on rare epilepsy. Our data base will facilitate future observational studies, clinical trials, and comparative effectiveness research.

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