

PCORnet®



Building Data Capacity for Comparative Clinical Effectiveness Research and Other Analyses on IDD

Nik Koscielniak, PhD, MPH, MSOT, OTR/L
Program Officer
Research Infrastructure and Innovation



Get To Know PCORI®

PCORI

- Nonprofit that funds patient-centered comparative clinical effectiveness research (CER)
- Widely acknowledged as a leader in driving U.S. clinical research to become more patient-centered
- Provides funding for CER, engagement in research, dissemination and implementation and research infrastructure projects



What is Patient-Centered CER?

Comparative Clinical Effectiveness Research (CER) compares benefits and harms of two or more medical treatments, clinical or care delivery strategies or other approaches to health care that are currently in use in clinical practice.

- Focuses on outcomes that are important to patients and other stakeholders
- Seeks to help patients and other stakeholders make better-informed decisions

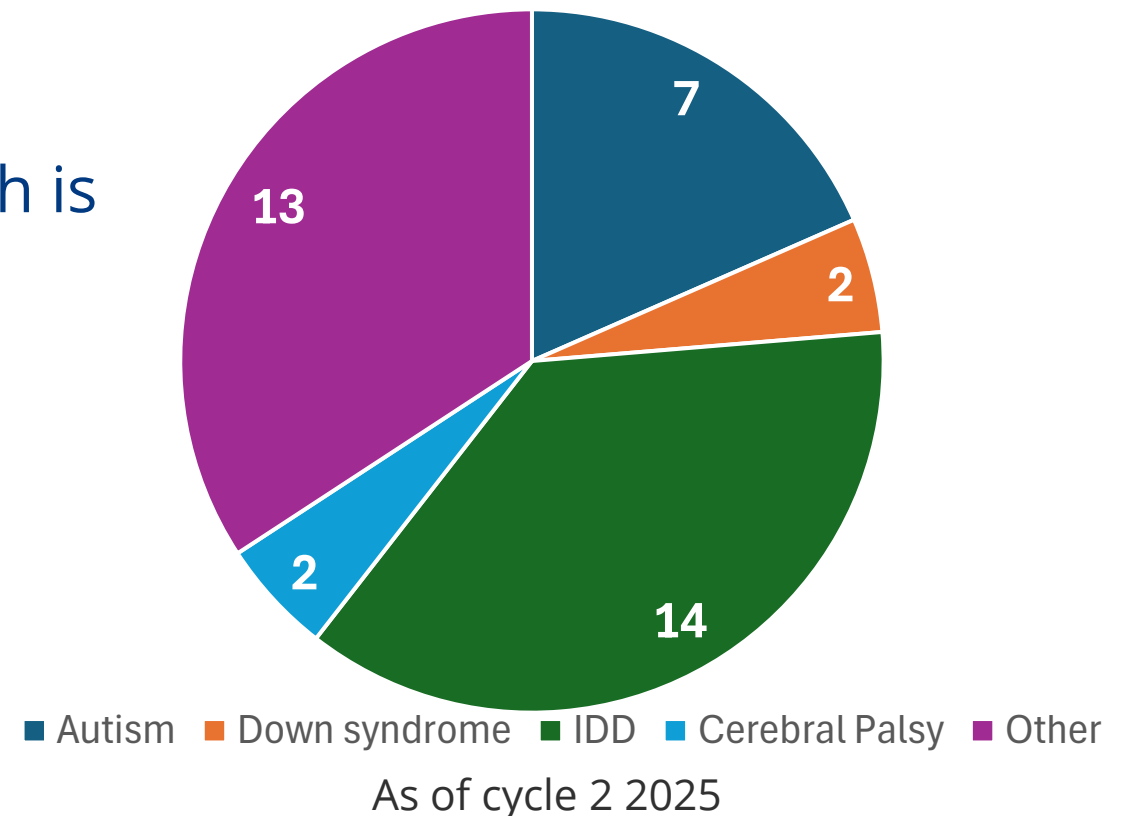
- Patient-centered CER studies evaluate at least two or more interventions and/or service delivery options with evidence of efficacy or widespread use to decide which is best at meeting the needs of people with IDD.

