PCORI Announces Upcoming Funding Opportunity

Addressing Health Outcomes for Individuals With Intellectual and Developmental Disabilities and/or Rare Diseases

The Patient-Centered Outcomes Research Institute (PCORI) intends to release the **Addressing Health Outcomes for individuals With Intellectual and Developmental Disabilities (IDD) and/or Rare Diseases (RD)** PCORI Funding Announcement (PFA) Aug. 4, 2026.Through this funding opportunity, PCORI seeks to support high-impact **patient-centered comparative clinical effectiveness research** (CER) studies focusing on people living with IDD and/or RD. PCORI acknowledges that some IDD diagnoses are also considered a RD, and some RD diagnoses are also considered an IDD. Applicants **do not need to address both IDD and RD in this PFA**. Responsive applications can focus

either on IDD or RD but may also propose to include both populations if appropriate for the research question (Figure 1).

Figure 1: Image to clarify that applications responsive to this PFA can focus on either IDD or RD populations but may propose to include both populations if appropriate for the research question.

Applicants may propose CER studies comparing clinical and/or systems approaches, which may include pharmacologic and/or non-pharmacologic interventions or system-level strategies delivered in hospital, clinic or community settings to improve patient-centered outcomes.

Interventions should be ready for CER, which generally requires documented evidence of efficacy or widespread use. Adaptations of efficacious interventions used in the general population or other situations may be responsive, but the level of adaptation must be minimal, clearly described and justified.

PCORI is particularly interested in submissions that address the following Special Areas of Emphasis (SAEs). The purpose of identifying these SAEs is

to encourage submissions to these areas, not to limit submissions to only these topics.

1. Better Health Outcomes by Improving Access to Patient-Centered Care

Care delivery for those with IDD and/or RD is influenced by many system-level factors that impact patients and caregivers. These challenges are not necessarily condition specific, allowing for a focus on cross-cutting issues and outcomes and increasing the potential for research impact. People with IDD and/or RD and their caregivers often face similar challenges such as finding relevant information and resources and accessing adequate and appropriate care, in many cases including the diagnosis itself for those with an RD. PCORI is interested in funding patient-centered CER comparing care delivery strategies to address these challenges and improve health outcomes for people with IDD and/or RD. These strategies could include interventions to improve access to care, quality of care or the use of technology. PCORI is interested in interventions that improve patient-centered outcomes, including health-related quality of life, community participation and healthcare utilization.

2. Health System Approaches to Improving Care Transitions

Transitions of care are critical for individuals with IDD and/or RD across the lifespan. Although evidence-based interventions to support transitions of care are in use for other populations and conditions, research is needed to determine which care models are optimal and feasible utilizing existing system resources for individuals with IDD and/or RD. PCORI invites applications for CER comparing models of care or components of such models to support care transitions and the continuation of patient-centered primary and specialty health care for individuals with IDD and/or RD. Outcomes may include but are not limited to health outcomes, including

physical and mental health and health-related quality of life, and process measures such as healthcare utilization and continuation of care.

3. Pharmacologic and Nonpharmacologic Approaches to Improving Physical and Mental Health

People with IDD experience higher rates of co-occurring physical and/or mental health conditions compared to their peers. Social and environmental barriers, such as inaccessible resources and limited exposure to health promotion, contribute to these health differences. Individuals with RD manage symptoms associated with their diagnosis, often with limited to no targeted treatment options. These barriers result in reduced health-related quality of life and lower participation in everyday activities. PCORI is interested in funding patient-centered CER to identify approaches to promote health and/or well-being among people with IDD and/or RD. These could include pharmacological or nonpharmacological approaches (e.g., physical activity, nutrition, complementary/adjunctive care). Outcomes may include but are not limited to improved health-related quality of life, physical health and mental health.

4. Addressing the Health and Well-Being of Caregivers for Individuals With Intellectual and Developmental Disabilities and Rare Diseases

Caregivers play a key role in supporting the health of individuals with IDD and/or RD. They face challenges including finding information resources as well as navigating the required care to promote the desired health outcomes for the individual with IDD and/or RD whom they support. PCORI is interested in studies that compare clinical interventions to support the health of caregivers as well as comparisons of multi-level care coordination approaches and other models of care delivery. PCORI recognizes there is often an interdependence of patient and caregiver social, emotional, psychological and physical health. Complex interventions that focus on one or more aspects of the caregiver/patient dyad's health are welcome when appropriate and feasible. Primary outcomes may include but are not limited to caregiver self-efficacy and caregiver health-related quality of life. Studies

focused only on caregiver health outcomes should provide justification for why collection of meaningful outcomes for care recipients is not feasible. Secondary outcomes could include patient-centered burdens and economic outcomes (e.g. time away from work to navigate care, costs of non-medical supplies required for care or sacrificing personal care for care of another).

Researchers interested in responding to this funding opportunity are encouraged to review the **preannouncement.** The complete PFA and application materials will be available Aug. 4.

To support preparation, PCORI offers several resources that provide guidance on developing responsive proposals, including:

- **Is Your CER Study Responsive to PCORI's Funding Announcements?**
- **Research PCORI Funds FAQs**
- **What You Need To Know To Apply**
- **Population Insights Reports Powered by PCORnet®**
- **A Roadmap for Accelerating IDD Research Using PCORnet®**

PCORI also invites potential applicants to register and attend the **Applicant Town Hall Aug. 12, 2026,** which will provide an overview of the PFA and offer an opportunity to engage directly with program staff. This session is designed to help researchers shape competitive Letters of Intent.

For questions about this opportunity or the application process, contact PCORI at **pfa@pcori.org.**

Please feel free to share this information with colleagues or collaborators who may be interested in applying.