



2019 IMPROVECARENOW™ ANNUAL DATA REPORT

prepared by: the ImproveCareNow Data Management Team



FROM THE NETWORK DIRECTOR

I am happy to report that 2019 was an excellent year for ImproveCareNow (ICN), which now includes more than 100 care centers in the United States, England, Qatar and Belgium, with 1,200 clinicians, including 950 pediatric gastroenterologists caring for pediatric patients with Inflammatory Bowel Disease (IBD). We are the largest pediatric improvement and research community in the world. Currently, half the children and youth cared for by pediatric gastroenterologists in the United States are cared for at participating ICN centers.

As ImproveCareNow continues to keep its primary focus on improvement, we are also moving to expand our research activities. With data from over 46,000 patients and 330,000 visits, the ICN Registry is a tremendous resource for advancing our knowledge about pediatric Crohn's disease and ulcerative colitis. In 2019, the ICN Research Committee received an additional 19 proposals for research—45 studies are underway or have been completed and another 2 are under consideration. In addition, there were 9 ImproveCareNow research publications in medical journals, 5 published abstracts, and 5 poster presentations at national research meetings.

We are pleased to present this report, which offers a closer look at some of the data in the ICN Registry - the world's largest and fastest growing pediatric IBD registry.



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EXECUTIVE NETWORK DIRECTOR

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ABOUT THIS REPORT

The 2019 Annual Data Report aims to present a brief summary of the patient data captured in the ImproveCareNow (ICN) Registry - a disease-specific, enhanced health registry that has been built by and for the ICN Network.

The ICN Registry is the centralized repository for standardized clinical data variables, which are routinely captured at the time of diagnosis or registration, and at every outpatient clinic visit for registered pediatric patients with Inflammatory Bowel Disease (IBD). The data in the ICN Registry enables participating centers to monitor individual and overall performance, compare outcomes, and provide reliable, timely and proactive IBD care. It also drives quality improvement projects focused on improving health, care and costs for cohorts of patients.

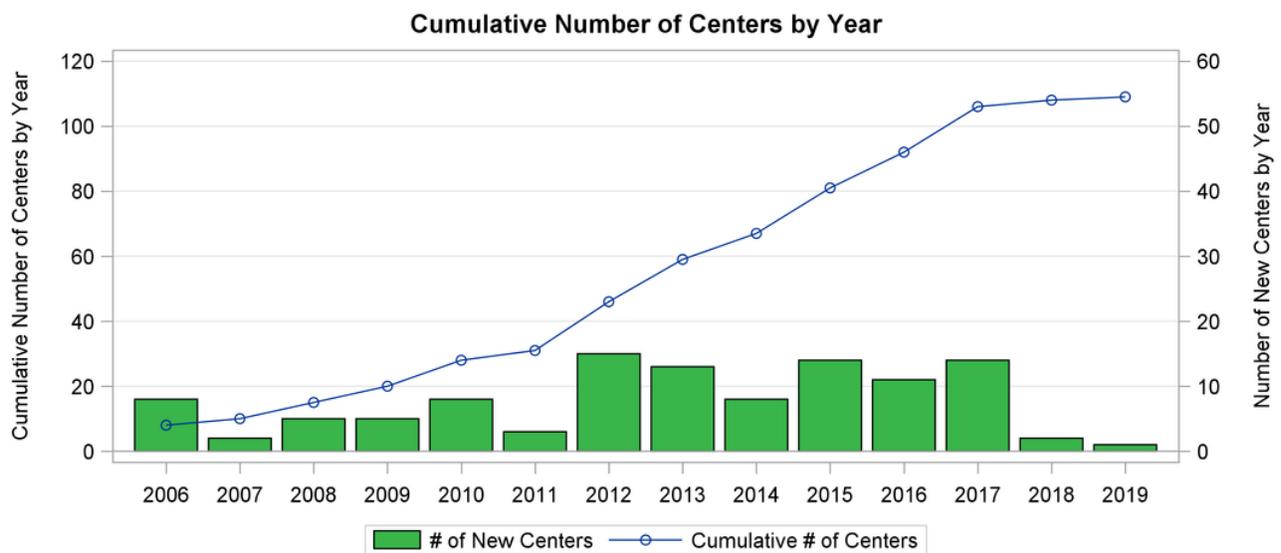
At a network level, the data in the ICN Registry can be used for network-wide quality improvement and for research. The ICN Registry is considered a “gold mine” for pediatric IBD research, and continues to grow rapidly. Stakeholders within ICN, as well as external researchers, are invited to submit their research proposals to the ICN Research Committee in order to be provided select access to ICN Registry data for approved research purposes.

The development and success of the ICN Registry is overseen by the ICN Data Management Team, which is comprised of clinical data specialists, statisticians, quality improvement coordinators, and pediatric gastroenterology providers who meet regularly to review and answer questions from care centers about data management and quality, to focus efforts to improve data quality within the network, and to review and make recommendations on proposals for data elements to be added or removed from the ICN Registry.

The ICN Data Management Team works in concert with the ICN Executive Directors, the ICN Research Committee, ICN staff, and various stakeholder groups to ensure the ICN Registry supports the success of ICN and our work to *transform the health, care and costs for all children and adolescents with Crohn’s disease and ulcerative colitis (Inflammatory Bowel Disease or IBD) by building a sustainable collaborative chronic care network; enabling patients, families, clinicians and researchers to work together in a learning health care system to accelerate innovation, discovery and the application of new knowledge.*

OUR NETWORK

Today, the network includes more than 100 care centers in the United States, England, Qatar and Belgium. **We are the largest pediatric improvement and research community in the world.**



DEMOGRAPHICS

AGE, ETHNICITY, AND RACE

The table below presents data on all patients who have ever been included in the ICN Registry. "Ever Registered" includes all patients who were ever added to the ICN Registry. "Active in Registry" includes patients who have not been deactivated from the ICN Registry (*deactivation can occur when a patient transitions to adult care, moves to a non-ICN care center/provider, is lost to follow-up, or undergoes colectomy for ulcerative colitis*). "Had Visits in Report Year" includes all patients who had an outpatient visit in 2019 entered into the registry. "Registered in Report Year" includes patients who had their initial registration entered in 2019 (*note: diagnosis may have been earlier than 2019*).

Demographics	Ever Registered (n = 46,981)	Active in Registry (n = 26,934)	Had Visits in Report Year (n = 23,249)	Registered in Report Year (n = 5,165)
Age at Registration (years)				
0 - 6	2,387 (5.1%)	1,765 (6.6%)	1,584 (6.8%)	264 (5.1%)
7 - 11	9,525 (20.3%)	7,272 (27.0%)	6,431 (27.7%)	1,071 (20.7%)
12 - 17	29,269 (62.3%)	15,968 (59.3%)	13,863 (59.6%)	3,344 (64.7%)
>18	5,636 (12.0%)	1,889 (7.0%)	1,371 (5.9%)	486 (9.4%)
Missing	164 (0.3%)	40 (0.1%)		
Age at End of Report (years)				
0 - 6	694 (1.5%)	578 (2.1%)	505 (2.2%)	218 (4.2%)
7 - 11	3,602 (7.7%)	3,076 (11.4%)	2,734 (11.8%)	923 (17.9%)
12 - 17	16,433 (35.0%)	13,887 (51.6%)	12,088 (52.0%)	3,218 (62.3%)
>18	26,250 (55.9%)	9,392 (34.9%)	7,922 (34.1%)	806 (15.6%)
Missing	2 (0.0%)	1 (0.0%)		
Gender				
Male	26,107 (55.6%)	15,125 (56.2%)	12,982 (55.8%)	2,805 (54.3%)
Female	20,873 (44.4%)	11,809 (43.8%)	10,267 (44.2%)	2,360 (45.7%)
Missing	1 (0.0%)			
Race				
American Indian/Alaska Native	91 (0.2%)	53 (0.2%)	46 (0.2%)	13 (0.3%)
Asian	1,050 (2.2%)	681 (2.5%)	594 (2.6%)	135 (2.6%)
Native Hawaiian or other Pacific Islander	54 (0.1%)	36 (0.1%)	31 (0.1%)	5 (0.1%)
Black or African American	3,856 (8.2%)	2,058 (7.6%)	1,878 (8.1%)	557 (10.8%)
White	28,711 (61.1%)	15,613 (58.0%)	13,714 (59.0%)	3,057 (59.2%)
Multiracial	300 (0.6%)	166 (0.6%)	130 (0.6%)	21 (0.4%)
Other or Unknown	1,373 (2.9%)	860 (3.2%)	747 (3.2%)	220 (4.3%)
Missing	11,546 (24.6%)	7,467 (27.7%)	6,109 (26.3%)	1,157 (22.4%)
Ethnicity				
Hispanic	2,709 (5.8%)	1,678 (6.2%)	1,453 (6.2%)	372 (7.2%)
Non-Hispanic	30,530 (65.0%)	19,481 (72.3%)	17,601 (75.7%)	4,260 (82.5%)
Missing	13,742 (29.3%)	5,775 (21.4%)	4,195 (18.0%)	533 (10.3%)