Focus Areas

Community living
Healthcare use
Mental health
Caregiving

Symptom management/medications

38 CER Awards



PCORnet®: Access to Clinical Data and Research Expertise on a National Scale

8

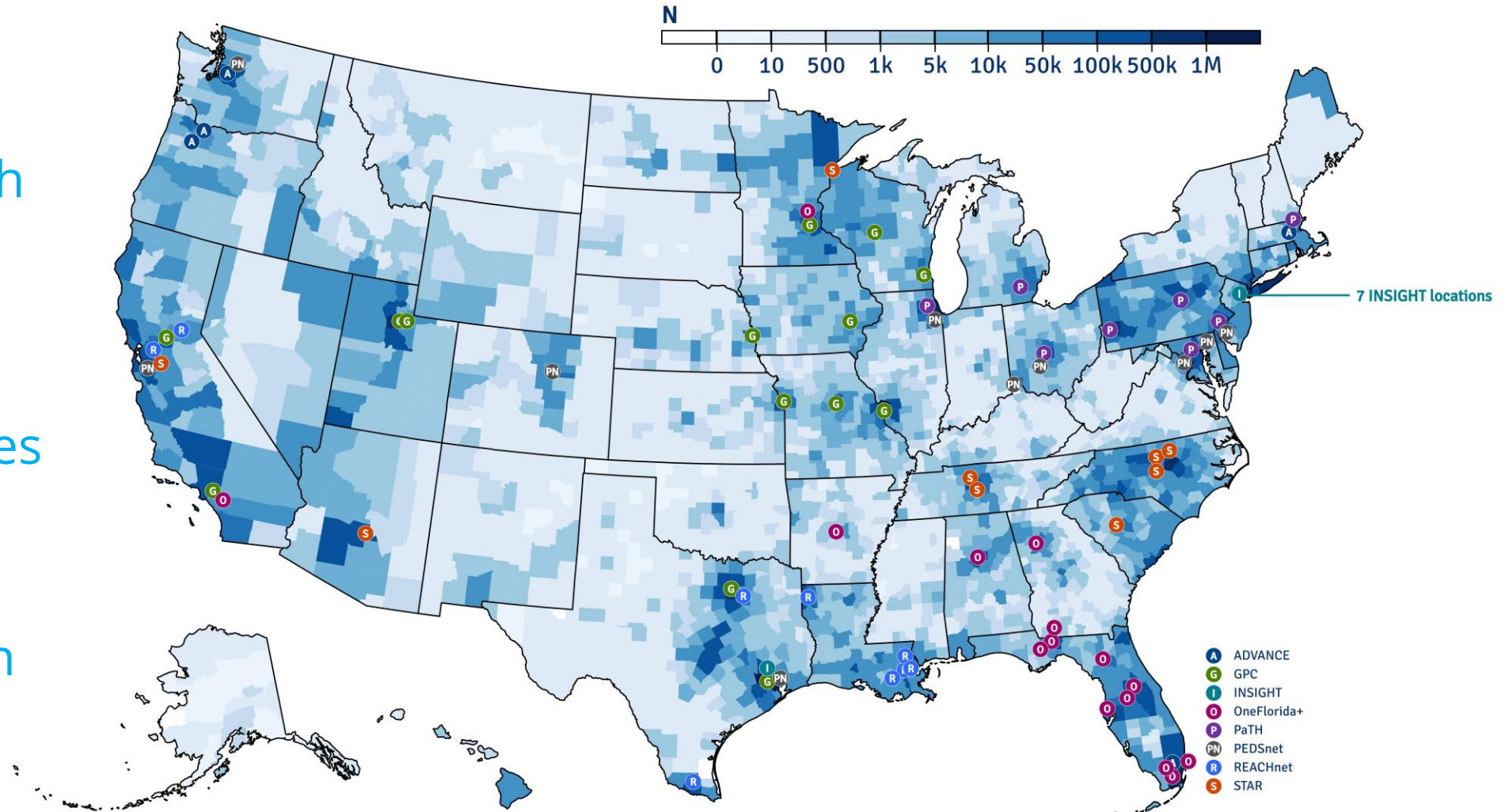
Clinical Research Networks

13K+

Clinical Care Sites

50M+

Patients With an Encounter



PCORnet®: A Vetted National Resource



50

States

PCORnet is linked to patients in every state in the U.S.

