IMPROVECARENOW 2020
ANNUAL DATA REPORT

prepared by: the ImproveCareNow Data Management Team

ImproveCareNow Spring 2017 Community Conference

FROM THE DIRECTORS

ImproveCareNow (ICN) has had enormous success since it began more than 14 years ago, increasing remission rates for thousands of young people with IBD, transforming how pediatric IBD care is being provided, enlightening and exciting physicians and other care providers, and engaging patients and parents in our shared purpose and work. In 2020, even as COVID-19 demanded dramatic shifts across the healthcare landscape, ICN pivoted to support and maintain active participation across our network of 100+ care centers, with 1,200 clinicians serving 30,400 patients with IBD and their families.

As new members of the ICN leadership team, we are committed to building on the network's strong foundation of quality improvement while actively broadening the reach and impact of our research activities. Our registry continues to grow as a powerful resource for advancing knowledge about pediatric Crohn’s disease and ulcerative colitis - in 2020 we had 44 active studies underway, and our Research Committee approved 13 new proposals for research. Results of our research were shared via 5 articles published in medical journals, 4 published abstracts and 4 poster presentations.

We are pleased to present our 2020 Annual Data Report, which offers a closer look at some of the data in the ICN Registry - our enhanced, disease-specific IBD registry developed for continuous improvement and research.

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ABOUT THIS REPORT

The 2020 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 Crohn's disease or ulcerative colitis (also known as Inflammatory Bowel Disease or IBD).

As the COVID-19 pandemic spread across the world in 2020, all members of the ICN community felt its effects. Medical professionals were challenged with a new disease, new protocols, and new safety measures. Patients and their families faced difficult decisions about the risks and benefits of their medical care during a pandemic.

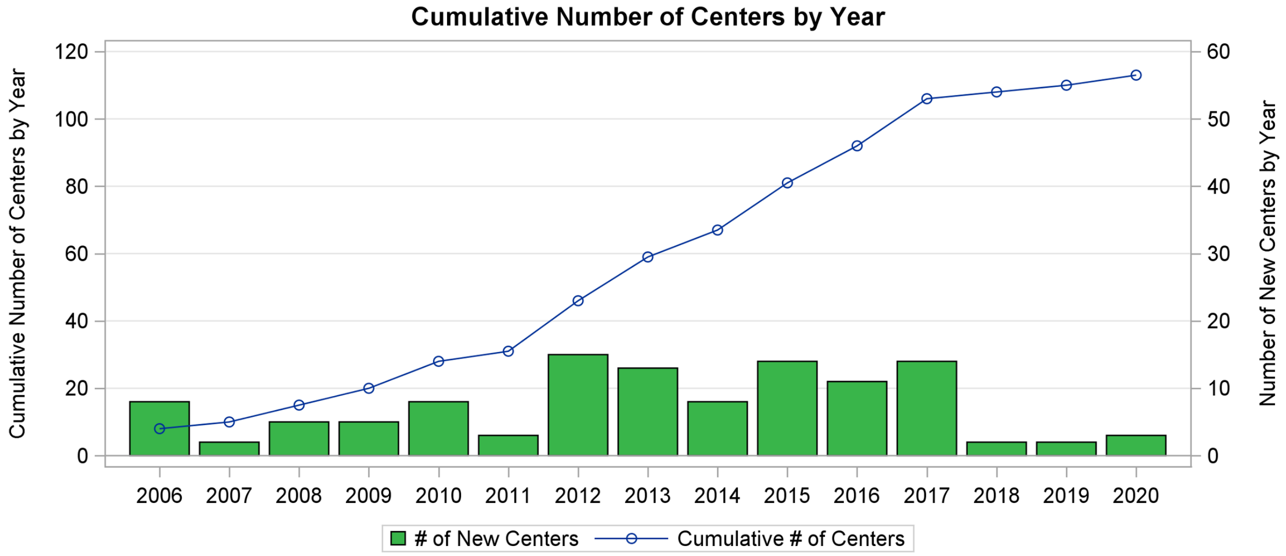
Medical professionals rapidly adopted telemedicine, and the ICN Registry responded. The ICN Data Management Team amended the ICN Registry to allow for the classification of outpatient clinic visits as “Telehealth” or “Phone” visits. Many data elements typically captured at regular outpatient clinic visits were not captured at telemedicine visits, and the registry accounted for this.

The COVID-19 pandemic had a remarkable effect on ICN’s Data Quality Outcomes. In this 2020 Annual Data Report, a notable decline in Monthly Critical Data was noticed at the beginning of the pandemic. This returned to baseline with the ability to differentiate telemedicine visits from in-office visits in the registry. The ICN Data Management Team continues to assess the effects of the COVID-19 pandemic on ICN Registry data.

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.