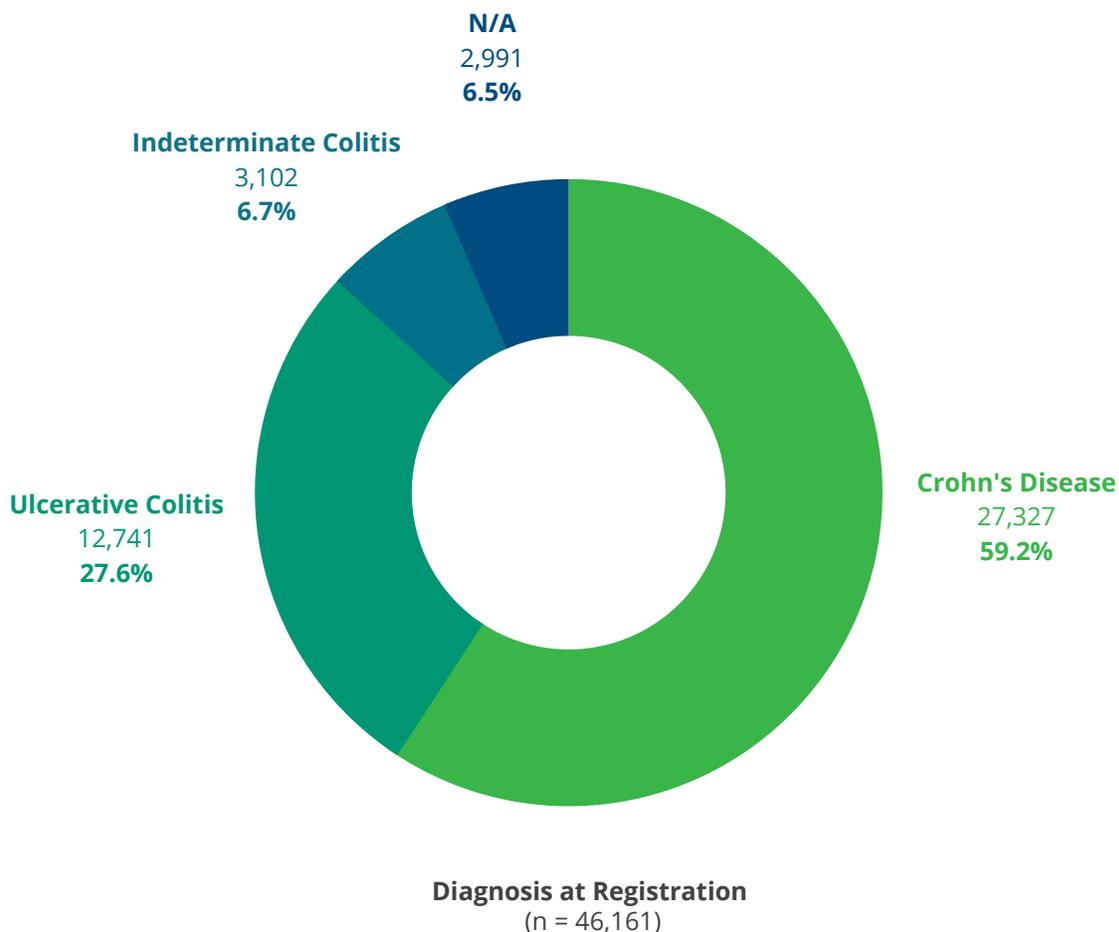
DEMOGRAPHICS

DISEASE TYPE

The table below summarizes the diagnosis at the time of registration for all patients who have ever been included in the ICN Registry. "Ever Registered" includes all patients who were ever added to the ICN Registry. "Registered in Report Year" includes patients who had their initial registration entered in 2019 (note: diagnosis may have been earlier than 2019). "Active in Registry" includes patients who have not been deactivated from the ICN Registry (deactivation can occur when a patient transitions to adult care, moves to a non-ICN care center/provider, is lost to follow-up, or undergoes colectomy for ulcerative colitis).

Characteristics	Ever Registered (n = 46,161)	Registered in Report Year (n = 5,165)	Active in Registry (n = 26,934)
Diagnosis			
Crohn's Disease	27,327 (59.2%)	3,159 (61.2%)	16,094 (59.8%)
Ulcerative Colitis	12,741 (27.6%)	1,616 (31.3%)	7,062 (26.2%)
Indeterminate Colitis	3,102 (6.7%)	337 (6.5%)	1,741 (6.5%)
Don't Know	2,991 (6.5%)	53 (1.0%)	2,037 (7.6%)

The graph below depicts the diagnosis at the time of the patient's registration into the ICN Registry. It is a visual representation of the data in the "Ever Registered" column of the above table.



DEMOGRAPHICS

CROHN'S DISEASE - AGE, ETHNICITY, AND RACE

This table presents data on patients who have ever been included in the ICN Registry and whose initial diagnosis was **Crohn's disease**. "Ever Registered" includes all patients who were ever added to the ICN Registry. "Active in Registry" includes patients who have not been deactivated from the ICN Registry (*deactivation can occur when a patient transitions to adult care, moves to a non-ICN care center/provider, is lost to follow-up, or undergoes colectomy for ulcerative colitis*). "Had Visits in Report Year" includes all patients who had an outpatient visit in 2019 entered into the registry. "Registered in Report Year" includes patients who had their initial registration entered in 2019 (*note: diagnosis may have been earlier than 2019*).

Demographics	Ever Registered (n = 27,327)	Active in Registry (n = 16,094)	Had Visits in Report Year (n = 14,395)	Registered in Report Year (n = 3,159)
Age at Registration (years)				
0 - 6	989 (3.6%)	780 (4.8%)	712 (4.9%)	121 (3.8%)
7 - 11	5,638 (20.6%)	4,509 (28.0%)	4,100 (28.5%)	670 (21.2%)
12 - 17	17,464 (63.9%)	9,781 (60.8%)	8,777 (61.0%)	2,068 (65.5%)
>18	3,228 (11.8%)	1,019 (6.3%)	806 (5.6%)	300 (9.5%)
Missing	8 (0.0%)	5 (0.0%)		
Age at End of Report (years)				
0 - 6	275 (1.0%)	234 (1.5%)	207 (1.4%)	98 (3.1%)
7 - 11	1,799 (6.6%)	1,591 (9.9%)	1,472 (10.2%)	562 (17.8%)
12 - 17	9,615 (35.2%)	8,437 (52.4%)	7,570 (52.6%)	2,008 (63.6%)
>18	15,637 (57.2%)	5,832 (36.2%)	5,146 (35.7%)	491 (15.5%)
Missing	1 (0.0%)			
Gender				
Male	15,993 (58.5%)	9,523 (59.2%)	8,471 (58.8%)	1,823 (57.7%)
Female	11,334 (41.5%)	6,571 (40.8%)	5,924 (41.2%)	1,336 (42.3%)
Race				
American Indian/Alaska Native	44 (0.2%)	28 (0.2%)	24 (0.2%)	6 (0.2%)
Asian	605 (2.2%)	413 (2.6%)	356 (2.5%)	77 (2.4%)
Native Hawaiian or other Pacific Islander	31 (0.1%)	22 (0.1%)	18 (0.1%)	3 (0.1%)
Black or African American	2,531 (9.3%)	1,371 (8.5%)	1,278 (8.9%)	369 (11.7%)
White	17,812 (65.2%)	10,118 (62.9%)	8,969 (62.3%)	1,858 (58.8%)
Multiracial	186 (0.7%)	122 (0.8%)	94 (0.7%)	11 (0.3%)
Other or Unknown	717 (2.6%)	457 (2.8%)	400 (2.8%)	122 (3.9%)
Missing	5,401 (19.8%)	3,563 (22.1%)	3,256 (22.6%)	713 (22.6%)
Ethnicity				
Hispanic	1,232 (4.5%)	805 (5.0%)	693 (4.8%)	150 (4.7%)
Non-Hispanic	19,194 (70.2%)	12,724 (79.1%)	11,562 (80.3%)	2,677 (84.7%)
Missing	6,901 (25.3%)	2,565 (15.9%)	2,140 (14.9%)	332 (10.5%)

DEMOGRAPHICS

ULCERATIVE COLITIS - AGE, ETHNICITY, AND RACE

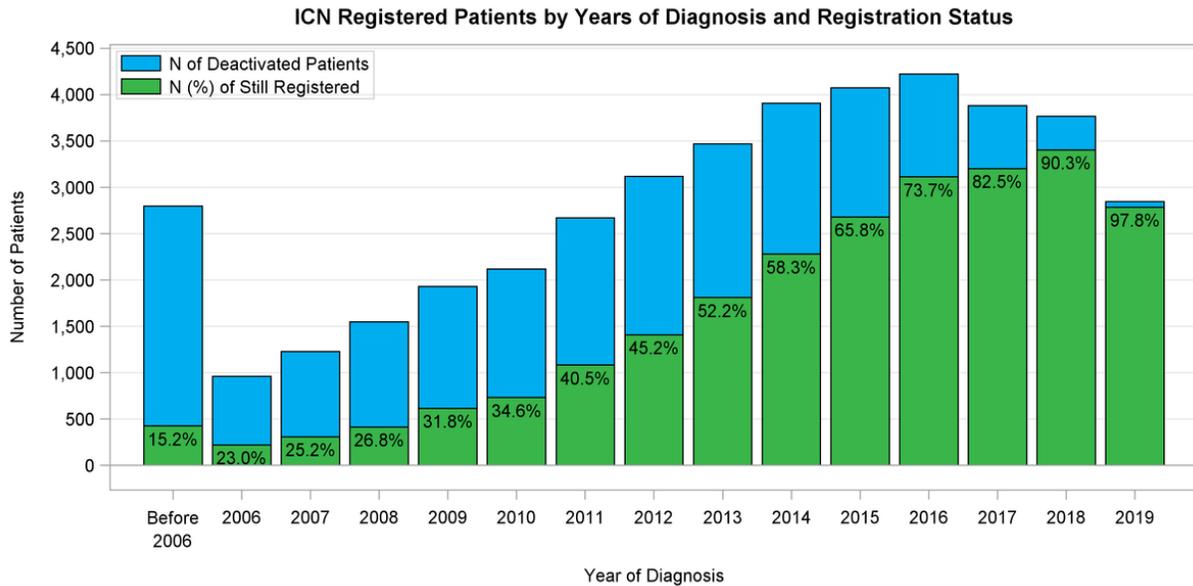
The table below presents data on patients who have ever been included in the ICN Registry and whose initial diagnosis was **ulcerative colitis**. "Ever Registered" includes all patients who were ever added to the ICN Registry. "Active in Registry" includes patients who have not been deactivated from the ICN Registry (*deactivation can occur when a patient transitions to adult care, moves to a non-ICN care center/provider, is lost to follow-up, or undergoes colectomy for ulcerative colitis*). "Had Visits in Report Year" includes all patients who had an outpatient visit in 2019 entered into the registry. "Registered in Report Year" includes patients who had their initial registration entered in 2019 (*note: diagnosis may have been earlier than 2019*).