>50

Million People

PCORnet represents data from everyday healthcare encounters with >50 million people annually across the U.S.

66

PCORnet® Studies

Funded by

PCORI
38 (58%)

Federal
18 (27%)

Industry
10 (15%)

78

PCORnet® Network Partners

8 PCORnet® Clinical Research Networks across the U.S.

1,110

Publications

Powered by PCORnet®

\$760

Million

PCORnet® Studies funding by source

PCORI
\$382M
(50%)

Federal
\$328M
(43%)

Industry \$51M (7%)

Over the last 10 years, PCORnet® Studies have already answered critical patient-centered questions on heart disease, metabolic conditions, obesity, and more, demonstrating the power of PCORnet® to improve patient care through efficient, high-quality research.

Research that leverages this network is tapping into a proven engine for discovery.

Data as of May 2026

Unique Features of PCORnet® That Investigators Can Use To Optimize Patient-Centered Research



**Prep-to-
Research**



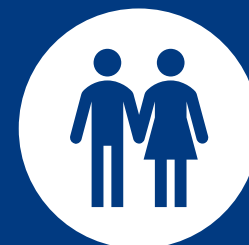
**Tools for Study
Startup**



**Sites for
Recruitment**



**PCORnet®
Common Data
Model**



**Engagement
Tools**



**Dissemination
Tools**

The PCORnet® Front Door

The access point for PCORnet resources and services



A “knock” on the PCORnet® Front Door can support:



STUDY DESIGN

Preliminary data for proposals, effect sizes, and potential study power



DATA NETWORK REQUEST

- Get data insights from PCORnet® Clinical Research Networks
- Obtain aggregated results for informing research project development



CONNECTIONS TO NETWORK COLLABORATORS

- Partners to co-design research
- People with specific expertise



PCORnet® STUDY SUPPORT

Deeper partnership with PCORnet provides access to best practice sharing, patient engagement, and transparent quality improvement initiatives



[Learn More About the Front Door](#)

Ways PCORnet® Can Support IDD Research



In 2024, PCORI awarded funding to PCORnet to convene an IDD Workgroup to develop a roadmap to demonstrate a community-engaged approach to accelerate patient-centered CER using PCORnet, including:

- Identifying critical gaps and needs in knowledge, and prioritizing unanswered CER questions
- Conducting a PCORnet query to identify populations with specific conditions that are eligible for study participation
- Identifying questions that can be answered with PCORnet now as well as recommendations for infrastructure enhancements

- Ex: What is the comparative effectiveness of *clinic-based peer support vs community-based peer support* for individuals with IDD on *health-related quality of life, self-reported connection to community resources, and overall well-being*?
- Ex: What is the comparative effectiveness of delivering *melatonin vs behavioral therapy for sleep* among individuals with IDD on *sleep duration, sleep quality, quality of life, and other patient-reported outcome measures (PROMs)*?

[Access the IDD Workgroup Report](#)

Franklin MS, Dolor RJ, Hendren S, Jelliffe-Pawlowski L, Wiley S, Myers SM, Quiñones A, Nowell K, Kanne SM, Kramer JM, Thompson B, Thomas E, Bello J, Pham HMH, Maslow GR.
Medical Care. 2026 Feb 1;64(2S Suppl 3):S301-S313. doi: 10.1097/MLR.0000000000002259

Characterizing Patients with IDD Served by PCORnet® Network Partners

PCORnet® Population Insights Report

Characteristics of the Patient Population with Intellectual and Developmental Disabilities (IDD) Receiving Health Care Services Across PCORnet® Clinical Research Networks in 2025

Rationale for Network Query of PCORnet® Data Resources:

This report characterizes the population of patients with diagnosis codes for intellectual and developmental disabilities (IDD) reflected in their medical record and encounters in a health care setting across PCORnet® between January 1 – December 31, 2025.

The report aligns with the Patient-Centered Outcomes Research Institute's® (PCORI®) strategic goal to demonstrate ways PCORnet can be used to address national-scale patient-centered comparative clinical effectiveness research (CER) questions. The results in this report may support planning for future patient-centered CER using PCORnet on the topic of IDD.