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 2020 entered into the registry. "Registered in Report Year" includes patients who had their initial registration entered in 2020 (*note: diagnosis may have been earlier than 2020*).

Demographics	**Ever Registered (n = 51,955)**	**Active in Registry (n = 28,490)**	**Had Visits in Report Year (n = 23,705)**	**Registered in Report Year (n = 4,127)**
Age at Registration (years)				
0 - 6	2,686 (5.2%)	1,979 (6.9%)	1,677 (7.1%)	250 (6.1%)
7 - 11	10,539 (20.3%)	7,797 (27.4%)	6,733 (28.4%)	852 (20.6%)
12 - 17	32,367 (62.3%)	16,670 (58.5%)	13,969 (58.9%)	2,640 (64.0%)
>18	6,110 (11.8%)	1,917 (6.7%)	1,326 (5.6%)	385 (9.3%)
Missing	253 (0.5%)	127 (0.4%)		
Age at End of Report (years)				
0 - 6	693 (1.3%)	603 (2.1%)	506 (2.1%)	208 (5.0%)
7 - 11	3,557 (6.8%)	2,985 (10.5%)	2,594 (10.9%)	752 (18.2%)
12 - 17	16,650 (32.0%)	13,970 (49.0%)	12,023 (50.7%)	2,535 (61.4%)
>18	31,053 (59.8%)	10,931 (38.4%)	8,582 (36.2%)	632 (15.3%)
Missing	2 (0.0%)	1 (0.0%)		
Gender				
Male	28,876 (55.6%)	16,051 (56.3%)	13,192 (55.7%)	2,260 (54.8%)
Female	23,078 (44.4%)	12,439 (43.7%)	10,513 (44.3%)	1,867 (45.2%)
Missing	1 (0.0%)			
Race				
American Indian/Alaska Native	113 (0.2%)	67 (0.2%)	63 (0.3%)	13 (0.3%)
Asian	1,315 (2.5%)	830 (2.9%)	709 (3.0%)	141 (3.4%)
Native Hawaiian or other Pacific Islander	68 (0.1%)	44 (0.2%)	42 (0.2%)	9 (0.2%)
Black or African American	5,005 (9.6%)	2,635 (9.2%)	2,354 (9.9%)	461 (11.2%)
White	35,658 (68.6%)	19,103 (67.1%)	16,463 (69.4%)	2,799 (67.8%)
Multiracial	366 (0.7%)	191 (0.7%)	145 (0.6%)	27 (0.7%)
Other or Unknown	1,770 (3.4%)	1,126 (4.0%)	948 (4.0%)	193 (4.7%)
Missing	7,660 (14.7%)	4,494 (15.8%)	2,981 (12.6%)	484 (11.7%)
Ethnicity				
Hispanic	3,126 (6.0%)	1,890 (6.6%)	1,549 (6.5%)	354 (8.6%)
Non-Hispanic	34,165 (65.8%)	20,726 (72.7%)	18,094 (76.3%)	3,319 (80.4%)
Missing	14,664 (28.2%)	5,874 (20.6%)	4,062 (17.1%)	454 (11.0%)

