All in the Family: Parents Meaningfully Engaged in Pediatric Research Consortium

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Clinician-researchers in the Pediatric Research Consortium (PeRC) at Children's Hospital of Philadelphia didn't have to look far to find specialists to provide novel insights into their research projects: They are the families who are the experts on their children visiting CHOP's primary care practices.

Four parents from different backgrounds, levels of education, and geographic areas partnered with PeRC in 2013 as a Parent Advisory Board to provide meaningful input to guide implementation of PeRC's portfolio of research studies. PeRC is a 31-practice, two-state research network with 205 physicians and 41 nurse practitioners who have published about 200 peer-reviewed accepted published manuscripts over the last decade or so.

A new paper appearing in *Pediatrics* described how the Parent Advisory Board took shape. PeRC Medical Director Alexander Fiks, MD, MSCE, a practicing primary care pediatrician; PeRC Director James Massey, RN; and PeRC founder and researcher Louis Bell, MD, chief of CHOP's Division of General Pediatrics; described the rationale and workflow for parent review of proposed research studies, and co-author Melanie Cutler, Parent Advisory Board member, shared some of her experiences working with the group.

"When a study comes along, we simply wear our 'mom' or 'dad' hats and read the description as if our own children are being asked to participate," Cutler wrote in the article. "I look at the study's objective, recruitment practices, number of visits, and of course, what will actually happen during visits."

Participation in the Parent Advisory Group has been steady since its formation, and the dedicated members have reviewed more than 95 studies so far. Often their feedback reveals helpful ways to enhance the projects' overall success, Massey and Dr. Fiks said. An important aspect is they encourage researchers to think through the needs of families from diverse backgrounds to ensure that their projects are feasible. Potential logistical barriers such as frequently traveling to CHOP's main campus to participate in a study may be easier for some families to deal with than others, depending on how far away they live or if they rely on mass transit.

"Everybody brings a different perspective and lens to view what the research study is about, what it means to them," Massey said.

Input from families also allows the researchers to adjust their study approaches and methods so that they're the right fit for the patient population that the clinicians serve. When questions arise, the research team can go back to the drawing board and figure out how to address their concerns.

One proposed study reviewed by the Parent Advisory Board involved an intervention delivered via a social media platform for mothers with postpartum depression. The parent advisors wondered if using social media was the ideal forum to conduct the study. The principle investigator connected with the parents and shared prior work that demonstrated the project had a high chance of success. They came to a consensus that it was a novel idea and important to investigate.

With each opportunity for parents to give comments, the research network gains collective knowledge that can help to inform future studies, Dr. Fiks said. The PeRC administrators have begun to identify common challenges and can work with researchers to overcome them. For example, they have found that it is often difficult to find people willing to participate in research as healthy controls if the study requires lengthy procedures. Early on as they're designing a study protocol, the research team can consider ways to minimize this time commitment.

Another way the Parent Advisory Board helps to refine a research study is by working with investigators on how to structure patient interviews and craft research questions to obtain the information they want to gather. The parents can flag sensitive topics researchers should be aware of and give guidance on how to word questions carefully so that families aren't defensive about answering them.

Parent engagement when you conduct research in a practice-based research network not only sets up a research project for successful outcomes, it also stands out to the organizations and agencies that fund research. Highlighting the Parent Advisory Board's input is an important dimension to include in grant proposals, Dr. Fiks said, because it demonstrates the project has been vetted by these important stakeholders.

"That can be really important to the research team as they frame the study and communicate its value," Dr. Fiks said.

In the future, Dr. Fiks anticipates other regional pediatric research networks around the country will integrate PeRC's Parent Advisory Board model into the fabric of their research to improve clinical practice and patient health. With an efficient system for how to involve parents in practice-based research in place, the next step for

PeRC researchers is to think about how to form deeper connections with parents who want to become more active members of research teams.

“We spend a lot of time taking care of patients and families, and it is very rewarding to work with them as partners instead of seeing them on opposite sides of the exam room,” Dr. Fiks said. “It’s great to hear what they have to say about a whole range of different projects. Our pediatric research network — with 250,000 parents — is a unique base to implement this kind of program and invite them to weigh in on these projects and have their voice heard.”

Research Communications is a part of the Administration within the CHOP Research Institute.