Demographics	Ever Registered (n = 12,741)	Active in Registry (n = 7,062)	Had Visits in Report Year (n = 6,159)	Registered in Report Year (n = 1,616)
Age at Registration (years)				
0 - 6	788 (6.2%)	561 (7.9%)	507 (8.2%)	91 (5.6%)
7 - 11	2,507 (19.7%)	1,815 (25.7%)	1,591 (25.8%)	309 (19.1%)
12 - 17	7,925 (62.2%)	4,144 (58.7%)	3,649 (59.2%)	1,056 (65.3%)
>18	1,518 (11.9%)	540 (7.6%)	412 (6.7%)	160 (9.9%)
Missing	3 (0.0%)	2 (0.0%)		
Age at End of Report (years)				
0 - 6	186 (1.5%)	154 (2.2%)	144 (2.3%)	77 (4.8%)
7 - 11	1,073 (8.4%)	903 (12.8%)	808 (13.1%)	273 (16.9%)
12 - 17	4,338 (34.0%)	3,522 (49.9%)	3,140 (51.0%)	994 (61.5%)
>18	7,144 (56.1%)	2,483 (35.2%)	2,067 (33.6%)	272 (16.8%)
Gender				
Male	6,352 (49.9%)	3,508 (49.7%)	3,043 (49.4%)	790 (48.9%)
Female	6,389 (50.1%)	3,554 (50.3%)	3,116 (50.6%)	826 (51.1%)
Race				
American Indian/Alaska Native	40 (0.3%)	22 (0.3%)	20 (0.3%)	5 (0.3%)
Asian	331 (2.6%)	206 (2.9%)	173 (2.8%)	44 (2.7%)
Native Hawaiian or other Pacific Islander	20 (0.2%)	13 (0.2%)	13 (0.2%)	2 (0.1%)
Black or African American	948 (7.4%)	528 (7.5%)	455 (7.4%)	151 (9.3%)
White	8,038 (63.1%)	4,216 (59.7%)	3,613 (58.7%)	958 (59.3%)
Multiracial	79 (0.6%)	34 (0.5%)	29 (0.5%)	8 (0.5%)
Other or Unknown	511 (4.0%)	318 (4.5%)	273 (4.4%)	81 (5.0%)
Missing	2,774 (21.8%)	1,725 (24.4%)	1,583 (25.7%)	367 (22.7%)
Ethnicity				
Hispanic	1,169 (9.2%)	734 (10.4%)	635 (10.3%)	192 (11.9%)
Non-Hispanic	8,232 (64.6%)	5,170 (73.2%)	4,592 (74.6%)	1,255 (77.7%)
Missing	3,340 (26.2%)	1,158 (16.4%)	932 (15.1%)	169 (10.5%)

DEMOGRAPHICS

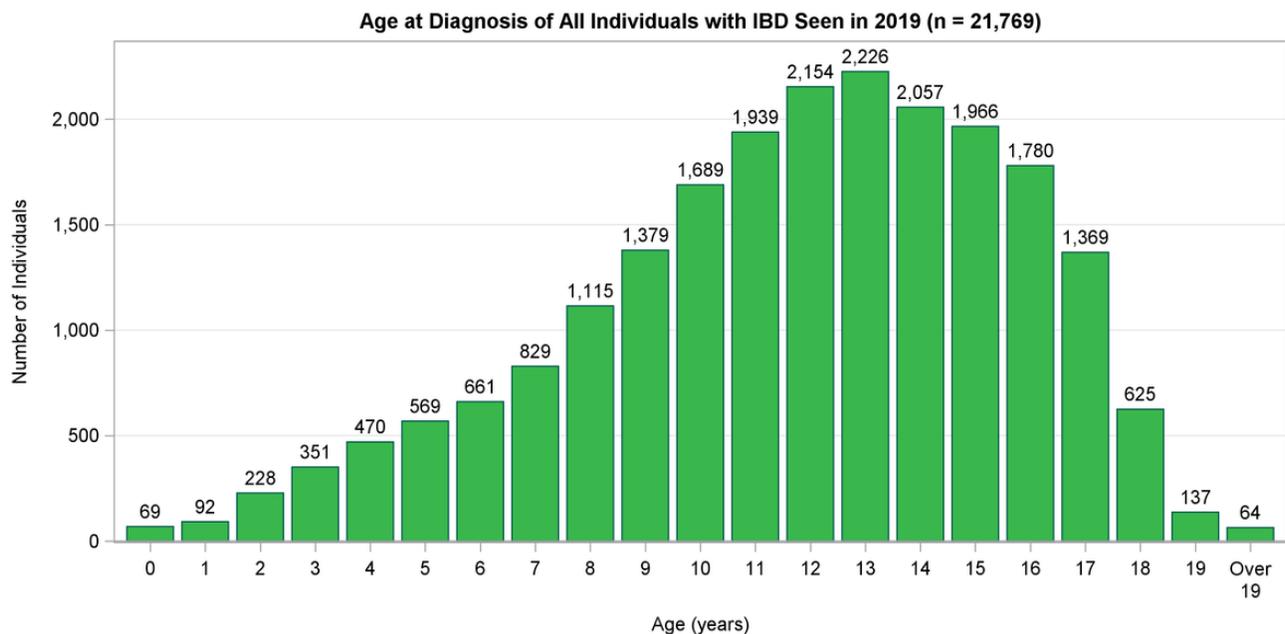
YEAR AND AGE OF DIAGNOSIS

The graph below demonstrates the **year of diagnosis** of inflammatory bowel disease for all patients who were ever included in the ICN Registry. The green bars represent the number of patients who were diagnosed in that year who remain active in the ICN Registry, and the blue bars represent the number of patients who were diagnosed in that year who have been deactivated from the ICN Registry. Each percentage represents the percent of patients ever included in the ICN Registry from that year of diagnosis who remain active in the ICN Registry.



AGE OF DIAGNOSIS

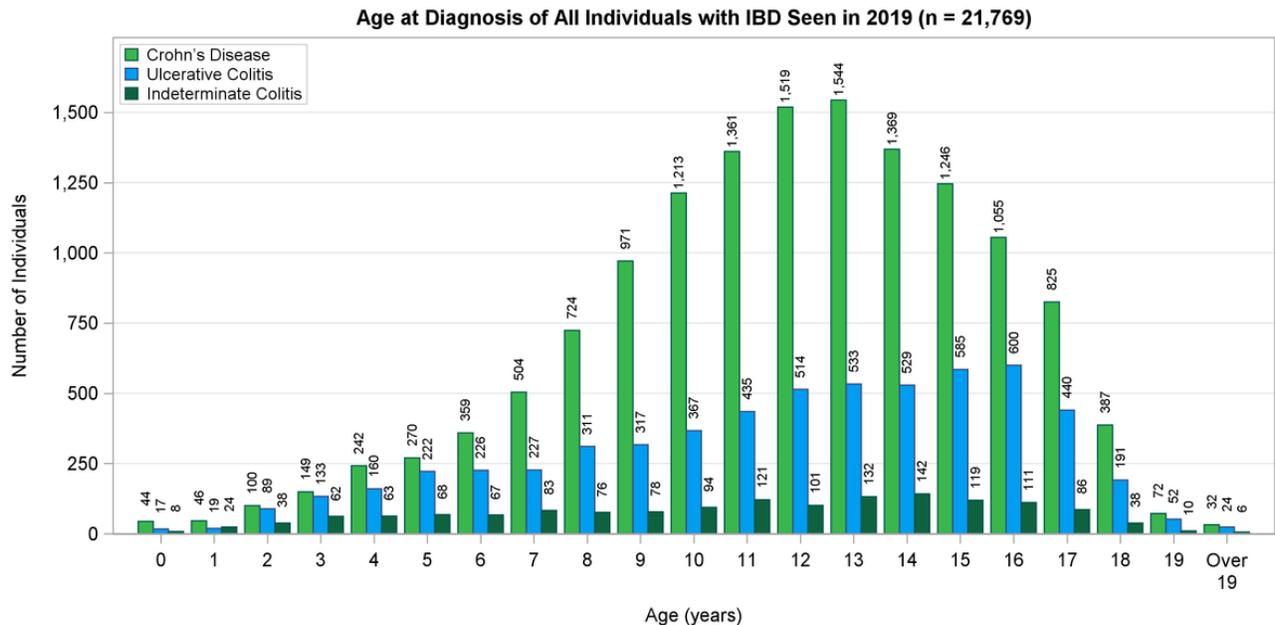
The graph below demonstrates the **age of diagnosis** for all patients who were included in the ICN Registry and had an outpatient clinic visit entered into the registry in 2019.



