

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](#).

Population Insights Report Description:

This report describes the results of a data query of the patients with IDD conditions with at least 1 face-to-face encounter and a recorded diagnosis code (e.g., ICD-10) at a health care setting across PCORnet between January 1 – December 31, 2025. The query used a 5-year “look-back” period between January 1, 2021 – December 31, 2025, to identify patients with diagnosis codes for IDD conditions reflected in the electronic health record. The query results will enhance public awareness of the population of patients with IDD conditions as well as utilization of health care services by these patients across sites participating in PCORnet that potentially would be available for future health care research.

Data Query Methodology and Criteria:

The Coordinating Center collaborated with PCORI to develop the specifications and criteria for this data query. Collaborators developed a comprehensive list of diagnosis codes related to IDD to be included. The query identified demographic and geographic characteristics of the referenced patient population with at least 1 face-to-face encounter at a site participating in PCORnet during the 1-year query period (January 1 – December 31, 2025). From this patient population, the query characterized patients who had a diagnosis code for any IDD conditions in their electronic health record within a 5-year period (January 1, 2021 – December 31, 2025). The data query also described additional co-occurring conditions, medications, rehab/treatment, and utilization of health care settings for this patient group.

Additional methods and information used to specify the query and define the cohorts are available upon request by emailing frontdoor@pcornet.org.

The Coordinating Center programmed and distributed this data query to 74 partners in PCORnet.

Population Insights Report Results:

Seventy-four (74) PCORnet partners contributed data to this report, reflecting the experience of patients who received health care services across sites participating in PCORnet during a 1-year period (January 1 – December 31, 2025).

Results of the query are provided in tables referenced below:

- **Table 1.** Demographic characteristics of the patient population with IDD conditions receiving health care services across sites participating in PCORnet between January 1, 2025 – December 31, 2025.
- **Table 2.** Care setting and geographic characteristics for patients with a diagnosis code for IDD conditions with a face-to-face clinical encounter at a site participating in PCORnet between January 1, 2025 – December 31, 2025.
- **Table 3.** Co-occurring conditions, rehab and treatment, and prescribed or administered medications for patients with a face-to-face clinical encounter at a site participating in PCORnet between January 1, 2025 – December 31, 2025, and a recorded diagnosis code for an IDD condition between January 1, 2021 – December 31, 2025.

Limitations:

Data presented are descriptive and derived from diagnosis and procedure codes collected in the electronic health record (EHR) during health care encounters. Rows and percentages may not add up to a total due to missing values and/or if counts are less than 11. If counts are between 1-10, then they are reported as “-” to protect patient privacy and risk of identification from aggregate values as outlined in the [Data Privacy Statement for PCORnet®](#).

No inferential analyses were conducted to compare populations or test hypotheses, as these are descriptive data only. Limitations with any EHR data analysis are applicable to this data, including the possibility for misclassification due to imperfect algorithms and lack of consistent definition of enrollment to define cohorts, in addition to limitations associated with processes to collect clinical data during health care encounters, including collection of demographic information. Data should be interpreted with these limitations in mind.

To ensure PCORnet data resources are of high quality for research and to mitigate the limitations above, all PCORnet-accessible data resources undergo [rigorous quality curation](#) and screening as part of quarterly coordinated data quality assessment. For more information on data curation activities and strategies to improve data quality for PCORnet, please contact frontdoor@pcornet.org.

Disclaimer:

PCORnet® is intended to improve the nation's capacity to efficiently conduct patient-centered health research, particularly CER, by providing a large, highly representative network of health data, research expertise, and patient insights. PCORnet has been developed with funding from the Patient-Centered Outcomes Research Institute® (PCORI®).

Network queries that return only aggregate or limited data sets are covered by [the PCORnet® Master Data Sharing Agreement](#) (version 5.0), and site-level blanket Institutional Review Board approvals. The statements presented in this report do not necessarily represent the views of PCORI or other organizations participating in, collaborating with, or funding PCORnet.

For questions, comments, or suggestions related to this PCORnet® Front Door query or other PCORnet queries, please contact frontdoor@pcornet.org.

Tables

Table 1. Demographic characteristics of the patient population with IDD conditions receiving health care services across sites participating in PCORnet® between January 1, 2025 – December 31, 2025.^{1, 2}

	Total Patients With a Visit and Diagnosis in 2025		Patients with Any IDD		ADHD ⁴		Learning Disabilities ⁴		Autism Spectrum Disorder ⁴		Developmental Delay ⁴		Cerebral Palsy ⁴		Congenital Malformations of the Brain ⁴	
Total	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
UNIQUE PATIENT RECORDS	53,351,854	100	3,803,734	7.1	2,038,650	53.6	1,170,205	30.8	681,450	17.9	448,308	11.8	139,547	3.7	138,739	3.6
MEAN AGE (SD)	41.6 (±23.0)		21.0 (±16.8)		26.6 (±15.5)		10.5 (±12.3)		15.3 (±11.9)		8.2 (±8.5)		26.6 (±17.8)		21.0 (±19.6)	
AGE																
Children 0-9	7,127,465	13.4	1,314,596	34.6	251,469	12.3	788,617	67.4	279,238	41.0	324,228	72.3	31,531	22.6	59,472	42.9
Children 10-19	6,550,128	12.3	1,004,098	26.4	683,196	33.5	278,509	23.8	239,695	35.2	100,743	22.5	36,276	26.0	28,120	20.3
Adults 20-34	8,443,612	15.8	664,562	17.5	508,526	24.9	42,795	3.7	109,949	16.1	14,464	3.2	29,989	21.5	18,477	13.3
Adults 35-54	12,229,983	22.9	545,319	14.3	430,451	21.1	25,698	2.2	35,673	5.2	4,449	1.0	23,678	17.0	16,836	12.1
Adults 55-64	6,658,945	12.5	138,565	3.6	92,799	4.6	12,382	1.1	7,611	1.1	1,593	0.4	8,397	6.0	6,520	4.7
Adults 65-74	6,760,487	12.7	88,261	2.3	50,169	2.5	11,571	1.0	5,533	0.8	1,456	0.3	6,425	4.6	5,658	4.1
Adults 75+	5,581,234	10.5	48,333	1.3	22,040	1.1	10,633	0.9	3,751	0.6	1,375	0.3	3,251	2.3	3,656	2.6
SEX																
Female	29,931,408	56.1	1,705,814	44.9	979,638	48.1	434,941	37.2	201,894	29.6	175,354	39.1	64,020	45.9	72,274	52.1
Male	23,393,366	43.9	2,095,636	55.1	1,057,187	51.9	735,071	62.8	479,051	70.3	272,884	60.9	75,507	54.1	66,437	47.9
Unknown	14,852	<0.1	687	<0.1	530	<0.1	75	<0.1	123	<0.1	20	<0.1	-	-	20	<0.1
Missing ³	6,809	<0.1	630	<0.1	462	<0.1	81	<0.1	167	<0.1	27	<0.1	-	-	-	-
RACE																
American Indian or Alaska Native	326,272	0.6	25,870	0.7	13,857	0.7	8,178	0.7	4,580	0.7	3,062	0.7	901	0.6	872	0.6
Asian	2,608,574	4.9	138,514	3.6	53,166	2.6	55,741	4.8	30,967	4.5	20,971	4.7	4,556	3.3	5,232	3.8
Black or African American	7,708,879	14.4	541,937	14.2	234,196	11.5	227,618	19.5	116,802	17.1	70,774	15.8	24,732	17.7	24,156	17.4
Native Hawaiian or Other Pacific Islander	122,932	0.2	8,135	0.2	3,292	0.2	3,218	0.3	1,802	0.3	1,356	0.3	390	0.3	407	0.3
White	32,310,607	60.6	2,420,002	63.6	1,455,535	71.4	607,701	51.9	384,648	56.4	253,402	56.5	84,873	60.8	81,254	58.6
Multiple Race	1,123,950	2.1	120,781	3.2	55,532	2.7	47,461	4.1	24,605	3.6	18,540	4.1	3,886	2.8	4,151	3.0
Unknown	6,856,925	12.9	443,951	11.7	172,254	8.4	186,227	15.9	97,194	14.3	68,326	15.2	16,781	12.0	18,703	13.5
Missing ³	2,293,715	4.3	104,544	2.7	50,818	2.5	34,061	2.9	20,852	3.1	11,877	2.6	3,428	2.5	3,964	2.9
HISPANIC																
Yes	8,288,329	15.5	637,435	16.8	235,826	11.6	301,521	25.8	139,565	20.5	100,989	22.5	22,839	16.4	25,593	18.4
No	35,534,040	66.6	2,624,821	69.0	1,521,590	74.6	710,940	60.8	444,237	65.2	284,336	63.4	98,874	70.9	94,658	68.2
Unknown	4,709,340	8.8	268,171	7.1	132,292	6.5	83,433	7.1	55,872	8.2	33,071	7.4	9,938	7.1	9,946	7.2
Missing ³	4,820,145	9.0	273,307	7.2	148,942	7.3	74,311	6.4	41,776	6.1	29,912	6.7	7,896	5.7	8,542	6.2
PAYER STATUS (LAST VISIT IN 2025)																
Medicare	8,281,908	15.5	191,104	5.0	82,879	4.1	26,488	2.3	30,369	4.5	4,967	1.1	23,309	16.7	11,602	8.4
Medicaid	7,991,472	15.0	1,070,973	28.2	440,985	21.6	446,263	38.1	268,204	39.4	179,352	40.0	55,765	40.0	52,037	37.5
Private	21,692,487	40.7	1,527,436	40.2	951,029	46.6	386,245	33.0	212,433	31.2	145,124	32.4	29,759	21.3	43,801	31.6
Other	1,947,018	3.6	162,748	4.3	91,317	4.5	50,336	4.3	27,842	4.1	19,617	4.4	3,730	2.7	4,857	3.5
Missing ³	13,438,969	25.2	851,473	22.4	472,440	23.2	260,873	22.3	142,602	20.9	99,248	22.1	26,984	19.3	26,442	19.1
RECORD OF DEATH IN 2025																
Record of Death in 2025	316,713	0.6	11,627	0.3	3,865	0.2	2,066	0.2	1,212	0.2	1,278	0.3	1,639	1.2	1,606	1.2
No Record of Death in 2025	53,035,141	99.4	3,792,107	99.7	2,034,785	99.8	1,168,139	99.8	680,238	99.8	447,030	99.7	137,908	98.8	137,133	98.8