Background on PCORnet®:

PCORnet is a large, distributed "network of networks" funded by PCORI to improve the nation's capacity to efficiently conduct health research, particularly patient-centered CER.

The unique federated architecture of the network enables network sites to query clinical encounter data to identify patients and contact them for recruitment in research studies (with the appropriate regulatory and legal agreements). PCORnet has been used to conduct more than 300 studies, including pragmatic trials, observational research, and data science studies. [PCORnet® Population Insights Reports](#) are created to provide descriptive insights into the feasibility of research questions and the potential to recruit patients for future research using PCORnet.

At the time of this report, PCORnet® Network Partners include eight PCORnet® Clinical Research Networks (CRNs) with 78 partner sites in addition to Patient Partners and the Coordinating Center for PCORnet®. Collectively, these sites are connected to more than 50 million people in the United States and include large academic health systems, hospitals, federally qualified health centers, and community clinics.

For more information on the structure and governance of PCORnet, please see the [PCORnet® Playbook](#).

[Learn more about PCORnet Population Insights](#)

- PCORnet® Network Partners serve many patients with IDD-related conditions and co-occurring chronic conditions
- PCORI and the Coordinating Center for PCORnet® worked together to identify characteristics of the patients with IDD-related conditions and an encounter at a PCORnet site in 2025.
- PCORnet can be used to:
 - Describe use of healthcare services by patients with IDD
 - Describe experience of chronic conditions for people with IDD
 - Show how people with IDD can be identified in research data
 - Develop computable phenotypes for IDD
- PCORnet supports the largest known, national-scale descriptive analysis of IDD population using EHR data
 - PCORnet can support large studies for IDD research

IDD Population Insights Report From PCORnet®

Characteristics of Patients With an Encounter in 2025



3.8M
Patients seen in
2025 with at
least 1 **IDD**
Condition since
2021

45.0%
Female patients

IDD CONDITIONS	N	S%	P%
ADHD	2,038,650	53.6	3.8
Learning Disability	1,170,205	30.8	2.2
Autism Spectrum Disorder	681,450	17.9	1.3
Developmental Delay	448,308	11.8	0.8
Cerebral Palsy	139,547	3.7	0.3
Congenital Malformations of Brain	138,739	3.6	0.3
Failure to thrive	121,255	3.2	0.2
Intellectual Disability ICD-10 Codes	73,378	1.9	0.1
Down Syndrome	68,861	1.8	0.1
Muscular Dystrophy	39,414	1	0.1
Additional conditions representing less than 1% each in table at end of these slides.	35,358	0.9	0.1

28.2%
Medicaid

PAYER STATUS	N	S%	P%
Private	1,527,436	40.2	40.7
Medicare	191,104	5	15.5
Medicaid	1,070,973	28.2	15
Other	162,748	4.3	3.6
Missing	851,473	22.4	25.2

[Learn more about PCORnet Population Insights](#)

53,351,854 patients with at least one face-to-face encounter and a recorded diagnosis at a PCORnet® site in 2025.

IDD Population Insights Report From PCORnet®

Characteristics and Services for of Patients Identified with IDD and Encounter in 2025



CLINICAL SERVICES	N	S%	P%
Wellness Visit	1,510,281	39.7	24.4
Audiology	441,771	11.6	4.1
PT/OT Treatments	204,680	5.4	3.9
PT Evaluation/Re-evaluation	191,322	5	3.8
Vision services	114,723	3	3.7
Psych Evaluation/Psychotherapy	314,965	8.3	2.1
Oral Exams	72,460	1.9	1.7
OT Evaluation/re-evaluation	91,727	2.4	1.7
Speech Therapy	91,149	2.4	0.6
Neuropsych Evaluation	18,353	0.5	0.1
Orthotic	6,518	0.2	0.1
Wheelchair	7,021	0.2	0.1

53,351,854 patients with at least one face-to-face encounter and a recorded diagnosis at a PCORnet® site in 2025.