DEMOGRAPHICS

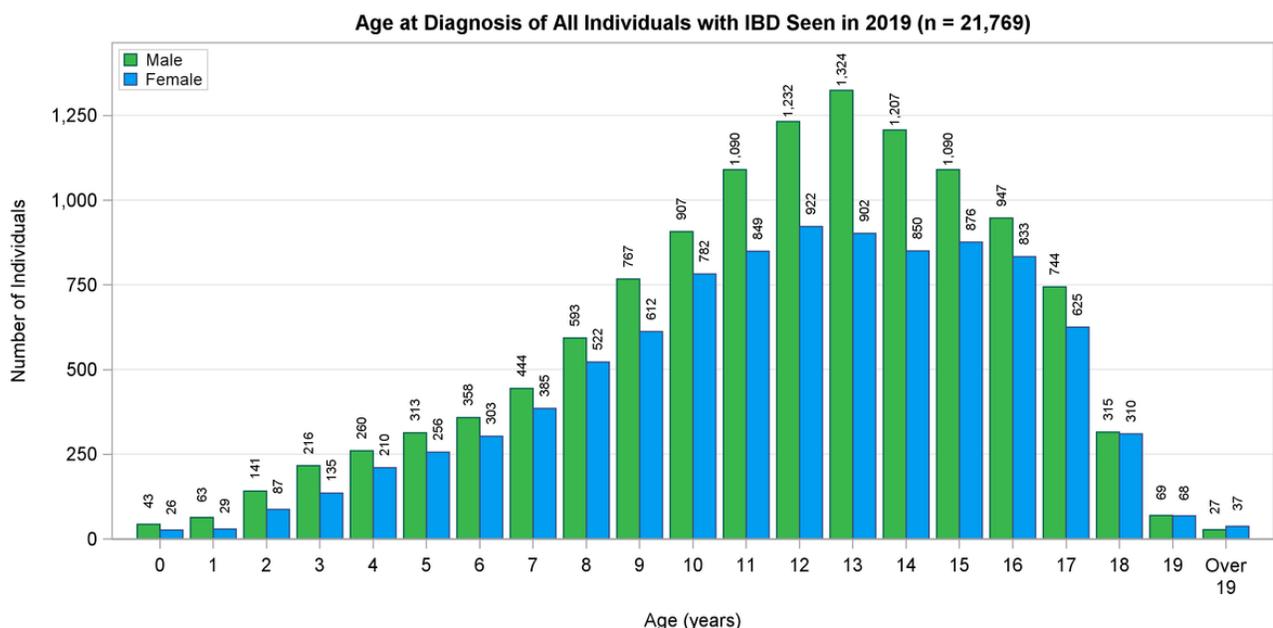
2019 AGE OF DIAGNOSIS

The graph below demonstrates the **age of diagnosis** for all patients who were included in the ICN Registry and had an outpatient clinic visit entered into the registry in 2019, **divided by diagnosis** (light green bars represent patients with Crohn's disease, blue bars represent patients with ulcerative colitis, and dark green bars represent patients with indeterminate colitis).



2019 DIAGNOSIS BY AGE AND GENDER

The graph below demonstrates the **age of diagnosis** for all patients who were included in the ICN Registry and had an outpatient clinic visit entered into the registry in 2019, **divided by gender** (light green bars represent male patients, and blue bars represent female patients).



CLINICAL CHARACTERISTICS

CROHN'S DISEASE

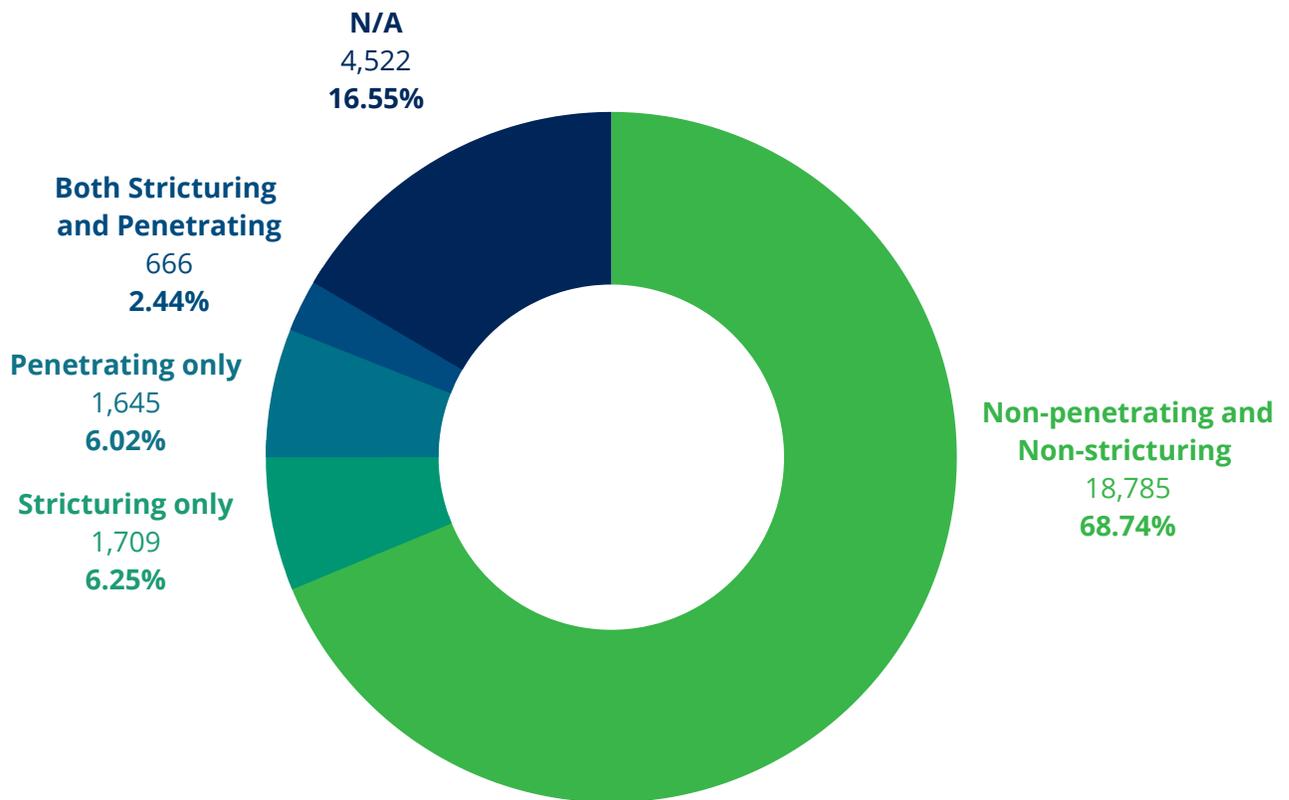
The table below contains clinical characteristics for patients with a diagnosis of **Crohn's disease** in the ICN Registry. The extent and phenotype of Crohn's disease at the time of registration are summarized for all patients ever registered, all newly registered patients in 2019, and all patients who remain active in the registry. The PGA (*Physician Global Assessment*) and sPCDAI (*short Pediatric Crohn's Disease Activity Index*) are summarized based on each patient's most recent outpatient clinic evaluation.

Characteristics	Ever Registered (n = 27,327)	Registered in Report Year (n = 3,159)	Active in Registry (n = 16,094)
Extent of Disease			
CD Extent of Disease			
Macroscopic Lower GI Disease			
None	690 (2.5%)	97 (3.1%)	389 (2.4%)
Ileal Only	3,511 (12.8%)	554 (17.5%)	2,364 (14.7%)
Colonic only	3,930 (14.4%)	449 (14.2%)	2,507 (15.6%)
Ileocolonic	11,597 (42.4%)	1,564 (49.5%)	9,691 (60.2%)
Not Assessed	281 (1.0%)	27 (0.9%)	128 (0.8%)
Don't Know	7,318 (26.8%)	468 (14.8%)	1,015 (6.3%)
Macroscopic Upper GI Disease proximal to the ligament of Treitz			
No	9,935 (36.4%)	1,487 (47.1%)	8,202 (51.0%)
Yes	8,810 (32.2%)	1,114 (35.3%)	6,431 (40.0%)
Not Assessed	569 (2.1%)	38 (1.2%)	242 (1.5%)
Don't Know	8,013 (29.3%)	520 (16.5%)	1,219 (7.6%)
Macroscopic Upper GI Disease distal to the ligament of Treitz			
No	11,279 (41.3%)	1,724 (54.6%)	9,765 (60.7%)
Yes	4,457 (16.3%)	616 (19.5%)	3,692 (22.9%)
Not Assessed	2,988 (10.9%)	202 (6.4%)	1,122 (7.0%)
Don't Know	8,603 (31.5%)	617 (19.5%)	1,515 (9.4%)
CD Phenotype			
Inflammatory, non-penetrating, non-stricturing	18,785 (68.7%)	2,128 (67.4%)	11,693 (72.7%)
Stricturing only	1,709 (6.3%)	213 (6.7%)	1,399 (8.7%)
Penetrating only	1,645 (6.0%)	218 (6.9%)	1,029 (6.4%)
Both stricturing and penetrating	666 (2.4%)	82 (2.6%)	550 (3.4%)
Don't Know	4,522 (16.5%)	518 (16.4%)	1,423 (8.8%)
Perianal Disease Phenotype			
No	17,241 (63.1%)	2,020 (63.9%)	11,203 (69.6%)
Yes	5,136 (18.8%)	580 (18.4%)	3,275 (20.3%)
Don't Know	4,950 (18.1%)	559 (17.7%)	1,616 (10.0%)
PGA			
Quiescent		1,884 (59.6%)	12,416 (77.1%)
Mild		636 (20.1%)	2,215 (13.8%)
Moderate		196 (6.2%)	581 (3.6%)
Severe		22 (0.7%)	47 (0.3%)
Missing and No Visit in 2019		383 (12.1%)	777 (4.8%)
Don't Know/Not Assessed		38 (1.2%)	58 (0.4%)
sPCDAI			
Number of Patients		2,566	14,636
Mean (SD)		10.7 (14.85)	8.1 (12.56)
Median [Q1, Q3]		0.0 [0.0, 20.0]	0.0 [0.0, 10.0]
Min - Max		0.0 - 85.0	0.0 - 85.0

CLINICAL CHARACTERISTICS

CROHN'S DISEASE PHENOTYPE AT REGISTRATION

The graph below depicts the phenotype of the patients with **Crohn's disease** at the time of the patient's registration into the ICN Registry (*note: diagnosis may have been earlier than the time of registration*).