¹Total includes 74 partners in PCORnet.
²Some totals may not add up due to masking low cell sizes.
³Missing includes those values that are null, refuse to answer, and no information.
⁴Denominator for percentage is the count for all patients with IDD conditions.

Table 1 (cont’d). Demographic characteristics of the patient population with IDD conditions receiving health care services across sites participating in PCORnet® between January 1, 2025 – December 31, 2025.^{1, 2}

	Total Patients With a Visit and Diagnosis in 2025		Patients with Any IDD		Failure to Thrive ⁴		Codes Defining Severity of IDD ⁴		Down Syndrome ⁴		Muscular Dystrophy ⁴		Spina Bifida ⁴		Hypoxic-ischemic Encephalopathy ⁴	
Total	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
UNIQUE PATIENT RECORDS	53,351,854	100	3,803,734	7.1	121,255	3.2	73,378	1.9	68,861	1.8	39,414	1.0	35,358	0.9	21,646	0.6
MEAN AGE (SD)	41.6 (±23.0)		21.0 (±16.8)		1.9 (±4.3)		31.7 (±17.3)		19.9 (±15.5)		39.9 (±20.9)		28.8 (±18.8)		8.5 (±13.9)	
AGE																
Children 0-9	7,127,465	13.4	1,314,596	34.6	120,442	99.3	5,946	8.1	23,486	34.1	4,097	10.4	7,732	21.9	16,654	76.9
Children 10-19	6,550,128	12.3	1,004,098	26.4	122	0.1	22,109	30.1	18,355	26.7	6,709	17.0	7,263	20.5	2,924	13.5
Adults 20-34	8,443,612	15.8	664,562	17.5	105	0.1	17,663	24.1	13,497	19.6	6,915	17.5	7,562	21.4	721	3.3
Adults 35-54	12,229,983	22.9	545,319	14.3	226	0.2	14,451	19.7	9,698	14.1	8,767	22.2	7,591	21.5	479	2.2
Adults 55-64	6,658,945	12.5	138,565	3.6	98	0.1	6,399	8.7	2,589	3.8	5,035	12.8	2,441	6.9	300	1.4
Adults 65-74	6,760,487	12.7	88,261	2.3	106	0.1	4,850	6.6	840	1.2	4,813	12.2	1,719	4.9	289	1.3
Adults 75+	5,581,234	10.5	48,333	1.3	156	0.1	1,960	2.7	396	0.6	3,078	7.8	1,050	3.0	279	1.3
SEX																
Female	29,931,408	56.1	1,705,814	44.9	61,460	50.7	31,472	42.9	33,339	48.4	17,480	44.4	20,394	57.7	8,994	41.6
Male	23,393,366	43.9	2,095,636	55.1	59,785	49.3	41,893	57.1	35,515	51.6	21,921	55.6	14,956	42.3	12,648	58.4
Unknown	14,852	<0.1	687	<0.1	-	-	-	-	-	-	-	-	-	-	-	-
Missing ³	6,809	<0.1	630	<0.1	-	-	-	-	-	-	-	-	-	-	-	-
RACE																
American Indian or Alaska Native	326,272	0.6	25,870	0.7	587	0.5	498	0.7	388	0.6	230	0.6	235	0.7	141	0.7
Asian	2,608,574	4.9	138,514	3.6	7,237	6.0	2,188	3.0	2,554	3.7	1,440	3.7	1,089	3.1	1,003	4.6
Black or African American	7,708,879	14.4	541,937	14.2	18,836	15.5	14,613	19.9	8,221	11.9	3,087	7.8	3,887	11.0	4,351	20.1
Native Hawaiian or Other Pacific Islander	122,932	0.2	8,135	0.2	229	0.2	137	0.2	192	0.3	80	0.2	66	0.2	90	0.4
White	32,310,607	60.6	2,420,002	63.6	67,366	55.6	45,078	61.4	42,906	62.3	28,462	72.2	23,930	67.7	10,946	50.6
Multiple Race	1,123,950	2.1	120,781	3.2	5,227	4.3	1,884	2.6	2,018	2.9	713	1.8	728	2.1	998	4.6
Unknown	6,856,925	12.9	443,951	11.7	18,444	15.2	7,337	10.0	10,696	15.5	4,332	11.0	4,546	12.9	3,570	16.5
Missing ³	2,293,715	4.3	104,544	2.7	3,329	2.7	1,643	2.2	1,886	2.7	1,070	2.7	877	2.5	547	2.5
HISPANIC																
Yes	8,288,329	15.5	637,435	16.8	20,001	16.5	10,327	14.1	15,865	23.0	4,969	12.6	6,413	18.1	4,103	19.0
No	35,534,040	66.6	2,624,821	69.0	78,457	64.7	55,361	75.4	43,534	63.2	28,936	73.4	24,090	68.1	13,962	64.5
Unknown	4,709,340	8.8	268,171	7.1	9,086	7.5	3,561	4.9	5,122	7.4	2,777	7.0	2,763	7.8	1,968	9.1
Missing ³	4,820,145	9.0	273,307	7.2	13,711	11.3	4,129	5.6	4,340	6.3	2,732	6.9	2,092	5.9	1,613	7.5
PAYER STATUS (LAST VISIT IN 2025)																
Medicare	8,281,908	15.5	191,104	5.0	270	0.2	18,474	25.2	9,468	13.7	8,401	21.3	5,389	15.2	630	2.9
Medicaid	7,991,472	15.0	1,070,973	28.2	35,642	29.4	28,289	38.6	27,176	39.5	8,336	21.1	10,966	31.0	9,458	43.7
Private	21,692,487	40.7	1,527,436	40.2	54,616	45.0	9,896	13.5	16,536	24.0	12,702	32.2	10,533	29.8	6,888	31.8
Other	1,947,018	3.6	162,748	4.3	5,498	4.5	2,257	3.1	2,276	3.3	1,173	3.0	1,218	3.4	794	3.7
Missing ³	13,438,969	25.2	851,473	22.4	25,229	20.8	14,462	19.7	13,405	19.5	8,802	22.3	7,252	20.5	3,876	17.9
RECORD OF DEATH IN 2025																
Record of Death in 2025	316,713	0.6	11,627	0.3	122	0.1	910	1.2	538	0.8	641	1.6	303	0.9	868	4.0
No Record of Death in 2025	53,035,141	99.4	3,792,107	99.7	121,133	99.9	72,468	98.8	68,323	99.2	38,773	98.4	35,055	99.1	20,778	96.0

¹Total includes 74 partners in PCORnet.
²Some totals may not add up due to masking low cell sizes.
³Missing includes those values that are null, refuse to answer, and no information.
⁴Denominator for percentage is the count for all patients with IDD conditions.