26.4%
With Telehealth visits

Demographics and Geography

- 63.6% White, 14.2% Black or African American, 3.6% Asian, 3.2% multiple race
- 93.2% have address data at 5-digit ZIP
- ~4% live in small towns or rural areas

[Learn more about PCORnet Population Insights](#)

Example of a Focused Funding Award

SAE: Gastrointestinal Health

What PCORI heard:

- Gastrointestinal (GI) symptoms are prevalent in the IDD population
- Strategies addressing GI health are often applied without evidence of effectiveness

Funding opportunity:

- Comparative Effectiveness Research (CER) addressing GI health that consider the physical, cognitive, behavioral and communication needs of this population

FUNDING CER AWARD

Comparing Polyethylene Glycol 3350 versus Linaclootide in Autistic Children with Constipation

BRIEF REPORT

High Burden of Constipation Among Autistic Youth: A Nationwide Query Powered by PCORnet

- More than double the prevalence of constipation in autistic youths (aged 6-17) compared with non-autistic youths
- Constipation associated with greater unplanned use of healthcare such as emergency room visits or hospitalizations

Chumpitazi BP, Zelinski A, Marchesani N, Brantner CL, Tomaiuolo M, Kappelman MD. High Burden of Constipation Among Autistic Youth: A Nationwide Query Powered by PCORnet. Am J Gastroenterol. 2026 Feb 18. doi: 10.14309/ajg.00000000000003967.

Example of a Focused Funding Award

SAE: Improving GI Health for Individuals with IDD

FUNDING AWARD

Comparing Polyethylene Glycol 3350 versus Linaclotide in Autistic Children With Constipation

Principal Investigator – Bruno Chumpitazi (awarded 2026)

Organization – Duke University

Key Study Features

Design: Randomized controlled trial of 320 autistic children (ages 6-17) with functional constipation across 30 primary care and behavioral health clinics across the U.S.

- Polyethylene Glycol 3350
- Linaclotide

Primary Outcome: Constipation burden

Secondary Outcomes: Spontaneous bowel movements, undesirable behaviors, patient, caregiver and clinician perspectives on acceptability and barriers to implementation.

Community Partners:

- Individuals with autism, parents of autistic children, clinicians, patient advocacy organizations, payers and health policymakers.

Leveraging PCORnet®

- Learning system to assess generalizability of study findings

Comparing Polyethylene Glycol 3350 Versus Linaclotide in Autistic Children With Constipation | PCORI

Contact Information

Nik Koscielniak, Program Officer



nkoscielniak@pcori.org



www.pcori.org



/PCORI



@PCORI_ORG



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@PCORI



@PCORINews

Data Security and Privacy of the PCORnet® Infrastructure



- The following steps have been taken to minimize risks to patient privacy and ensure that the PCORnet data infrastructure is aligned with best practices for data security
 - **PCORnet® Data Sharing Agreement** defines the standard terms to which the Coordinating Center for PCORnet® will adhere when data are sent from the Network Partners to the Coordinating Center for network data requests (e.g., prep-to-research queries).
 - The **PCORnet® CDM** maintained by sites exists at the level of a HIPAA Limited Data Set, allowing for the inclusion of data elements like dates of service and zip codes.
 - Patient level data are only shared as part of specific study activities, which are governed by separate IRB protocols and data use agreements
 - The Coordinating Center for PCORnet® distributes prep-to-research queries to Network Partners, with queries **returning aggregate count information**. Table cells with values <11 are suppressed.
 - Capability to support linkage to other data sources or , as PCORnet maintains a **privacy-preserving record linkage** across the network.

IDD Population Insights Report From PCORnet®

Characteristics of Patients With an Encounter in 2025



3.8M

Patients seen in 2025 with at least
1 **IDD Condition** since 2021

45.0%

Female patients

28.2%

Medicaid at encounter in 2025

26.4%

With Telehealth visits in 2025

IDD CONDITIONS	N	S%	P%
ADHD	2,038,650	53.6	3.8
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Down Syndrome	68,861	1.8	0.1
Muscular Dystrophy	39,414	1	0.1
Spina Bifida	35,358	0.9	0.1
Hypoxic-ischemic Encephalopathy	21,646	0.6	<0.1
Fetal Alcohol Syndrome	7,124	0.2	<0.1
Fragile X Syndrome	5,247	0.1	<0.1
Neonatal Stroke	5,165	0.1	<0.1

PAYER STATUS	N	S%	P%
Private	1,527,436	40.2	40.7
Medicare	191,104	5	15.5
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