CD Phenotype at Registration

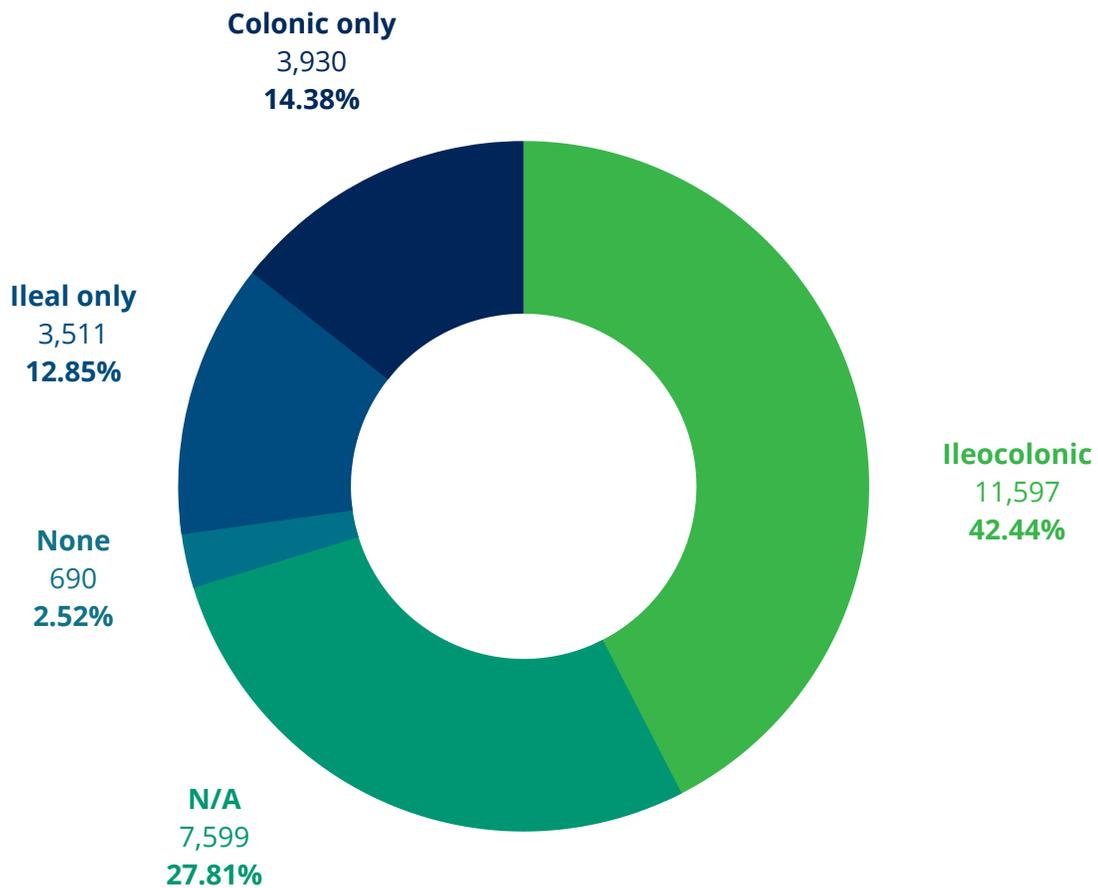
(n = 27,327)

CLINICAL CHARACTERISTICS

CROHN'S DISEASE EXTENT OF DISEASE AT REGISTRATION

Macroscopic Lower GI Disease

The graph below depicts the extent of lower gastrointestinal disease of the patients with **Crohn's disease** at the time of the patient's registration into the ICN Registry (*note: diagnosis may have been earlier than the time of registration*).



CD Extent of Disease at Registration - Macroscopic Lower GI Disease
(n = 27,327)

CLINICAL CHARACTERISTICS

ULCERATIVE COLITIS

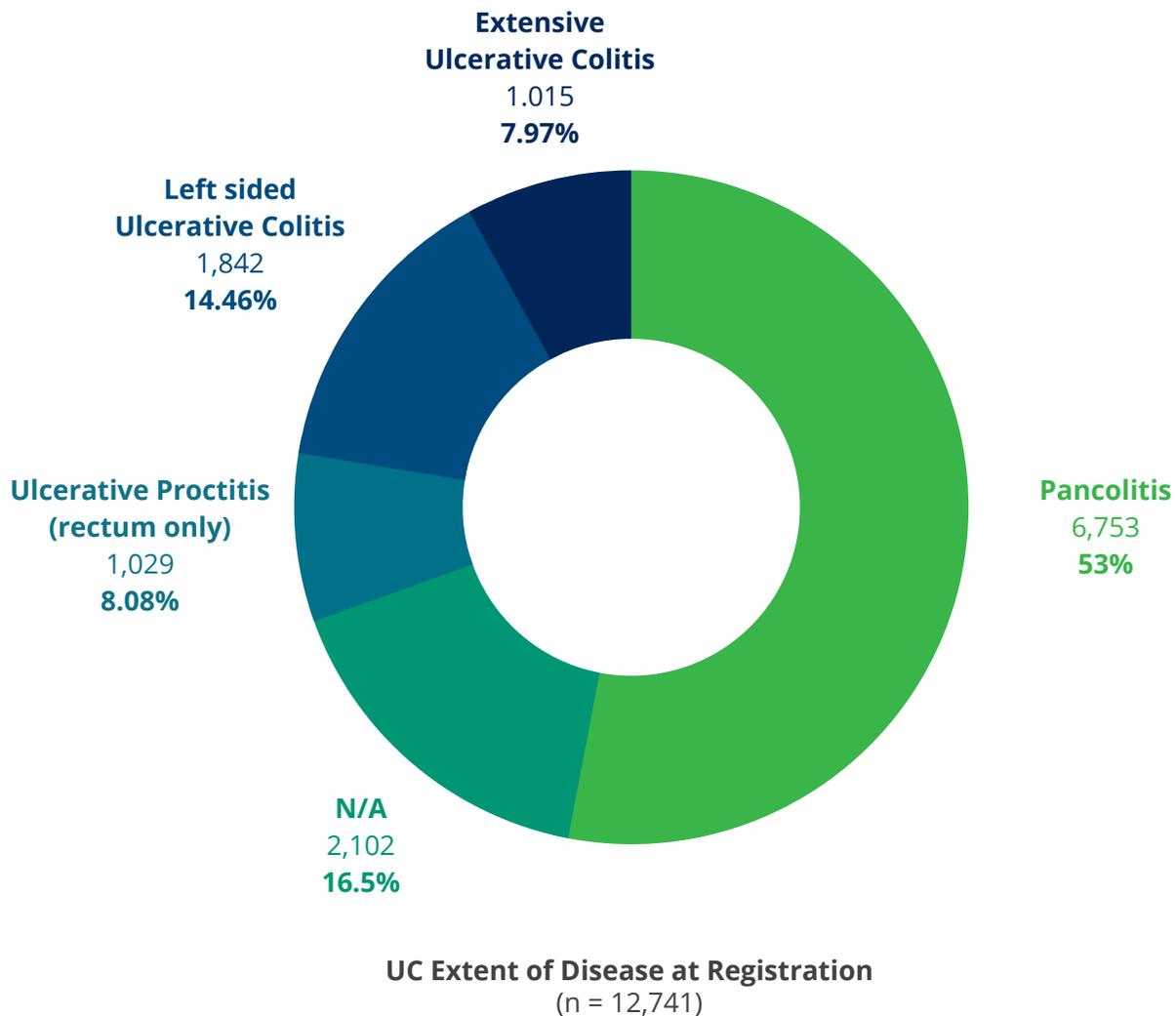
This table contains clinical characteristics for patients with a diagnosis of **ulcerative colitis** in the ICN Registry. The extent of ulcerative colitis at the time of registration is summarized for all patients ever registered, all newly registered patients in 2019, and all patients who remain active in the registry. The PGA (*Physician Global Assessment*) and PUCAI (*Pediatric Ulcerative Colitis Activity Index*) are summarized based on each patient's most recent outpatient clinic evaluation.

Characteristics	Ever Registered (n = 12,741)	Registered in Report Year (n = 1,616)	Active in Registry (n = 7,062)
Extent of Disease			
UC Extent of Disease			
Ulcerative Proctitis (rectum only)	1,029 (8.1%)	122 (7.5%)	515 (7.3%)
Left sided Ulcerative Colitis	1,842 (14.5%)	208 (12.9%)	1,012 (14.3%)
Extensive Ulcerative Colitis	1,015 (8.0%)	112 (6.9%)	496 (7.0%)
Pancolitis (the entire colon)	6,753 (53.0%)	857 (53.0%)	4,345 (61.5%)
Not assessed completely	162 (1.3%)	19 (1.2%)	60 (0.8%)
Don't Know	1,940 (15.2%)	298 (18.4%)	634 (9.0%)
PGA			
Quiescent		855 (52.9%)	5,180 (73.4%)
Mild		377 (23.3%)	1,141 (16.2%)
Moderate		126 (7.8%)	319 (4.5%)
Severe		13 (0.8%)	19 (0.3%)
Missing and No Visit in 2019		217 (13.4%)	361 (5.1%)
Don't Know/Not Assessed		28 (1.7%)	42 (0.6%)
PUCAI			
Number of Patients		1,310	6,466
Mean (SD)		11.6 (16.20)	7.6 (13.33)
Median [Q1, Q3]		5.0 [0.0, 15.0]	0.0 [0.0, 10.0]
Min - Max		0.0 - 85.0	0.0 - 85.0

CLINICAL CHARACTERISTICS

ULCERATIVE COLITIS EXTENT OF DISEASE AT REGISTRATION

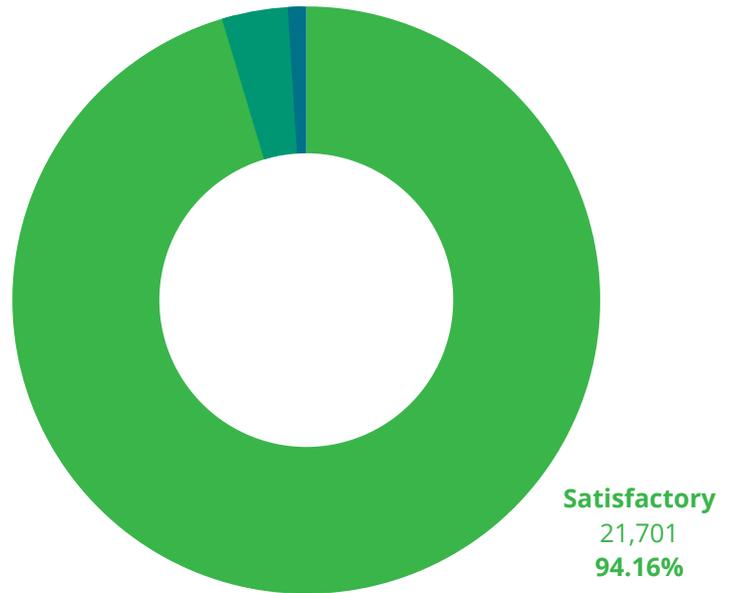
This graph depicts the extent disease of the patients with **ulcerative colitis** at the time of the patient's registration into the ICN Registry (*note: diagnosis may have been earlier than the time of registration*).