Table 1 (cont’d). Demographic characteristics of the patient population with IDD conditions receiving health care services across sites participating in PCORnet® between January 1, 2025 – December 31, 2025.^{1, 2}

	Total Patients With a Visit and Diagnosis in 2025		Patients with Any IDD		Fetal Alcohol Syndrome ⁴		Fragile X Syndrome ⁴		Neonatal Stroke ⁴	
Total	N	%	N	%	N	%	N	%	N	%
UNIQUE PATIENT RECORDS	53,351,854	100	3,803,734	7.1	7,124	0.2	5,247	<0.1	5,165	0.1
MEAN AGE (SD)	41.6 (±23.0)		21.0 (±16.8)		21.2 (±12.9)		29.2 (±18.4)		9.2 (±12.8)	
AGE										
Children 0-9	7,127,465	13.4	1,314,596	34.6	1,369	19.2	907	17.3	3,629	70.3
Children 10-19	6,550,128	12.3	1,004,098	26.4	2,673	37.5	1,204	22.9	994	19.2
Adults 20-34	8,443,612	15.8	664,562	17.5	1,906	26.8	1,307	24.9	275	5.3
Adults 35-54	12,229,983	22.9	545,319	14.3	949	13.3	1,097	20.9	124	2.4
Adults 55-64	6,658,945	12.5	138,565	3.6	138	1.9	273	5.2	39	0.8
Adults 65-74	6,760,487	12.7	88,261	2.3	63	0.9	299	5.7	40	0.8
Adults 75+	5,581,234	10.5	48,333	1.3	26	0.4	160	3.0	64	1.2
SEX										
Female	29,931,408	56.1	1,705,814	44.9	3,355	47.1	2,020	38.5	2,195	42.5
Male	23,393,366	43.9	2,095,636	55.1	3,767	52.9	3,231	61.6	2,970	57.5
Unknown	14,852	<0.1	687	<0.1	0	0	0	0	0	0
Missing ³	6,809	<0.1	630	<0.1	-	-	-	-	0	0
RACE										
American Indian or Alaska Native	326,272	0.6	25,870	0.7	453	6.4	30	0.6	35	0.7
Asian	2,608,574	4.9	138,514	3.6	73	1.0	146	2.8	219	4.2
Black or African American	7,708,879	14.4	541,937	14.2	1,294	18.2	563	10.7	719	13.9
Native Hawaiian or Other Pacific Islander	122,932	0.2	8,135	0.2	25	0.4	12	0.2	-	-
White	32,310,607	60.6	2,420,002	63.6	4,315	60.6	3,566	68.0	3,121	60.4
Multiple Race	1,123,950	2.1	120,781	3.2	314	4.4	123	2.3	211	4.1
Unknown	6,856,925	12.9	443,951	11.7	508	7.1	626	11.9	736	14.2
Missing ³	2,293,715	4.3	104,544	2.7	142	2.0	181	3.4	120	2.3
HISPANIC										
Yes	8,288,329	15.5	637,435	16.8	625	8.8	827	15.8	904	17.5
No	35,534,040	66.6	2,624,821	69.0	5,190	72.9	3,678	70.1	3,589	69.5
Unknown	4,709,340	8.8	268,171	7.1	505	7.1	371	7.1	370	7.2
Missing ³	4,820,145	9.0	273,307	7.2	804	11.3	371	7.1	302	5.8
PAYER STATUS (LAST VISIT IN 2025)										
Medicare	8,281,908	15.5	191,104	5.0	832	11.7	897	17.1	157	3.0
Medicaid	7,991,472	15.0	1,070,973	28.2	2,731	38.3	1,517	28.9	2,073	40.1
Private	21,692,487	40.7	1,527,436	40.2	1,094	15.4	1,546	29.5	1,900	36.8
Other	1,947,018	3.6	162,748	4.3	397	5.6	164	3.1	190	3.7
Missing ³	13,438,969	25.2	851,473	22.4	2,070	29.1	1,123	21.4	845	16.4
RECORD OF DEATH IN 2025										
Record of Death in 2025	316,713	0.6	11,627	0.3	18	0.3	33	0.6	100	1.9
No Record of Death in 2025	53,035,141	99.4	3,792,107	99.7	7,106	99.7	5,214	99.4	5,065	98.1

¹Total includes 74 partners in PCORnet.
²Some totals may not add up due to masking low cell sizes.
³Missing includes those values that are null, refuse to answer, and no information.
⁴Denominator for percentage is the count for all patients with IDD conditions.

Table 2. Care setting and geographic characteristics for patients with a diagnosis code for IDD conditions with a face-to-face clinical encounter at a site participating in PCORnet® between January 1, 2025 – December 31, 2025.^{1,2}

	Total Patients With a Visit and Diagnosis in 2025		Patients with Any IDD		ADHD ⁴		Learning Disability ⁴		Autism Spectrum Disorder ⁴		Developmental Delay ⁴		Cerebral Palsy ⁴		Congenital Malformations of the Brain ⁴	
Total	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
UNIQUE PATIENT RECORDS	53,351,854	100	3,803,734	7.1	2,038,650	53.6	1,170,205	30.8	681,450	17.9	448,308	11.8	139,547	3.7	138,739	3.6
CARE SETTING ENCOUNTER 2025																
Ambulatory Visit	46,253,012	86.7	3,521,100	92.6	1,868,681	91.7	1,120,493	95.8	614,036	90.1	429,346	95.8	128,694	92.2	127,590	92.0
Emergency Department Visit	10,106,998	18.9	652,170	17.1	333,440	16.4	197,778	16.9	128,717	18.9	88,845	19.8	30,283	21.7	32,961	23.8
Emergency to Inpatient Stay	1,369,908	2.6	95,234	2.5	50,321	2.5	19,111	1.6	14,555	2.1	11,852	2.6	9,345	6.7	8,194	5.9
Inpatient Hospital Stay	3,310,281	6.2	245,399	6.5	112,810	5.5	53,511	4.6	39,094	5.7	38,180	8.5	19,642	14.1	27,652	19.9
Non-Acute Institutional Stay	671,777	1.3	20,943	0.6	9,114	0.4	5,319	0.5	3,465	0.5	3,246	0.7	2,489	1.8	1,830	1.3
Observation Stay	654,455	1.2	60,595	1.6	28,393	1.4	19,189	1.6	12,716	1.9	13,491	3.0	5,207	3.7	5,738	4.1
Telehealth	7,900,400	14.8	1,004,896	26.4	681,354	33.4	234,425	20.0	191,426	28.1	124,171	27.7	41,992	30.1	41,824	30.1
AREA DEPRIVATION INDEX (ADI) QUARTILE BASED ON 5-DIGIT ZIP ³																
ADI Quartile 1 (Higher Socioeconomic Status)	20,584,023	38.6	1,488,800	39.1	849,754	41.7	419,033	35.8	246,417	36.2	163,848	36.5	46,004	33.0	45,344	32.7
ADI Quartile 2	9,406,685	17.6	701,041	18.4	383,699	18.8	209,395	17.9	123,493	18.1	79,901	17.8	26,283	18.8	25,910	18.7
ADI Quartile 3	10,386,096	19.5	745,777	19.6	395,033	19.4	228,615	19.5	137,207	20.1	88,126	19.7	31,291	22.4	30,516	22.0
ADI Quartile 4 (Lower Socioeconomic Status)	8,375,144	15.7	575,142	15.1	253,554	12.4	224,076	19.1	114,400	16.8	74,155	16.5	24,765	17.7	24,772	17.9
Missing ⁵	4,599,906	8.6	292,974	7.7	156,610	7.7	89,086	7.6	59,933	8.8	42,278	9.4	11,204	8.0	12,197	8.8
RURAL-URBAN COMMUTING AREA CODES BASED ON 5-DIGIT ZIP ⁶																
Metropolitan Area	42,972,651	80.5	3,117,065	81.9	1,657,809	81.3	980,386	83.8	555,061	81.5	361,990	80.7	110,001	78.8	108,872	78.5
Micropolitan Area	3,674,470	6.9	259,314	6.8	147,647	7.2	66,357	5.7	45,014	6.6	28,762	6.4	11,914	8.5	11,163	8.0
Small Town	1,499,402	2.8	97,022	2.6	55,087	2.7	24,775	2.1	16,076	2.4	10,954	2.4	4,619	3.3	4,624	3.3
Rural	1,008,488	1.9	58,700	1.5	34,637	1.7	14,276	1.2	9,117	1.3	6,210	1.4	2,606	1.9	2,614	1.9
Missing ⁵	4,196,843	7.9	271,633	7.1	143,470	7.0	84,411	7.2	56,182	8.2	40,392	9.0	10,407	7.5	11,466	8.3
U.S. CENSUS REGION																
West	10,581,500	19.8	747,962	19.7	399,135	19.6	212,610	18.2	141,491	20.8	85,512	19.1	28,167	20.2	24,342	17.5
Midwest	9,158,648	17.2	781,665	20.5	459,624	22.5	221,879	19.0	124,182	18.2	96,811	21.6	29,518	21.2	28,335	20.4
Northeast	9,636,477	18.1	642,472	16.9	315,275	15.5	213,419	18.2	126,939	18.6	72,290	16.1	21,398	15.3	24,554	17.7
South	18,845,286	35.3	1,330,247	35.0	706,481	34.7	430,281	36.8	228,118	33.5	150,824	33.6	48,650	34.9	49,055	35.4
Other	785,513	1.5	23,744	0.6	10,579	0.5	6,528	0.6	2,916	0.4	2,394	0.5	1,263	0.9	1,130	0.8
Missing ⁵	4,344,430	8.1	277,644	7.3	147,556	7.2	85,488	7.3	57,804	8.5	40,477	9.0	10,551	7.6	11,323	8.2
AVAILABILITY OF 5-DIGIT ZIP DATA																
Total Number of Unique Patients	49,282,819	92.4	3,546,729	93.2	1,900,784	93.2	1,091,728	93.3	626,902	92.0	410,180	91.5	129,454	92.8	127,820	92.1

¹Total includes 74 partners in PCORnet.

