

NEWS

Funds add up for research plans that put focus on families

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People with disorders typically have little say in the design of studies on their disorder. They sign up for the studies but rarely get to hear the results. Mostly, they are treated as ‘research subjects’ with little agency. For the past five years, a different type of research project — one that involves families from the beginning — has been the focus of a well-funded initiative.

The **Patient-Centered Outcomes Research Institute** (PCORI) supports efforts to find treatments that are both effective and practical, and places a high premium on making results available to families. Created in 2010, PCORI’s funds are funneled from health insurance companies. As of 5 May, the institute had awarded close to \$870 million to researchers studying a range of topics, from

hip fracture remedies to oral health. The group plans to dole out another \$3.5 billion by 2019.

Among the 400 studies the institute funds is an analysis of treatments for improving executive function — thinking skills such as reasoning and planning — in children with autism and attention deficit hyperactivity disorder (ADHD) from low-income families. Researchers at the **Children's Research Institute** in Washington, D.C., a nonprofit academic center focused on childhood disorders, designed the study in collaboration with parents of children who have ADHD or autism. The parents had the opportunity to comment on all aspects of the study, including how the treatment room should be set up.

“It has been so overwhelmingly positive to have the input,” says **Laura Anthony**, associate director of the Children's Research Institute's Center for Autism Spectrum Disorders. “It creates this kind of passion and ease of accessibility to the community. I just don't know if you can get it any other way.”

Money talks:

PCORI is also supporting a pilot project to **identify and prioritize autism research topics**. Along with researchers, individuals with autism and caregivers suggested topics, and then a separate group of affected individuals ranked them by importance.

“It speaks to PCORI's values of including stakeholders in the research process,” says **Kathleen Thomas**, a research associate at the University of North Carolina's Cecil G. Sheps Center for Health Services Research, who led the study ranking research topics.

Although PCORI is a nongovernmental organization, the Affordable Care Act requires that health insurance companies fund the group. For policies active for the year up to this October, companies must send \$2.08 per insured American to PCORI. The fee has gradually increased since it was first introduced in 2012, when it was \$1.

The money comes at a key time, as a burgeoning number of grant applications compete for a stagnant stash of funds — roughly \$30 billion per year — from the National Institutes of Health (NIH). The PCORI grant process is also competitive. Eligible projects must engage affected individuals and their caregivers in every step of the process, from identifying research questions to disseminating findings.

“Writing the PCORI proposal was nothing like writing an NIH proposal,” Anthony says. NIH proposals highlight what the researchers plan to accomplish, whereas pitches for PCORI must involve input from those who might benefit from its results.

Once the results from funded projects are final, the institute makes them available to the general public via its website within 90 days. “We don’t want to leave research on a shelf for 17 years anymore,” says **Kara Odom Walker**, PCORI’s deputy chief science officer.

Overall, PCORI-funded studies may reveal whether greater involvement of people with disorders and their families in research leads to results that are useful to families. “This is a hypothesis that we are testing,” says Odom Walker. “We don’t have hard evidence yet, but we believe and embrace it.”