GROWTH & NUTRITION

Growth and nutritional status are important outcomes for pediatric patients with inflammatory bowel disease. The following graphs summarize the growth and nutritional status at the most recent outpatient clinic visit for all patients who remain active in the ICN Registry.

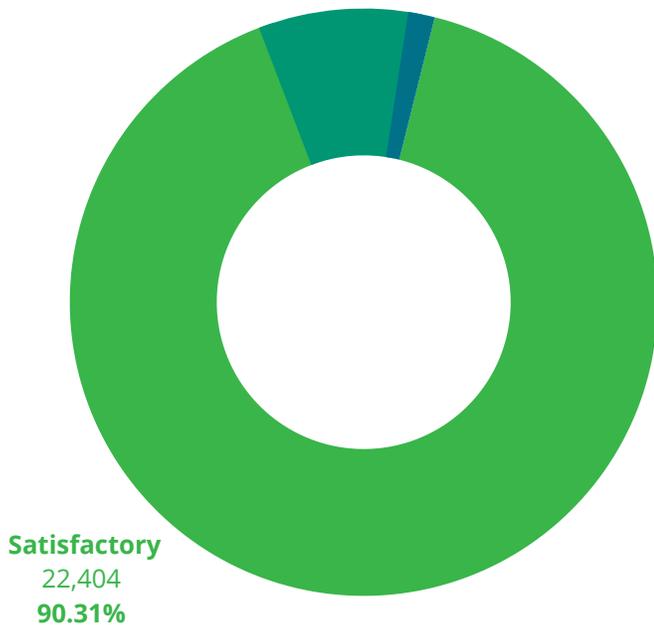
At Risk	In Failure
1,053	293
4.57%	1.27%



Growth Status at Most Recent Visit
(n = 23,047)

At each outpatient visit, a patient's **growth status** (for patients less than 18 years old) is classified as satisfactory, at risk, or in failure. Failure is defined as a height percentile <3rd percentile for age or height velocity <3rd percentile for age or height percentile changed lower by two isobars. At risk is defined as height percentile <10th percentile for age or height velocity <10th percentile for age or height percentile changed lower by one isobar. All other patients are classified as satisfactory growth status.

At Risk	In Failure
2,039	364
8.22%	1.47%

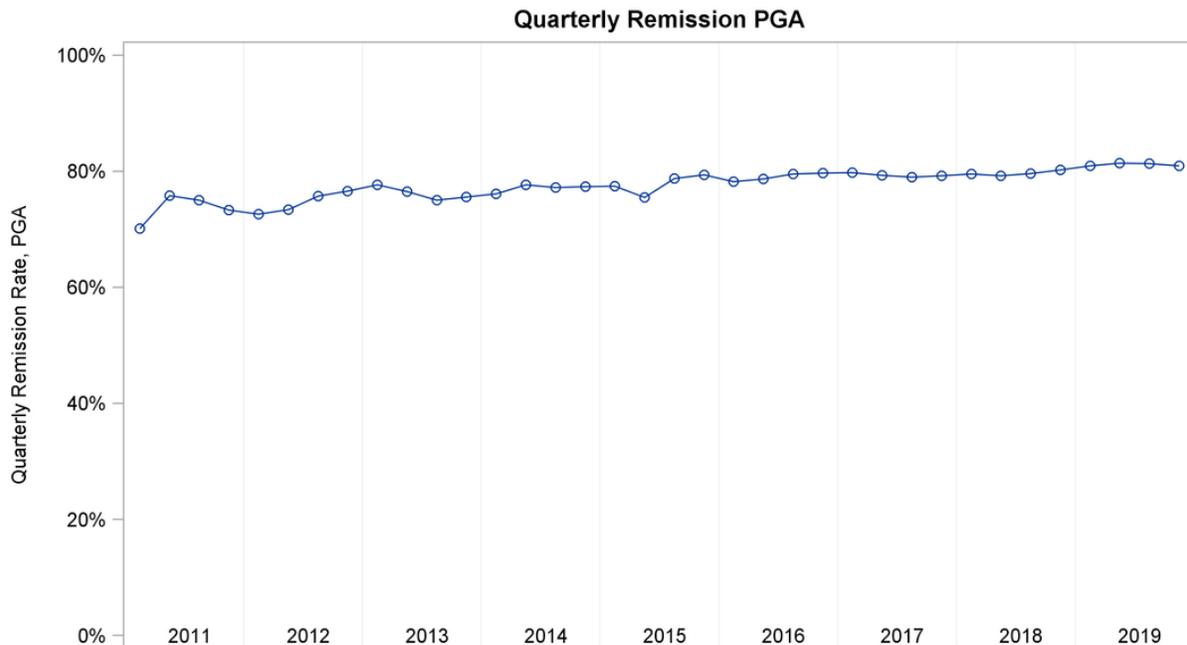


Nutrition Status at Most Recent Visit
(n = 24,807)

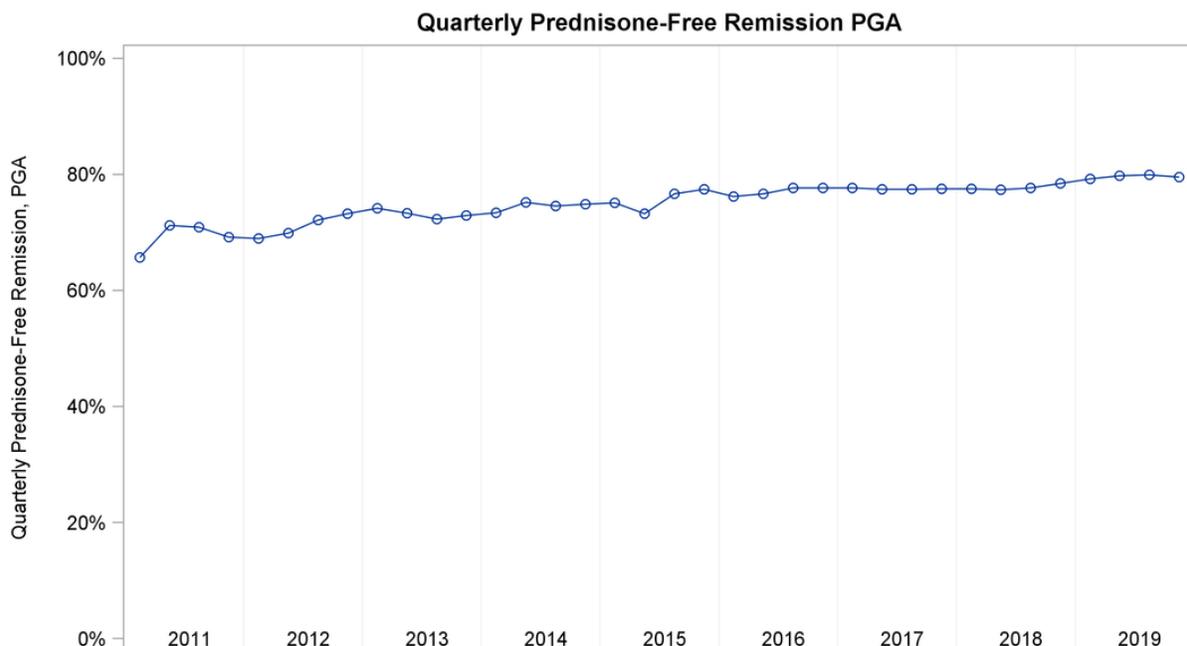
At each outpatient visit, a patient's **nutritional status** is classified as satisfactory, at risk, or in failure. Failure is defined as weight loss $\geq 10\%$ or body mass index <3rd percentile for age or weight percentile changed lower by two isobars. At risk is defined as weight stable (no gain) or 1-9% weight loss or body mass index <10th percentile for age or weight percentile changed lower by one isobar. All other patients are classified as satisfactory nutritional status.

QI MEASURES: REMISSION

Remission is an important outcome for all stakeholders in the ICN Network and is measured in several different ways, using data only from centers with greater than 75% registration of their eligible IBD population. **Clinical remission** is determined by the Physician Global Assessment (PGA), and clinical remission rate is determined by the percentage of patients whose PGA is marked as “quiescent” by the pediatric gastroenterology provider at the time of the patient’s most recent outpatient clinic visit.