²Some totals may not add up due to masking low cell sizes.

³Area Deprivation Index (ADI): Patient 5-digit zip codes are mapped to socioeconomic status by normalized Area Deprivation Index (ADI) value (0-100). Lower values are associated with higher socioeconomic status (SES) and higher values are associated with lower SES. A ranking of 1 indicates the highest level of SES within the nation and an ADI with a ranking of 100 indicates the lowest level of SES. In this table, values are grouped into quartiles using the count of zip codes. Quartile 1 (Higher SES) represents the lowest range of ADI values and Quartile 4 (Lower SES) represents the highest range of ADI values (Q1=0-38, Q2=39-43, Q3=44-49, and Q4=50-100). For additional information regarding the ADI index, see the Neighborhood Atlas: <https://www.neighborhoodatlas.medicine.wisc.edu>. Note that the Area Deprivation Index (ADI) is designed for validity at the 9-digit zip or census block group level rather than the 5-digit zip level.

⁴Denominator for percentage is the count for all patients with IDD conditions.

⁵Missing includes those values that are null, refuse to answer, and no information.

⁶Represented as combined [Rural-Urban Commuting Area \(RUCA\) codes](#) as referenced on https://hcup-us.ahrq.gov/db/vars/siddistnote.jsp?var=pl_ruca4. RUCA contains 10 primary and 21 secondary codes which delineate components of rural and urban areas and define county-level metropolitan (urban) and nonmetropolitan areas (i.e., micropolitan/large rural areas, small towns, and isolated rural areas).

Table 2 (cont’d). Care setting and geographic characteristics for patients with a diagnosis code for IDD conditions with a face-to-face clinical encounter at a site participating in PCORnet® between January 1, 2025 – December 31, 2025.^{1,2}

	Total Patients With a Visit and Diagnosis in 2025		Patients with Any IDD		Failure to Thrive ⁴		Codes Defining Severity of IDD ⁴		Down Syndrome ⁴		Muscular Dystrophy ⁴		Spina Bifida ⁴		Hypoxic-ischemic Encephalopathy ⁴	
Total	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
UNIQUE PATIENT RECORDS	53,351,854	100	3,803,734	7.1	121,255	3.2	73,378	1.9	68,861	1.8	39,414	1.0	35,358	0.9	21,646	0.6
CARE SETTING ENCOUNTER 2025																
Ambulatory Visit	46,253,012	86.7	3,521,100	92.6	118,579	97.8	67,272	91.7	64,535	93.7	36,880	93.6	32,820	92.8	19,235	88.9
Emergency Department Visit	10,106,998	18.9	652,170	17.1	22,163	18.3	18,642	25.4	11,147	16.2	6,134	15.6	7,793	22.0	5,196	24.0
Emergency to Inpatient Stay	1,369,908	2.6	95,234	2.5	1,983	1.6	5,962	8.1	2,483	3.6	2,180	5.5	2,371	6.7	1,558	7.2
Inpatient Hospital Stay	3,310,281	6.2	245,399	6.5	18,152	15.0	9,289	12.7	7,360	10.7	3,962	10.1	6,029	17.1	6,199	28.6
Non-Acute Institutional Stay	671,777	1.3	20,943	0.6	294	0.2	806	1.1	899	1.3	763	1.9	752	2.1	363	1.7
Observation Stay	654,455	1.2	60,595	1.6	1,505	1.2	2,348	3.2	1,813	2.6	986	2.5	1,128	3.2	1,011	4.7
Telehealth	7,900,400	14.8	1,004,896	26.4	11,575	9.5	24,202	33.0	13,601	19.8	11,862	30.1	10,129	28.6	5,617	25.9
AREA DEPRIVATION INDEX (ADI) QUARTILE BASED ON 5-DIGIT ZIP³																
ADI Quartile 1 (Higher Socioeconomic Status)	20,584,023	38.6	1,488,800	39.1	52,023	42.9	20,623	28.1	25,040	36.4	15,332	38.9	11,003	31.1	7,457	34.4
ADI Quartile 2	9,406,685	17.6	701,041	18.4	22,110	18.2	14,611	19.9	12,669	18.4	7,375	18.7	7,009	19.8	3,912	18.1
ADI Quartile 3	10,386,096	19.5	745,777	19.6	21,233	17.5	18,371	25.0	13,869	20.1	7,944	20.2	8,297	23.5	4,559	21.1
ADI Quartile 4 (Lower Socioeconomic Status)	8,375,144	15.7	575,142	15.1	17,756	14.6	13,718	18.7	11,210	16.3	5,063	12.8	6,161	17.4	3,595	16.6
Missing ⁵	4,599,906	8.6	292,974	7.7	8,133	6.7	6,055	8.3	6,073	8.8	3,700	9.4	2,888	8.2	2,123	9.8
RURAL-URBAN COMMUTING AREA CODES BASED ON 5-DIGIT ZIP⁶																
Metropolitan Area	42,972,651	80.5	3,117,065	81.9	103,268	85.2	55,409	75.5	54,438	79.1	30,394	77.1	26,980	76.3	17,094	79.0
Micropolitan Area	3,674,470	6.9	259,314	6.8	6,924	5.7	7,658	10.4	5,174	7.5	3,303	8.4	3,398	9.6	1,568	7.2
Small Town	1,499,402	2.8	97,022	2.6	2,002	1.7	3,013	4.1	2,305	3.3	1,392	3.5	1,410	4.0	656	3.0
Rural	1,008,488	1.9	58,700	1.5	1,200	1.0	1,701	2.3	1,309	1.9	905	2.3	899	2.5	310	1.4
Missing ⁵	4,196,843	7.9	271,633	7.1	7,861	6.5	5,597	7.6	5,635	8.2	3,420	8.7	2,671	7.6	2,018	9.3
U.S. CENSUS REGION																
West	10,581,500	19.8	747,962	19.7	16,205	13.4	10,693	14.6	15,748	22.9	7,872	20.0	6,389	18.1	4,837	22.3
Midwest	9,158,648	17.2	781,665	20.5	16,795	13.9	22,423	30.6	12,996	18.9	8,605	21.8	7,373	20.9	4,007	18.5
Northeast	9,636,477	18.1	642,472	16.9	36,585	30.2	15,075	20.5	9,866	14.3	5,645	14.3	5,151	14.6	3,238	15.0
South	18,845,286	35.3	1,330,247	35.0	42,635	35.2	19,119	26.1	23,984	34.8	13,332	33.8	13,428	38.0	7,282	33.6
Other	785,513	1.5	23,744	0.6	1,369	1.1	591	0.8	748	1.1	523	1.3	369	1.0	271	1.3
Missing ⁵	4,344,430	8.1	277,644	7.3	7,666	6.3	5,477	7.5	5,519	8.0	3,437	8.7	2,648	7.5	2,011	9.3
AVAILABILITY OF 5-DIGIT ZIP DATA																
Total Number of Unique Patients	49,282,819	92.4	3,546,729	93.2	114,753	94.6	68,117	92.8	63,631	92.4	36,059	91.5	32,789	92.7	19,773	91.3

¹Total includes 74 partners in PCORnet.

²Some totals may not add up due to masking low cell sizes.

³Area Deprivation Index (ADI): Patient 5-digit zip codes are mapped to socioeconomic status by normalized Area Deprivation Index (ADI) value (0-100). Lower values are associated with higher socioeconomic status (SES) and higher values are associated with lower SES. A ranking of 1 indicates the highest level of SES within the nation and an ADI with a ranking of 100 indicates the lowest level of SES. In this table, values are grouped into quartiles using the count of zip codes. Quartile 1 (Higher SES) represents the lowest range of ADI values and Quartile 4 (Lower SES) represents the highest range of ADI values (Q1=0-38, Q2=39-43, Q3=44-49, and Q4=50-100). For additional information regarding the ADI index, see the Neighborhood Atlas: <https://www.neighborhoodatlas.medicine.wisc.edu>. Note that the Area Deprivation Index (ADI) is designed for validity at the 9-digit zip or census block group level rather than the 5-digit zip level.

⁴Denominator for percentage is the count for all patients with IDD conditions.

⁵Missing includes those values that are null, refuse to answer, and no information.

⁶Represented as combined [Rural-Urban Commuting Area \(RUCA\) codes](#) as referenced on https://hcup-us.ahrq.gov/db/vars/siddistnote.jsp?var=pl_ruca4. RUCA contains 10 primary and 21 secondary codes which delineate components of rural and urban areas and define county-level metropolitan (urban) and nonmetropolitan areas (i.e., micropolitan/large rural areas, small towns, and isolated rural areas).

