Partnering With Parents to Create a Research Advisory Board in a Pediatric Research Network

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Practice-based research networks (PBRNs) are ongoing collaborations of clinicians and researchers to conduct studies that improve clinical practice and patient health. PBRNs have long emphasized input from clinicians as a key component of practice-based research. For example, the American Academy of Pediatrics Pediatric Research in Office Settings network relies on practitioners, as opposed to investigators or administrators, to decide which studies are approved.1 In recent years, the importance of getting input from additional stakeholders, especially patients and their families, has been increasingly prioritized. Patient engagement in research may lead to increased study enrollment rates and greater relevance of study outcomes to families.2 The 2010 Patient Protection and Affordable Care Act funded the creation of the Patient-Centered Outcomes Research Institute, which promotes clinical effectiveness research with sustained engagement of patients, families, and other stakeholders throughout the research process.3 Given this focus, practice-based research studies in which researchers partner with patients and families have become more common. However, models for meaningfully and efficiently engaging parents in pediatric PBRN research decisions, regardless of funder, are needed.4

The Children's Hospital of Philadelphia (CHOP) created the Pediatric Research Consortium (PeRC) Parent Advisory Board to gather input from families that is used to inform the implementation of practice-based studies. PeRC is a 31-practice, 2-state PBRN involving 205 physicians and 41 nurse practitioners. PeRC includes a diverse population of patients from urban, suburban, and more rural practice settings. To date, 95 research projects have been completed in conjunction with parents. In this article, we describe the partnership between PBRN leaders, researchers, and parents that created and sustains the Parent Advisory Board.

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