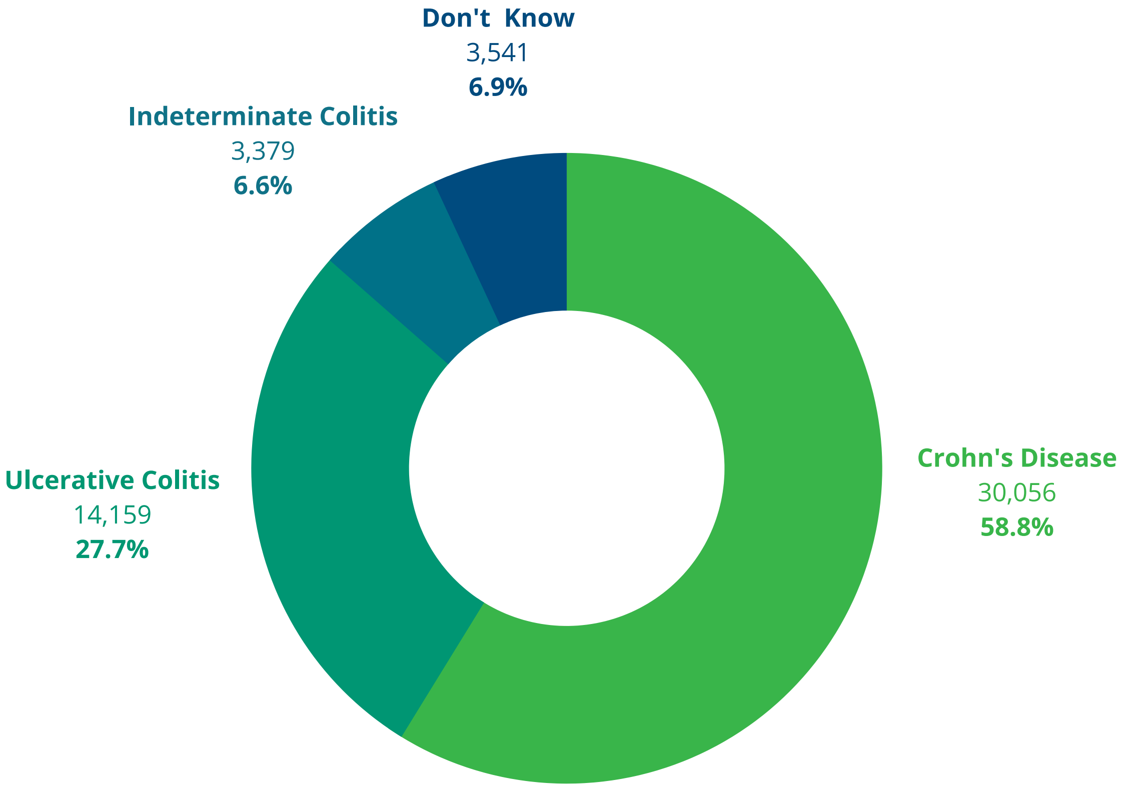
DEMOGRAPHICS

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 2020 (*note: diagnosis may have been earlier than 2020*). "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 = 51,135)	Registered in Report Year (n = 4,127)	Active in Registry (n = 28,490)
Diagnosis			
Crohn's Disease	30,056 (58.8%)	2,503 (60.6%)	16,918 (59.4%)
Ulcerative Colitis	14,159 (27.7%)	1,304 (31.6%)	7,532 (26.4%)
Indeterminate Colitis	3,379 (6.6%)	267 (6.5%)	1,802 (6.3%)
Don't Know	3,541 (6.9%)	53 (1.3%)	2,238 (7.9%)

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.



Diagnosis at Registration
(n = 51,135)

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 2020 entered into the registry. "Registered in Report Year" includes patients who had their initial registration entered in 2020 (*note: diagnosis may have been earlier than 2020*).

Demographics	Ever Registered (n = 30,056)	Active in Registry (n = 16,918)	Had Visits in Report Year (n = 14,552)	Registered in Report Year (n = 2,503)
Age at Registration (years)				
0 - 6	1,111 (3.7%)	868 (5.1%)	754 (5.2%)	113 (4.5%)
7 - 11	6,237 (20.8%)	4,848 (28.7%)	4,300 (29.5%)	546 (21.8%)
12 - 17	19,236 (64.0%)	10,177 (60.2%)	8,731 (60.0%)	1,631 (65.2%)
>18	3,464 (11.5%)	1,020 (6.0%)	767 (5.3%)	213 (8.5%)
Missing	8 (0.0%)	5 (0.0%)		
Age at End of Report (years)				
0 - 6	274 (0.9%)	239 (1.4%)	211 (1.4%)	93 (3.7%)
7 - 11	1,751 (5.8%)	1,537 (9.1%)	1,393 (9.6%)	470 (18.8%)
12 - 17	9,643 (32.1%)	8,466 (50.0%)	7,513 (51.6%)	1,591 (63.6%)
>18	18,387 (61.2%)	6,676 (39.5%)	5,435 (37.3%)	349 (13.9%)
Missing	1 (0.0%)			
Gender				
Male	17,560 (58.4%)	10,024 (59.3%)	8,512 (58.5%)	1,418 (56.7%)
Female	12,496 (41.6%)	6,894 (40.7%)	6,040 (41.5%)	1,085 (43.3%)
Race				
American Indian/Alaska Native	56 (0.2%)	36 (0.2%)	32 (0.2%)	8 (0.3%)
Asian	758 (2.5%)	491 (2.9%)	421 (2.9%)	76 (3.0%)
Native Hawaiian or other Pacific Islander	39 (0.1%)	24 (0.1%)	25 (0.2%)	4 (0.2%)
Black or African American	3,325 (11.1%)	1,797 (10.6%)	1,612 (11.1%)	326 (13.0%)
White	22,098 (73.5%)	12,267 (72.5%)	10,628 (73.0%)	1,703 (68.0%)
Multiracial	229 (0.8%)	141 (0.8%)	106 (0.7%)	18 (0.7%)
Other or Unknown	922 (3.1%)	590 (3.5%)	494 (3.4%)	100 (4.0%)
Missing	2,629 (8.7%)	1,572 (9.3%)	1,234 (8.5%)	268 (10.7%)
Ethnicity				
Hispanic	1,407 (4.7%)	891 (5.3%)	716 (4.9%)	152 (6.1%)
Non-Hispanic	21,450 (71.4%)	13,483 (79.7%)	11,817 (81.2%)	2,082 (83.2%)
Missing	7,199 (24.0%)	2,544 (15.0%)	2,019 (13.9%)	269 (10.7%)