Table 2 (cont’d). Care setting and geographic characteristics for patients with a diagnosis code for IDD conditions with a face-to-face clinical encounter at a site participating in PCORnet® between January 1, 2025 – December 31, 2025.^{1,2}

	Total Patients With a Visit and Diagnosis in 2025		Patients with Any IDD		Fetal Alcohol Syndrome ⁴		Fragile X Syndrome ⁴		Neonatal Stroke ⁴	
Total	N	%	N	%	N	%	N	%	N	%
UNIQUE PATIENT RECORDS	53,351,854	100	3,803,734	7.1	7,124	0.2	5,247	<0.1	5,165	0.1
CARE SETTING ENCOUNTER 2025										
Ambulatory Visit	46,253,012	86.7	3,521,100	92.6	6,344	89.1	4,718	89.9	4,822	93.4
Emergency Department Visit	10,106,998	18.9	652,170	17.1	1,954	27.4	818	15.6	1,145	22.2
Emergency to Inpatient Stay	1,369,908	2.6	95,234	2.5	404	5.7	177	3.4	235	4.5
Inpatient Hospital Stay	3,310,281	6.2	245,399	6.5	653	9.2	476	9.1	1,174	22.7
Non-Acute Institutional Stay	671,777	1.3	20,943	0.6	36	0.5	36	0.7	48	0.9
Observation Stay	654,455	1.2	60,595	1.6	154	2.2	105	2.0	261	5.1
Telehealth	7,900,400	14.8	1,004,896	26.4	2,242	31.5	1,542	29.4	1,548	30.0
AREA DEPRIVATION INDEX (ADI) QUARTILE BASED ON 5-DIGIT ZIP ³										
ADI Quartile 1 (Higher Socioeconomic Status)	20,584,023	38.6	1,488,800	39.1	2,252	31.6	2,118	40.4	2,003	38.8
ADI Quartile 2	9,406,685	17.6	701,041	18.4	1,385	19.4	969	18.5	974	18.9
ADI Quartile 3	10,386,096	19.5	745,777	19.6	1,582	22.2	1,014	19.3	981	19.0
ADI Quartile 4 (Lower Socioeconomic Status)	8,375,144	15.7	575,142	15.1	810	11.4	703	13.4	780	15.1
Missing ⁵	4,599,906	8.6	292,974	7.7	1,095	15.4	443	8.4	427	8.3
RURAL-URBAN COMMUTING AREA CODES BASED ON 5-DIGIT ZIP ⁶										
Metropolitan Area	42,972,651	80.5	3,117,065	81.9	4,809	67.5	4,160	79.3	4,105	79.5
Micropolitan Area	3,674,470	6.9	259,314	6.8	744	10.4	434	8.3	404	7.8
Small Town	1,499,402	2.8	97,022	2.6	313	4.4	162	3.1	168	3.3
Rural	1,008,488	1.9	58,700	1.5	210	2.9	87	1.7	90	1.7
Missing ⁵	4,196,843	7.9	271,633	7.1	1,048	14.7	404	7.7	398	7.7
U.S. CENSUS REGION										
West	10,581,500	19.8	747,962	19.7	1,483	20.8	1,126	21.5	1,150	22.3
Midwest	9,158,648	17.2	781,665	20.5	2,545	35.7	1,166	22.2	1,051	20.3
Northeast	9,636,477	18.1	642,472	16.9	465	6.5	986	18.8	975	18.9
South	18,845,286	35.3	1,330,247	35.0	1,546	21.7	1,520	29.0	1,564	30.3
Other	785,513	1.5	23,744	0.6	29	0.4	32	0.6	40	0.8
Missing ⁵	4,344,430	8.1	277,644	7.3	1,056	14.8	417	7.9	385	7.5
AVAILABILITY OF 5-DIGIT ZIP DATA										
Total Number of Unique Patients	49,282,819	92.4	3,546,729	93.2	6,088	85.5	4,852	92.5	4,797	92.9

¹Total includes 74 partners in PCORnet.

²Some totals may not add up due to masking low cell sizes.

³Area Deprivation Index (ADI): Patient 5-digit zip codes are mapped to socioeconomic status by normalized Area Deprivation Index (ADI) value (0-100). Lower values are associated with higher socioeconomic status (SES) and higher values are associated with lower SES. A ranking of 1 indicates the highest level of SES within the nation and an ADI with a ranking of 100 indicates the lowest level of SES. In this table, values are grouped into quartiles using the count of zip codes. Quartile 1 (Higher SES) represents the lowest range of ADI values and Quartile 4 (Lower SES) represents the highest range of ADI values (Q1=0-38, Q2=39-43, Q3=44-49, and Q4=50-100). For additional information regarding the ADI index, see the Neighborhood Atlas: <https://www.neighborhoodatlas.medicine.wisc.edu>. Note that the Area Deprivation Index (ADI) is designed for validity at the 9-digit zip or census block group level rather than the 5-digit zip level.

⁴Denominator for percentage is the count for all patients with IDD conditions.

⁵Missing includes those values that are null, refuse to answer, and no information.

⁶Represented as combined [Rural-Urban Commuting Area \(RUCA\) codes](#) as referenced on https://hcup-us.ahrq.gov/db/vars/siddistnote.jsp?var=pl_ruca4. RUCA contains 10 primary and 21 secondary codes which delineate components of rural and urban areas and define county-level metropolitan (urban) and nonmetropolitan areas (i.e., micropolitan/large rural areas, small towns, and isolated rural areas).

Table 3. Co-occurring conditions, rehab and treatment, and prescribed or administered medications for patients with a face-to-face clinical encounter at a site participating in PCORnet® between January 1, 2025 – December 31, 2025, and a recorded diagnosis code for an IDD condition between January 1, 2021 – December 31, 2025.^{1,2}