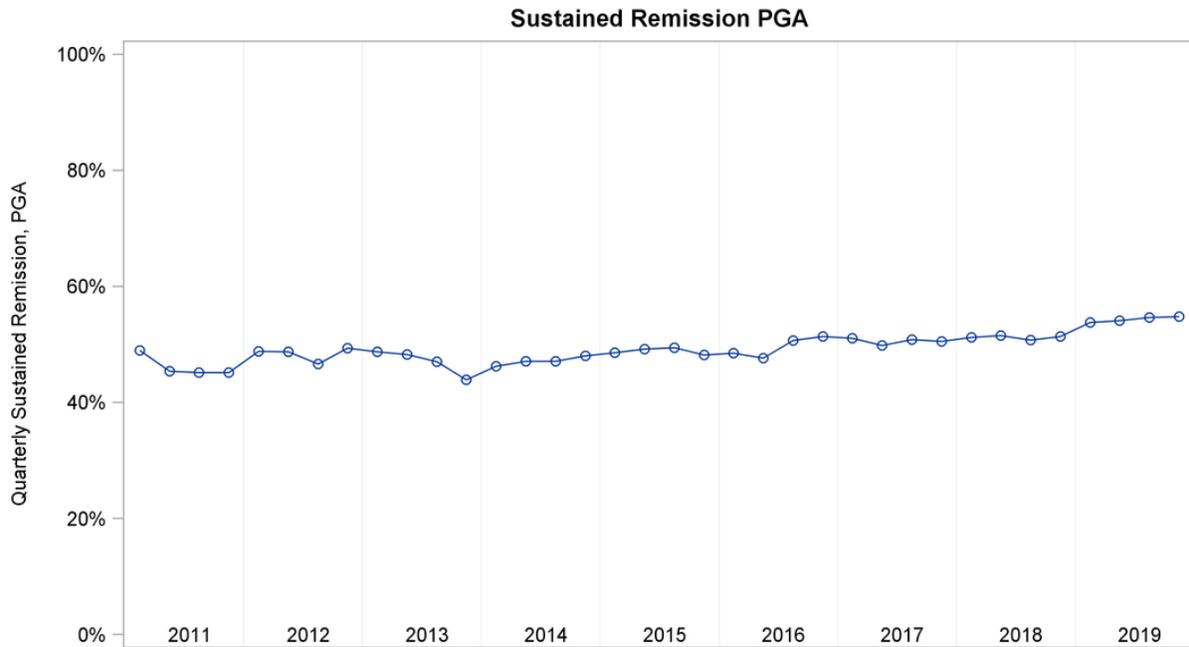


Prednisone-free remission is also determined by the percentage of patients whose PGA is marked as “quiescent” by the pediatric gastroenterology provider at the time of the patient’s most recent outpatient clinic visit, with the additional criterion of having no planned steroid exposure at the time of discharge from the most recent outpatient clinic visit.



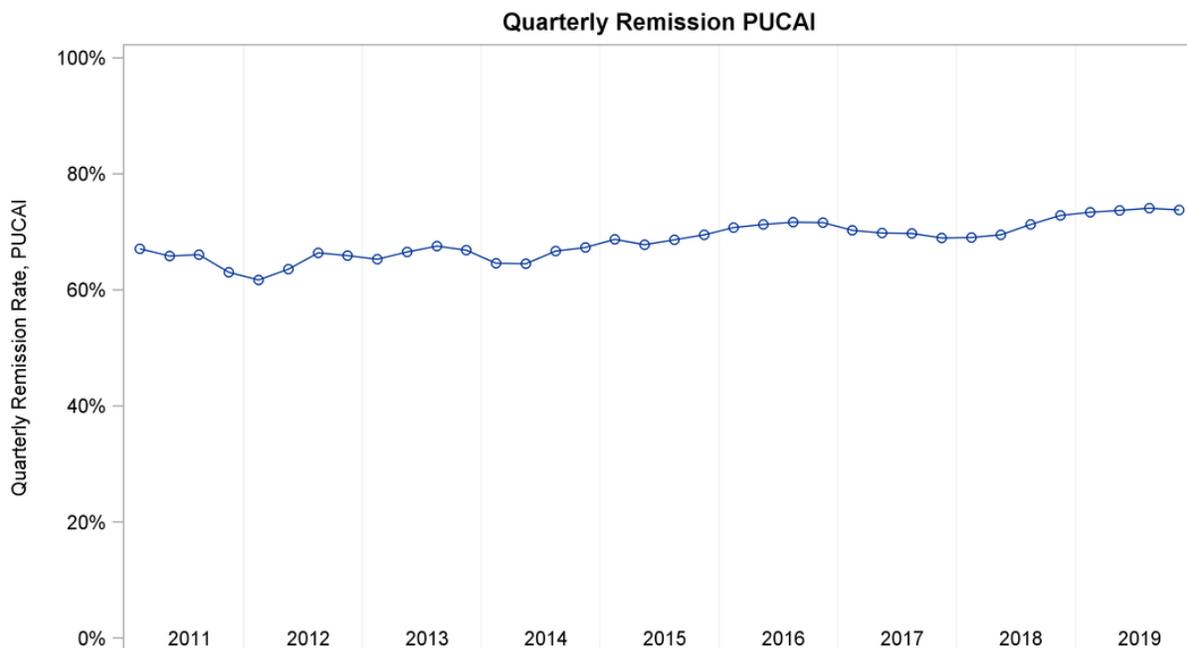
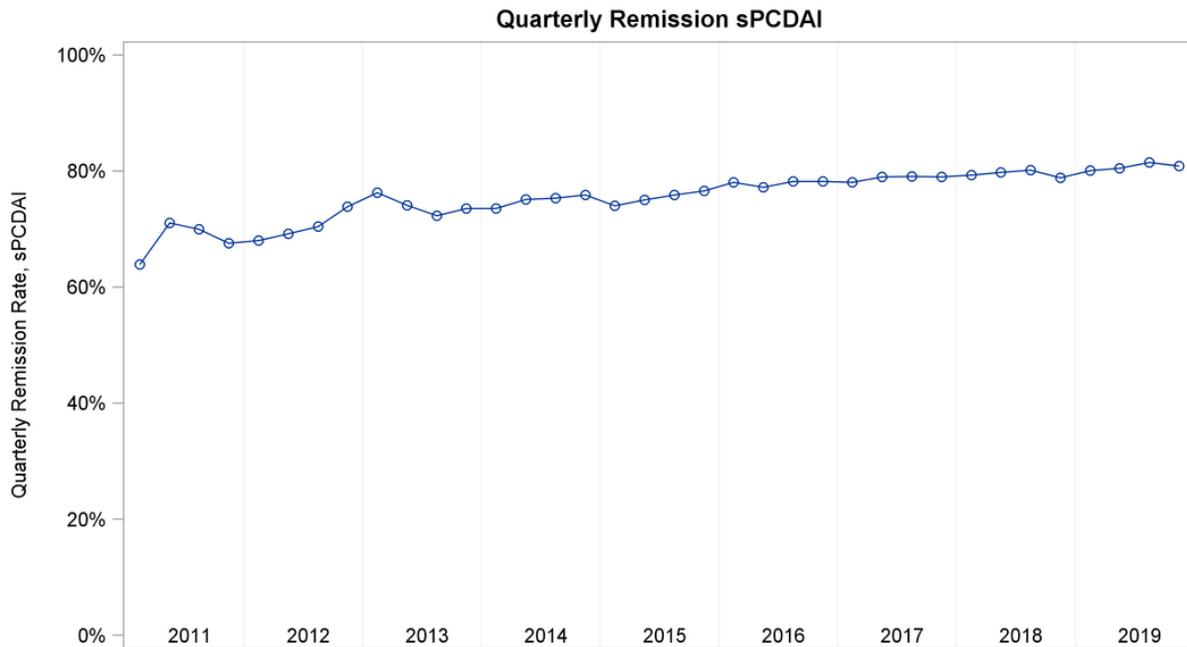
QI MEASURES: REMISSION

Sustained remission is calculated based on two criteria at all visits in the last one year: the pediatric gastroenterology provider marked the PGA as “quiescent”, and the pediatric gastroenterology provider marked “yes” to the question of whether the patient had been in continuous remission since the most recent outpatient visit.



QI MEASURES: REMISSION

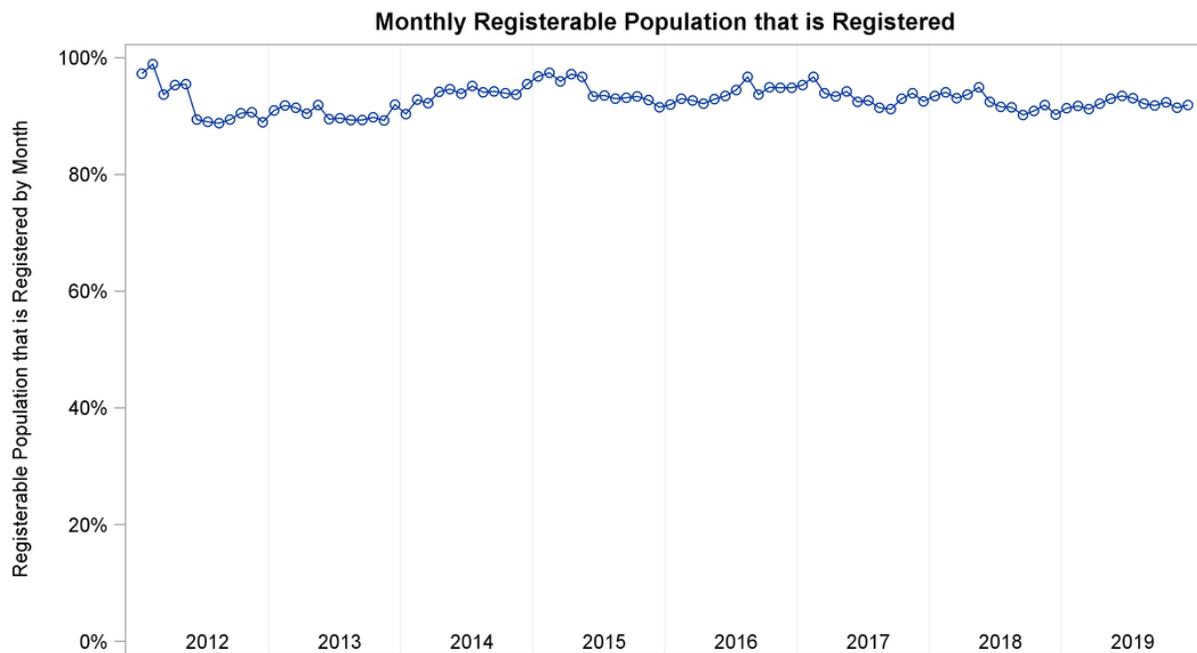
In addition to using the Physician Global Assessment to track Clinical Remission, the ICN Registry collects data that allows for the calculation of an **sPCDAI (short Pediatric Crohn's Disease Activity Index)** or **PUCAI (Pediatric Ulcerative Colitis Activity Index)** at the time of each outpatient clinic visit. The sPCDAI chart demonstrates the percentage of Crohn's disease patients with an sPCDAI score of <15 at the most recent outpatient clinic visit, and the PUCAI chart demonstrates the percentage of ulcerative colitis patients with a PUCAI score of <10 at the most recent outpatient clinic visit.