	Total Patients With a Visit and Diagnosis in 2025		Patients with Any IDD		ADHD ³		Learning Disability ³		Autism Spectrum Disorder ³		Developmental Delay ³		Cerebral Palsy ³		Congenital Malformations of the Brain ³	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Total	53,351,854	100	3,803,734	7.1	2,038,650	53.6	1,170,205	30.8	681,450	17.9	448,308	11.8	139,547	3.7	138,739	3.6
UNIQUE PATIENT RECORDS																
CO-OCCURRING IDD CONDITIONS (2021-2025)																
ADHD	2,038,650	3.8	2,038,650	53.6	2,038,650	100.0	225,382	19.3	231,387	34.0	93,509	20.9	10,887	7.8	11,879	8.6
Learning Disability	1,170,205	2.2	1,170,205	30.8	225,382	11.1	1,170,205	100.0	253,523	37.2	228,322	50.9	27,993	20.1	29,111	21.0
Autism Spectrum Disorder	681,450	1.3	681,450	17.9	231,387	11.4	253,523	21.7	681,450	100.0	142,958	31.9	15,826	11.3	14,594	10.5
Developmental Delay	448,308	0.8	448,308	11.8	93,509	4.6	228,322	19.5	142,958	21.0	448,308	100.0	40,100	28.7	36,877	26.6
Cerebral Palsy	139,547	0.3	139,547	3.7	10,887	0.5	27,993	2.4	15,826	2.3	40,100	8.9	139,547	100.0	23,431	16.9
Congenital Malformations of the Brain	138,739	0.3	138,739	3.6	11,879	0.6	29,111	2.5	14,594	2.1	36,877	8.2	23,431	16.8	138,739	100.0
Failure to Thrive	121,255	0.2	121,255	3.2	609	<0.1	15,223	1.3	2,094	0.3	9,551	2.1	468	0.3	2,209	1.6
Codes Defining Severity of IDD (Mild, Moderate, Severe, Profound)	73,378	0.1	73,378	1.9	19,402	1.0	21,536	1.8	24,919	3.7	15,579	3.5	12,299	8.8	7,005	5.0
Down Syndrome	68,861	0.1	68,861	1.8	3,437	0.2	14,479	1.2	6,799	1.0	9,991	2.2	823	0.6	1,435	1.0
Muscular Dystrophy	39,414	0.1	39,414	1.0	2,403	0.1	2,553	0.2	1,688	0.2	2,738	0.6	905	0.6	652	0.5
Spina Bifida	35,358	0.1	35,358	0.9	2,625	0.1	2,780	0.2	1,169	0.2	3,119	0.7	1,740	1.2	4,177	3.0
Hypoxic-ischemic Encephalopathy	21,646	<0.1	21,646	0.6	959	<0.1	5,243	0.4	1,341	0.2	7,363	1.6	6,344	4.5	3,024	2.2
Fetal Alcohol Syndrome	7,124	<0.1	7,124	0.2	3,855	0.2	1,873	0.2	1,708	0.3	1,453	0.3	322	0.2	464	0.3
Fragile X Syndrome	5,247	<0.1	5,247	0.1	1,242	0.1	1,037	0.1	1,809	0.3	729	0.2	106	0.1	90	0.1
Neonatal Stroke	5,165	<0.1	5,165	0.1	472	<0.1	1,473	0.1	463	0.1	1,538	0.3	1,898	1.4	857	0.6
CO-OCCURRING OTHER CONDITIONS (2021-2025)																
Chronic Seizure	1,427,007	2.7	337,692	8.9	112,907	5.5	112,741	9.6	94,316	13.8	83,235	18.6	64,306	46.1	50,592	36.5
Congenital Heart Disease	885,312	1.7	172,479	4.5	39,901	2.0	69,602	5.9	30,652	4.5	55,380	12.4	12,235	8.8	22,912	16.5
ADRD (Alzheimer's Disease and Related Dementias)	682,198	1.3	28,694	0.8	11,937	0.6	8,451	0.7	3,455	0.5	2,073	0.5	2,379	1.7	2,286	1.6
Chronic Failure to Thrive	567,958	1.1	166,314	4.4	36,814	1.8	78,892	6.7	29,564	4.3	58,996	13.2	16,011	11.5	19,363	14.0
Torticollis	281,496	0.5	55,169	1.5	10,997	0.5	24,948	2.1	6,884	1.0	19,465	4.3	3,837	2.7	4,391	3.2
Low Birth Weight	236,476	0.4	70,545	1.9	5,027	0.2	35,542	3.0	8,614	1.3	29,097	6.5	5,891	4.2	14,011	10.1
REHAB/TREATMENT IN 2025																
Wellness Visit	13,038,576	24.4	1,510,281	39.7	736,559	36.1	588,066	50.3	224,666	33.0	190,506	42.5	27,940	20.0	33,392	24.1
Audiology	2,173,616	4.1	441,771	11.6	173,374	8.5	244,408	20.9	75,235	11.0	71,476	15.9	6,978	5.0	12,833	9.2
Physical Therapy/Occupational Therapy Treatments	2,068,416	3.9	204,680	5.4	93,765	4.6	60,652	5.2	36,103	5.3	56,968	12.7	21,759	15.6	17,366	12.5
Physical Therapy (Evaluation/Re-evaluation)	2,024,165	3.8	191,322	5.0	90,022	4.4	53,819	4.6	31,766	4.7	50,702	11.3	20,474	14.7	16,433	11.8
Vision Services	1,975,161	3.7	114,723	3.0	54,832	2.7	37,376	3.2	21,006	3.1	19,016	4.2	7,142	5.1	9,918	7.1
Psychological Evaluation/Psychotherapy	1,097,833	2.1	314,965	8.3	244,379	12.0	70,422	6.0	72,482	10.6	32,268	7.2	3,999	2.9	4,443	3.2
Oral Exams	901,270	1.7	72,460	1.9	26,787	1.3	35,626	3.0	13,930	2.0	13,038	2.9	2,830	2.0	2,368	1.7
Occupational Therapy (Evaluation/Re-evaluation)	890,307	1.7	91,727	2.4	35,112	1.7	31,750	2.7	18,229	2.7	29,473	6.6	10,297	7.4	9,743	7.0
Speech Therapy	301,814	0.6	91,149	2.4	15,940	0.8	67,875	5.8	21,915	3.2	30,070	6.7	5,766	4.1	6,902	5.0
Neuropsychiatric Evaluation	70,495	0.1	18,353	0.5	11,145	0.5	7,720	0.7	3,844	0.6	3,987	0.9	1,083	0.8	1,539	1.1
Orthotic	45,536	0.1	6,518	0.2	2,377	0.1	2,281	0.2	957	0.1	2,461	0.5	2,095	1.5	1,009	0.7
Wheelchair	28,790	0.1	7,021	0.2	1,323	0.1	2,464	0.2	1,271	0.2	2,383	0.5	3,121	2.2	1,076	0.8
Prosthetic	651	<0.1	98	<0.1	29	<0.1	33	<0.1	-	-	38	<0.1	25	<0.1	16	<0.1
MEDICATIONS (PRESCRIBED OR ADMINISTERED IN 2025)																
Antibiotic	11,984,489	22.5	931,723	24.5	485,757	23.8	282,008	24.1	131,901	19.4	121,497	27.1	43,307	31.0	44,802	32.3
Any Anti-hypertensive Medications	10,070,760	18.9	486,266	12.8	337,014	16.5	71,367	6.1	76,121	11.2	36,724	8.2	26,013	18.6	25,084	18.1
Reflux Medications	7,515,478	14.1	450,242	11.8	270,590	13.3	76,949	6.6	62,315	9.1	45,987	10.3	34,577	24.8	30,376	21.9
Opioids	7,430,050	13.9	423,488	11.1	245,798	12.1	86,537	7.4	56,253	8.3	45,367	10.1	29,436	21.1	30,334	21.9
Asthma-related Inhalers	6,753,687	12.7	637,418	16.8	346,118	17.0	202,611	17.3	103,196	15.1	86,765	19.4	34,936	25.0	30,300	21.8
Anti-depressants	5,697,562	10.7	666,624	17.5	539,959	26.5	76,206	6.5	108,467	15.9	31,833	7.1	19,298	13.8	16,278	11.7
Anti-epileptic Medications (Benzodiazepines)	4,707,578	8.8	441,458	11.6	232,991	11.4	105,227	9.0	92,930	13.6	71,103	15.9	45,580	32.7	40,421	29.1
Anti-epileptic Medications (Non-Benzodiazepines)	3,771,229	7.1	377,529	9.9	215,952	10.6	69,298	5.9	72,181	10.6	49,830	11.1	46,740	33.5	38,948	28.1
Anti-diabetic Medications	3,368,735	6.3	133,358	3.5	84,983	4.2	19,733	1.7	21,569	3.2	5,715	1.3	6,246	4.5	6,235	4.5
Anti-obesity Medications	2,047,950	3.8	123,407	3.2	102,126	5.0	8,943	0.8	10,522	1.5	1,948	0.4	2,039	1.5	3,065	2.2
GLP-1RA	2,009,234	3.8	119,439	3.1	97,911	4.8	9,062	0.8	10,528	1.5	1,937	0.4	2,068	1.5	3,025	2.2

Anti-psychotics (First and Second Generation)	1,646,148	3.1	236,442	6.2	170,407	8.4	34,455	2.9	67,792	9.9	16,661	3.7	10,281	7.4	7,393	5.3
ADHD Medications II (Stimulants, Non-stimulants, and Alpha Agonists)	1,535,583	2.9	947,807	24.9	903,268	44.3	119,624	10.2	125,653	18.4	57,221	12.8	10,747	7.7	9,951	7.2
ADHD Medications I (Stimulants and Alpha Agonists)	1,475,716	2.8	908,693	23.9	865,119	42.4	116,774	10.0	121,736	17.9	56,177	12.5	10,501	7.5	9,681	7.0
Anti-psychotics (Second Generation)	1,109,828	2.1	206,806	5.4	149,799	7.3	31,655	2.7	63,683	9.3	15,904	3.5	8,642	6.2	5,787	4.2
SGLT-2 Inhibitors	1,029,750	1.9	25,229	0.7	14,356	0.7	4,039	0.3	2,769	0.4	737	0.2	1,074	0.8	1,198	0.9
ADHD Stimulants	1,006,593	1.9	798,546	21.0	789,875	38.7	86,494	7.4	77,900	11.4	34,486	7.7	3,298	2.4	3,926	2.8
Anti-psychotics (First Generation)	712,507	1.3	56,254	1.5	38,777	1.9	6,671	0.6	11,857	1.7	2,116	0.5	2,666	1.9	2,384	1.7
ADHD Alpha Agonists	588,131	1.1	219,385	5.8	182,740	9.0	55,400	4.7	73,971	10.9	35,425	7.9	8,259	5.9	6,962	5.0
ADHD Non-stimulants	97,257	0.2	71,389	1.9	69,956	3.4	7,227	0.6	9,676	1.4	3,396	0.8	458	0.3	542	0.4
Lithium Medications	54,934	0.1	13,043	0.3	10,417	0.5	1,117	0.1	3,335	0.5	378	0.1	224	0.2	170	0.1

¹Total includes 74 partners in PCORnet.

²Some totals may not add up due to masking low cell sizes.

³Denominator for percentage is the count for all patients with an IDD-related condition.

Table 3 (cont’d). Co-occurring conditions, rehab and treatment, and prescribed or administered medications for patients with a face-to-face clinical encounter at a site participating in PCORnet® between January 1, 2025 – December 31, 2025, and a recorded diagnosis code for an IDD condition between January 1, 2021 – December 31, 2025.^{1, 2}

	Total Patients With a Visit and Diagnosis in 2025		Patients with Any IDD		Failure to Thrive ³		Codes Defining Severity of IDD ³		Down Syndrome ³		Muscular Dystrophy ³		Spina Bifida ³		Hypoxic-ischemic Encephalopathy ³	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Total	53,351,854	100	3,803,734	7.1	121,255	3.2	73,378	1.9	68,861	1.8	39,414	1.0	35,358	0.9	21,646	0.6
UNIQUE PATIENT RECORDS																
CO-OCCURRING IDD CONDITIONS (2021-2025)																
ADHD	2,038,650	3.8	2,038,650	53.6	609	0.5	19,402	26.4	3,437	5.0	2,403	6.1	2,625	7.4	959	4.4
Learning Disability	1,170,205	2.2	1,170,205	30.8	15,223	12.6	21,536	29.3	14,479	21.0	2,553	6.5	2,780	7.9	5,243	24.2
Autism Spectrum Disorder	681,450	1.3	681,450	17.9	2,094	1.7	24,919	34.0	6,799	9.9	1,688	4.3	1,169	3.3	1,341	6.2
Developmental Delay	448,308	0.8	448,308	11.8	9,551	7.9	15,579	21.2	9,991	14.5	2,738	6.9	3,119	8.8	7,363	34.0
Cerebral Palsy	139,547	0.3	139,547	3.7	468	0.4	12,299	16.8	823	1.2	905	2.3	1,740	4.9	6,344	29.3
Congenital Malformations of the Brain	138,739	0.3	138,739	3.6	2,209	1.8	7,005	9.5	1,435	2.1	652	1.7	4,177	11.8	3,024	14.0
Failure to Thrive	121,255	0.2	121,255	3.2	121,255	100.0	38	0.1	661	1.0	63	0.2	91	0.3	541	2.5
Codes Defining Severity of IDD (Mild, Moderate, Severe, Profound)	73,378	0.1	73,378	1.9	38	<0.1	73,378	100.0	2,806	4.1	407	1.0	636	1.8	950	4.4
Down Syndrome	68,861	0.1	68,861	1.8	661	0.5	2,806	3.8	68,861	100.0	54	0.1	87	0.2	161	0.7
Muscular Dystrophy	39,414	0.1	39,414	1.0	63	0.1	407	0.6	54	0.1	39,414	100.0	89	0.3	116	0.5
Spina Bifida	35,358	0.1	35,358	0.9	91	0.1	636	0.9	87	0.1	89	0.2	35,358	100.0	61	0.3
Hypoxic-ischemic Encephalopathy	21,646	<0.1	21,646	0.6	541	0.4	950	1.3	161	0.2	116	0.3	61	0.2	21,646	100.0
Fetal Alcohol Syndrome	7,124	<0.1	7,124	0.2	20	<0.1	832	1.1	41	0.1	23	0.1	38	0.1	18	0.1
Fragile X Syndrome	5,247	<0.1	5,247	0.1	-	-	463	0.6	22	<0.1	-	-	-	-	-	-
Neonatal Stroke	5,165	<0.1	5,165	0.1	150	0.1	149	0.2	48	0.1	15	<0.1	24	0.1	739	3.4
CO-OCCURRING OTHER CONDITIONS (2021-2025)																
Chronic Seizure	1,427,007	2.7	337,692	8.9	3,902	3.2	28,461	38.8	6,732	9.8	2,924	7.4	4,964	14.0	11,175	51.6
Congenital Heart Disease	885,312	1.7	172,479	4.5	10,399	8.6	5,783	7.9	28,946	42.0	2,059	5.2	2,643	7.5	5,927	27.4
ADRD (Alzheimer's Disease and Related Dementias)	682,198	1.3	28,694	0.8	83	0.1	2,860	3.9	1,796	2.6	658	1.7	432	1.2	271	1.3
Chronic Failure to Thrive	567,958	1.1	166,314	4.4	25,644	21.1	5,203	7.1	5,225	7.6	2,054	5.2	1,489	4.2	3,227	14.9
Torticollis	281,496	0.5	55,169	1.5	7,551	6.2	755	1.0	1,038	1.5	473	1.2	499	1.4	1,169	5.4
Low Birth Weight	236,476	0.4	70,545	1.9	11,179	9.2	791	1.1	1,894	2.8	227	0.6	792	2.2	2,048	9.5
REHAB/TREATMENT IN 2025																
Wellness Visit	13,038,576	24.4	1,510,281	39.7	95,841	79.0	17,185	23.4	15,565	22.6	6,384	16.2	5,772	16.3	6,028	27.8
Audiology	2,173,616	4.1	441,771	11.6	14,586	12.0	4,165	5.7	7,638	11.1	1,237	3.1	1,520	4.3	2,884	13.3
Physical Therapy/Occupational Therapy Treatments	2,068,416	3.9	204,680	5.4	3,863	3.2	7,675	10.5	5,817	8.4	6,557	16.6	5,459	15.4	4,657	21.5
Physical Therapy (Evaluation/Re-evaluation)	2,024,165	3.8	191,322	5.0	3,503	2.9	7,128	9.7	5,397	7.8	6,217	15.8	5,253	14.9	4,223	19.5
Vision Services	1,975,161	3.7	114,723	3.0	1,191	1.0	4,049	5.5	4,832	7.0	2,074	5.3	1,429	4.0	911	4.2
Psychological Evaluation/Psychotherapy	1,097,833	2.1	314,965	8.3	991	0.8	7,846	10.7	1,333	1.9	1,085	2.8	1,050	3.0	521	2.4
Oral Exams	901,270	1.7	72,460	1.9	3,032	2.5	1,956	2.7	1,444	2.1	286	0.7	287	0.8	350	1.6
Occupational Therapy (Evaluation/Re-evaluation)	890,307	1.7	91,727	2.4	2,181	1.8	4,287	5.8	3,329	4.8	2,816	7.1	2,439	6.9	2,891	13.4
Speech Therapy	301,814	0.6	91,149	2.4	3,014	2.5	2,945	4.0	3,555	5.2	886	2.2	696	2.0	2,045	9.4
Neuropsychiatric Evaluation	70,495	0.1	18,353	0.5	56	<0.1	1,268	1.7	146	0.2	229	0.6	334	0.9	192	0.9
Orthotic	45,536	0.1	6,518	0.2	100	0.1	282	0.4	176	0.3	183	0.5	150	0.4	332	1.5
Wheelchair	28,790	0.1	7,021	0.2	53	<0.1	723	1.0	163	0.2	585	1.5	651	1.8	259	1.2
Prosthetic	651	<0.1	98	<0.1	-	-	-	-	-	-	-	-	-	-	-	-
MEDICATIONS (PRESCRIBED OR ADMINISTERED IN 2025)																
Antibiotic	11,984,489	22.5	931,723	24.5	35,102	28.9	21,624	29.5	19,358	28.1	10,473	26.6	15,240	43.1	8,644	39.9
Any Anti-hypertensive Medications	10,070,760	18.9	486,266	12.8	2,264	1.9	19,215	26.2	7,473	10.9	12,623	32.0	7,428	21.0	3,691	17.1
Reflux Medications	7,515,478	14.1	450,242	11.8	9,208	7.6	19,559	26.7	10,619	15.4	9,231	23.4	8,536	24.1	5,128	23.7
Opioids	7,430,050	13.9	423,488	11.1	5,538	4.6	12,254	16.7	10,718	15.6	8,377	21.3	10,094	28.5	5,391	24.9
Asthma-related Inhalers	6,753,687	12.7	637,418	16.8	12,234	10.1	17,545	23.9	13,740	20.0	8,701	22.1	6,402	18.1	5,467	25.3
Anti-depressants	5,697,562	10.7	666,624	17.5	279	0.2	20,199	27.5	5,108	7.4	6,460	16.4	5,625	15.9	1,096	5.1
Anti-epileptic Medications (Benzodiazepines)	4,707,578	8.8	441,458	11.6	4,662	3.8	23,245	31.7	10,377	15.1	6,461	16.4	8,065	22.8	7,220	33.4
Anti-epileptic Medications (Non-Benzodiazepines)	3,771,229	7.1	377,529	9.9	1,193	1.0	24,484	33.4	4,525	6.6	6,000	15.2	6,196	17.5	6,503	30.0
Anti-diabetic Medications	3,368,735	6.3	133,358	3.5	253	0.2	7,749	10.6	2,743	4.0	3,104	7.9	2,214	6.3	936	4.3
Anti-obesity Medications	2,047,950	3.8	123,407	3.2	82	0.1	2,199	3.0	1,326	1.9	1,515	3.8	1,138	3.2	81	0.4
GLP-1RA	2,009,234	3.8	119,439	3.1	78	0.1	2,403	3.3	1,312	1.9	1,525	3.9	1,099	3.1	91	0.4

Anti-psychotics (First and Second Generation)	1,646,148	3.1	236,442	6.2	150	0.1	18,451	25.1	3,281	4.8	1,798	4.6	1,954	5.5	743	3.4
ADHD Medications II (Stimulants, Non-stimulants, and Alpha Agonists)	1,535,583	2.9	947,807	24.9	574	0.5	12,950	17.6	2,878	4.2	1,652	4.2	1,674	4.7	1,664	7.7
ADHD Medications I (Stimulants and Alpha Agonists)	1,475,716	2.8	908,693	23.9	573	0.5	12,570	17.1	2,828	4.1	1,600	4.1	1,598	4.5	1,654	7.6
Anti-psychotics (Second Generation)	1,109,828	2.1	206,806	5.4	135	0.1	16,958	23.1	2,774	4.0	1,244	3.2	1,245	3.5	637	2.9
SGLT-2 Inhibitors	1,029,750	1.9	25,229	0.7	43	<0.1	1,403	1.9	405	0.6	1,469	3.7	360	1.0	151	0.7
ADHD Stimulants	1,006,593	1.9	798,546	21.0	56	<0.1	5,810	7.9	1,081	1.6	859	2.2	866	2.4	280	1.3
Anti-psychotics (First Generation)	712,507	1.3	56,254	1.5	19	<0.1	4,570	6.2	841	1.2	756	1.9	901	2.5	202	0.9
ADHD Alpha Agonists	588,131	1.1	219,385	5.8	548	0.5	9,586	13.1	2,149	3.1	875	2.2	887	2.5	1,486	6.9
ADHD Non-stimulants	97,257	0.2	71,389	1.9	-	-	923	1.3	106	0.2	88	0.2	129	0.4	24	0.1
Lithium Medications	54,934	0.1	13,043	0.3	-	-	957	1.3	39	0.1	59	0.1	42	0.1	15	0.1

¹Total includes 74 partners in PCORnet.