NETWORK DATA QUALITY

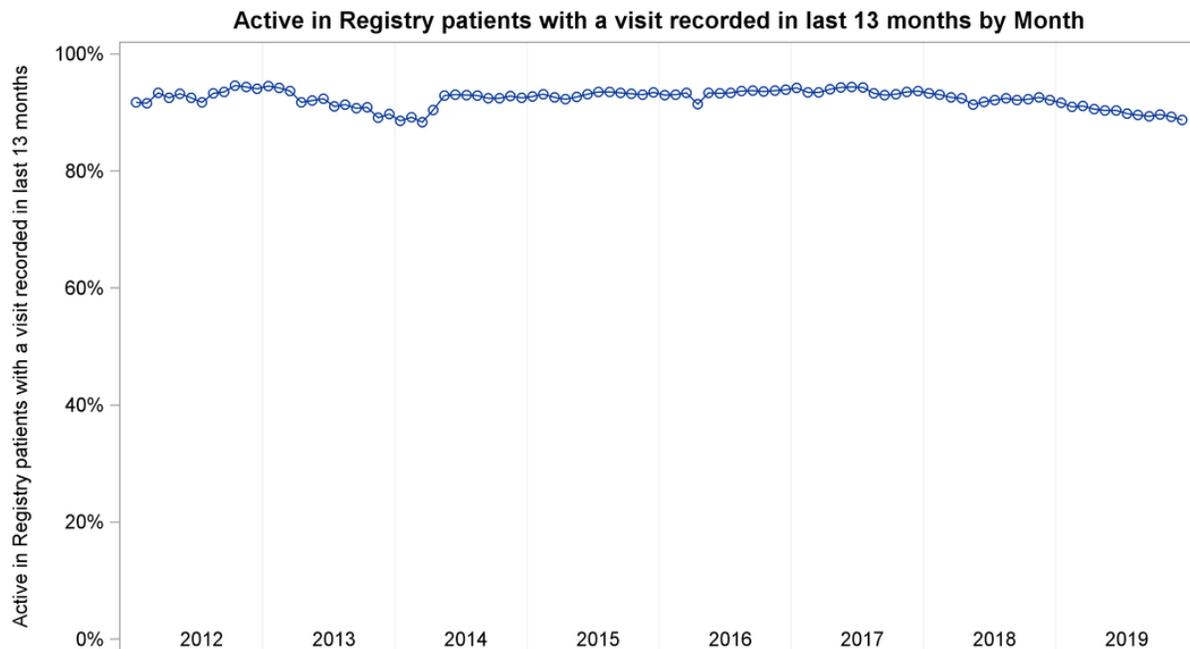
The ICN Registry captures data on centers' performance in registering their eligible IBD patient population, seeing patients in outpatient clinic on a regular basis, and several components of data quality, which measure the completeness, accuracy, and timeliness of the data that are captured during outpatient clinic visits.

Each participating care center is asked to submit and regularly update their Registerable Population, which consists of all pediatric IBD patients who are followed at their center, who have not had a colectomy for ulcerative colitis, have not been seen at that center only for another opinion, or will not be leaving that center soon for any reason.



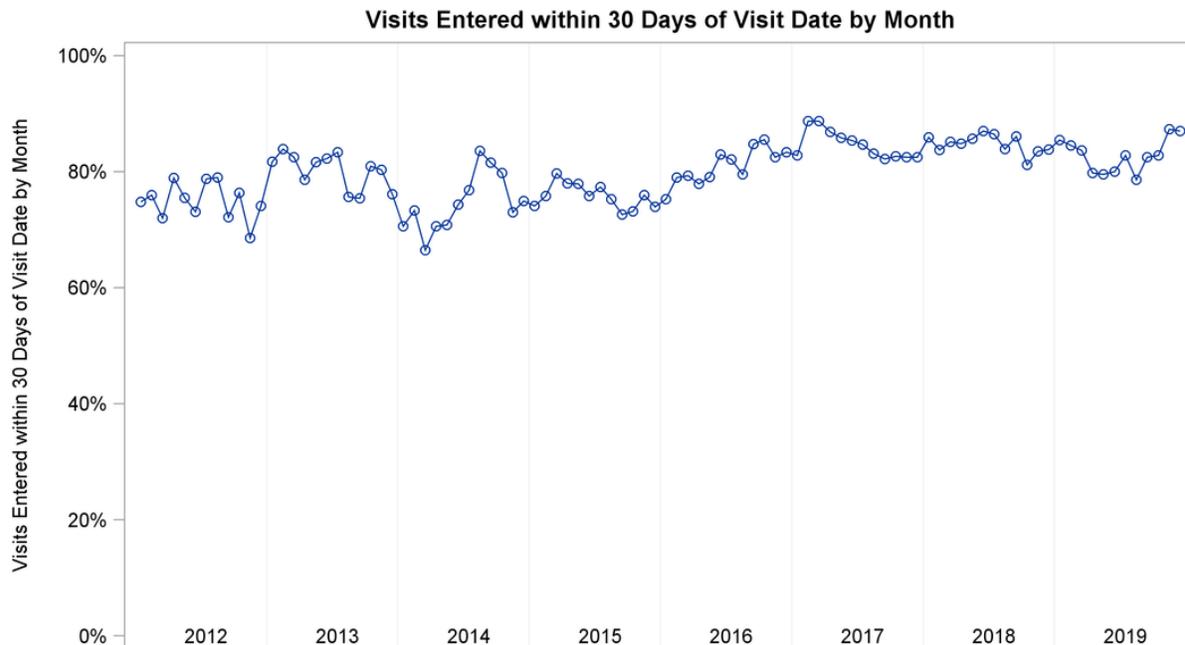
NETWORK DATA QUALITY

The ICN Registry determines the percentage of patients registered in the ICN Registry who have had an outpatient clinic visit recorded in the last 13 months. This allows participating care centers to identify patients who may have been lost to follow-up, moved, or transitioned to an adult gastroenterology provider, and thus allows the care center to arrange for needed follow-up or deactivate the patient.

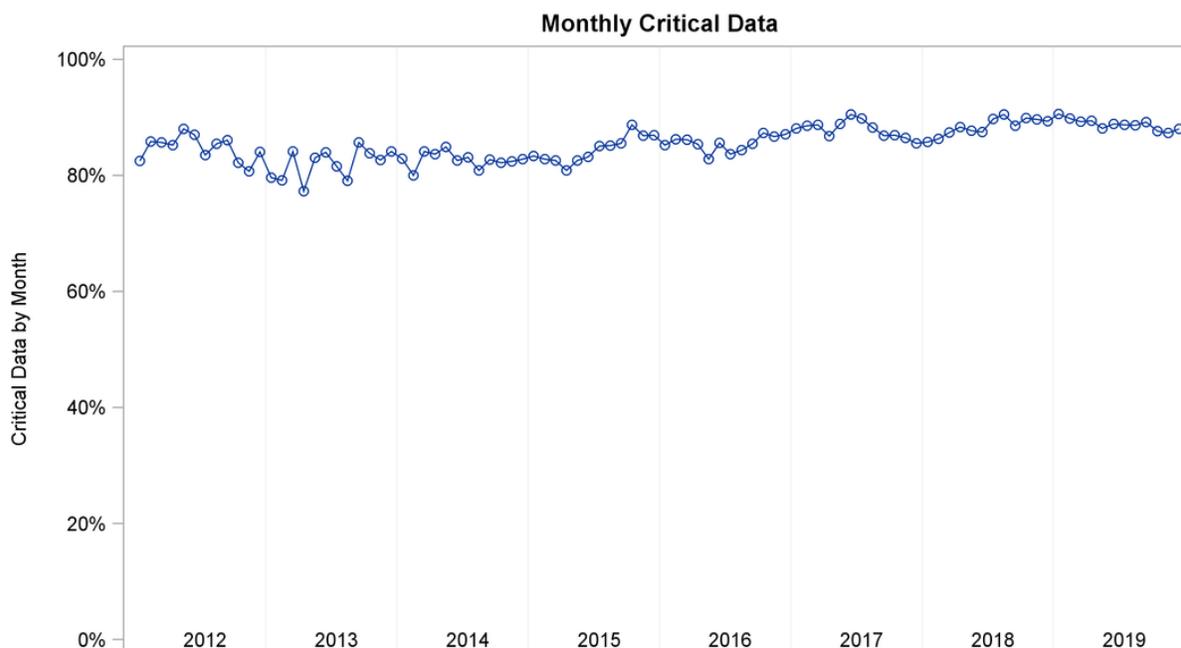


NETWORK DATA QUALITY

The ICN Registry measures the timely entry of data from outpatient clinic visits by calculating the percentage of visits which are entered into the ICN Registry within 30 days of the outpatient clinic visit date.



The ICN Registry measures the percentage of outpatient clinic visits for which key data points have been captured and entered into the ICN Registry. The critical data points are: height, weight, physician global assessment, medications, abdominal examination, and current symptoms including activity level, abdominal pain, general well-being, stool characteristics, and extraintestinal manifestations of disease.



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2. Turner D, Otley AR, Mack D, Hyams J, de Bruijne J, Uusoue K, Walters TD, Zachos M, Mamula P, Beaton DE, Steinhart AH, Griffiths AM. Development, validation, and evaluation of a pediatric ulcerative colitis activity index: A prospective multicenter study. *Gastroenterology.* 2007;133(2):423–432.

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