²Some totals may not add up due to masking low cell sizes.

³Denominator for percentage is the count for all patients with an IDD-related condition.

Table 3 (cont’d). Co-occurring conditions, rehab and treatment, and prescribed or administered medications for patients with a face-to-face clinical encounter at a site participating in PCORnet® between January 1, 2025 – December 31, 2025, and a recorded diagnosis code for an IDD condition between January 1, 2021 – December 31, 2025.^{1, 2}

	Total Patients With a Visit and Diagnosis in 2025		Patients with Any IDD		Fetal Alcohol Syndrome ³		Fragile X Syndrome ³		Neonatal Stroke ³	
	N	%	N	%	N	%	N	%	N	%
Total										
UNIQUE PATIENT RECORDS	53,351,854	100	3,803,734	7.1	7,124	0.2	5,247	<0.1	5,165	0.1
CO-OCCURRING IDD CONDITIONS (2021-2025)										
ADHD	2,038,650	3.8	2,038,650	53.6	3,855	54.1	1,242	23.7	472	9.1
Learning Disability	1,170,205	2.2	1,170,205	30.8	1,873	26.3	1,037	19.8	1,473	28.5
Autism Spectrum Disorder	681,450	1.3	681,450	17.9	1,708	24.0	1,809	34.5	463	9.0
Developmental Delay	448,308	0.8	448,308	11.8	1,453	20.4	729	13.9	1,538	29.8
Cerebral Palsy	139,547	0.3	139,547	3.7	322	4.5	106	2.0	1,898	36.7
Congenital Malformations of the Brain	138,739	0.3	138,739	3.6	464	6.5	90	1.7	857	16.6
Failure to Thrive	121,255	0.2	121,255	3.2	20	0.3	-	-	150	2.9
Codes Defining Severity of IDD (Mild, Moderate, Severe, Profound)	73,378	0.1	73,378	1.9	832	11.7	463	8.8	149	2.9
Down Syndrome	68,861	0.1	68,861	1.8	41	0.6	22	0.4	48	0.9
Muscular Dystrophy	39,414	0.1	39,414	1.0	23	0.3	-	-	15	0.3
Spina Bifida	35,358	0.1	35,358	0.9	38	0.5	-	-	24	0.5
Hypoxic-ischemic Encephalopathy	21,646	<0.1	21,646	0.6	18	0.3	-	-	739	14.3
Fetal Alcohol Syndrome	7,124	<0.1	7,124	0.2	7,124	100.0	13	0.2	-	-
Fragile X Syndrome	5,247	<0.1	5,247	0.1	13	0.2	5,247	100.0	-	-
Neonatal Stroke	5,165	<0.1	5,165	0.1	-	-	-	-	5,165	100.0
CO-OCCURRING OTHER CONDITIONS (2021-2025)										
Chronic Seizure	1,427,007	2.7	337,692	8.9	1,145	16.1	813	15.5	3,248	62.9
Congenital Heart Disease	885,312	1.7	172,479	4.5	529	7.4	211	4.0	1,653	32.0
ADRD (Alzheimer's Disease and Related Dementias)	682,198	1.3	28,694	0.8	75	1.1	94	1.8	76	1.5
Chronic Failure to Thrive	567,958	1.1	166,314	4.4	561	7.9	178	3.4	587	11.4
Torticollis	281,496	0.5	55,169	1.5	77	1.1	69	1.3	279	5.4
Low Birth Weight	236,476	0.4	70,545	1.9	187	2.6	42	0.8	624	12.1
REHAB/TREATMENT IN 2025										
Wellness Visit	13,038,576	24.4	1,510,281	39.7	1,778	25.0	1,359	25.9	1,278	24.7
Audiology	2,173,616	4.1	441,771	11.6	797	11.2	235	4.5	606	11.7
Physical Therapy/Occupational Therapy Treatments	2,068,416	3.9	204,680	5.4	802	11.3	269	5.1	1,086	21.0
Physical Therapy (Evaluation/Re-evaluation)	2,024,165	3.8	191,322	5.0	717	10.1	240	4.6	1,003	19.4
Vision Services	1,975,161	3.7	114,723	3.0	385	5.4	181	3.4	356	6.9
Psychological Evaluation/Psychotherapy	1,097,833	2.1	314,965	8.3	1,106	15.5	247	4.7	176	3.4
Oral Exams	901,270	1.7	72,460	1.9	119	1.7	97	1.8	52	1.0
Occupational Therapy (Evaluation/Re-evaluation)	890,307	1.7	91,727	2.4	387	5.4	146	2.8	675	13.1
Speech Therapy	301,814	0.6	91,149	2.4	293	4.1	114	2.2	464	9.0
Neuropsychiatric Evaluation	70,495	0.1	18,353	0.5	240	3.4	39	0.7	118	2.3
Orthotic	45,536	0.1	6,518	0.2	16	0.2	-	-	156	3.0
Wheelchair	28,790	0.1	7,021	0.2	11	0.2	-	-	34	0.7
Prosthetic	651	<0.1	98	<0.1	0	0	0	0	-	-
MEDICATIONS (PRESCRIBED OR ADMINISTERED IN 2025)										
Antibiotic	11,984,489	22.5	931,723	24.5	1,776	24.9	1,149	21.9	1,604	31.1
Any Anti-hypertensive Medications	10,070,760	18.9	486,266	12.8	1,508	21.2	907	17.3	733	14.2
Reflux Medications	7,515,478	14.1	450,242	11.8	1,398	19.6	849	16.2	842	16.3
Opioids	7,430,050	13.9	423,488	11.1	873	12.3	736	14.0	1,035	20.0
Asthma-related Inhalers	6,753,687	12.7	637,418	16.8	1,482	20.8	648	12.3	849	16.4
Anti-depressants	5,697,562	10.7	666,624	17.5	2,019	28.3	1,190	22.7	251	4.9
Anti-epileptic Medications (Benzodiazepines)	4,707,578	8.8	441,458	11.6	1,162	16.3	867	16.5	1,753	33.9
Anti-epileptic Medications (Non-Benzodiazepines)	3,771,229	7.1	377,529	9.9	1,347	18.9	753	14.4	1,722	33.3
Anti-diabetic Medications	3,368,735	6.3	133,358	3.5	538	7.6	431	8.2	153	3.0
Anti-obesity Medications	2,047,950	3.8	123,407	3.2	230	3.2	167	3.2	27	0.5
GLP-1RA	2,009,234	3.8	119,439	3.1	224	3.1	171	3.3	27	0.5

Anti-psychotics (First and Second Generation)	1,646,148	3.1	236,442	6.2	1,769	24.8	757	14.4	142	2.7
ADHD Medications II (Stimulants, Non-stimulants, and Alpha Agonists)	1,535,583	2.9	947,807	24.9	2,154	30.2	809	15.4	363	7.0
ADHD Medications I (Stimulants and Alpha Agonists)	1,475,716	2.8	908,693	23.9	2,067	29.0	784	14.9	356	6.9
Anti-psychotics (Second Generation)	1,109,828	2.1	206,806	5.4	1,669	23.4	694	13.2	125	2.4
SGLT-2 Inhibitors	1,029,750	1.9	25,229	0.7	79	1.1	60	1.1	31	0.6
ADHD Stimulants	1,006,593	1.9	798,546	21.0	1,291	18.1	427	8.1	151	2.9
Anti-psychotics (First Generation)	712,507	1.3	56,254	1.5	409	5.7	130	2.5	28	0.5
ADHD Alpha Agonists	588,131	1.1	219,385	5.8	1,510	21.2	502	9.6	261	5.1
ADHD Non-stimulants	97,257	0.2	71,389	1.9	220	3.1	58	1.1	15	0.3
Lithium Medications	54,934	0.1	13,043	0.3	129	1.8	18	0.3	-	-

¹Total includes 74 partners in PCORnet.

²Some totals may not add up due to masking low cell sizes.

³Denominator for percentage is the count for all patients with an IDD-related condition.