DEMOGRAPHICS

ULCERATIVE COLITIS - AGE, ETHNICITY, AND RACE

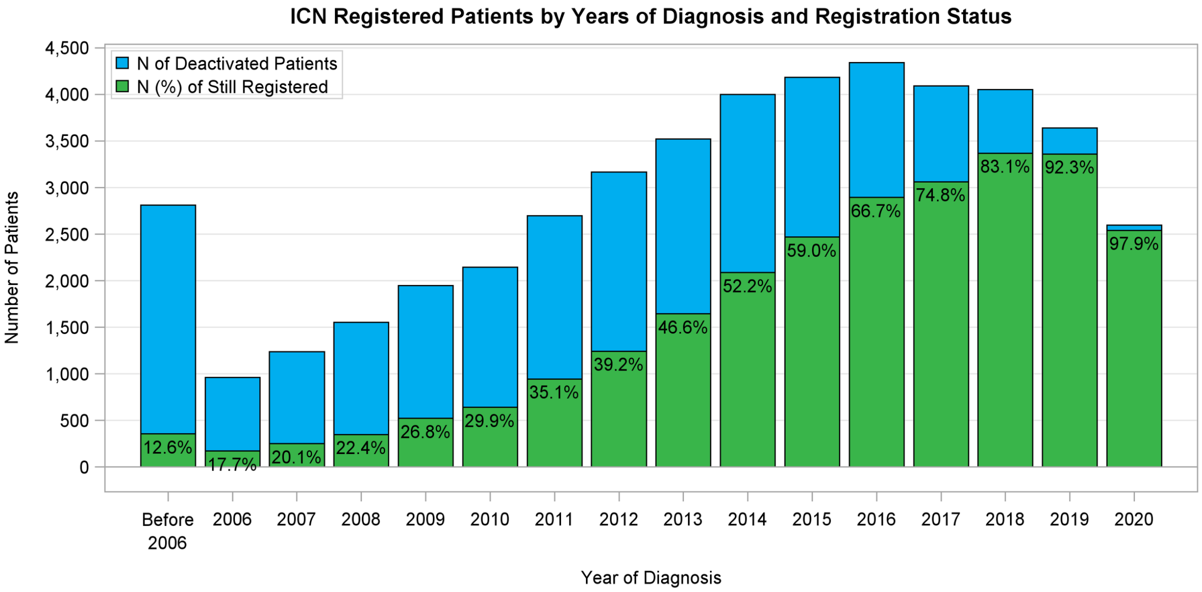
The table below presents data on patients who have ever been included in the ICN Registry and whose initial diagnosis was **ulcerative colitis**. "Ever Registered" includes all patients who were ever added to the ICN Registry. "Active in Registry" includes patients who have not been deactivated from 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 2020 entered into the registry. "Registered in Report Year" includes patients who had their initial registration entered in 2020 (*note: diagnosis may have been earlier than 2020*).

Demographics	Ever Registered (n = 14,159)	Active in Registry (n = 7,532)	Had Visits in Report Year (n = 6,396)	Registered in Report Year (n = 1,304)
Age at Registration (years)				
0 - 6	891 (6.3%)	640 (8.5%)	544 (8.5%)	90 (6.9%)
7 - 11	2,769 (19.6%)	1,943 (25.8%)	1,664 (26.0%)	236 (18.1%)
12 - 17	8,816 (62.3%)	4,384 (58.2%)	3,769 (58.9%)	828 (63.5%)
>18	1,680 (11.9%)	563 (7.5%)	419 (6.6%)	150 (11.5%)
Missing	3 (0.0%)	2 (0.0%)		
Age at End of Report (years)				
0 - 6	199 (1.4%)	177 (2.3%)	160 (2.5%)	72 (5.5%)
7 - 11	1,048 (7.4%)	875 (11.6%)	769 (12.0%)	219 (16.8%)
12 - 17	4,380 (30.9%)	3,556 (47.2%)	3,130 (48.9%)	771 (59.1%)
>18	8,532 (60.3%)	2,924 (38.8%)	2,337 (36.5%)	242 (18.6%)
Gender				
Male	7,082 (50.0%)	3,789 (50.3%)	3,184 (49.8%)	671 (51.5%)
Female	7,077 (50.0%)	3,743 (49.7%)	3,212 (50.2%)	633 (48.5%)
Race				
American Indian/Alaska Native	50 (0.4%)	28 (0.4%)	28 (0.4%)	4 (0.3%)
Asian	422 (3.0%)	259 (3.4%)	222 (3.5%)	51 (3.9%)
Native Hawaiian or other Pacific Islander	25 (0.2%)	18 (0.2%)	16 (0.3%)	5 (0.4%)
Black or African American	1,212 (8.6%)	626 (8.3%)	554 (8.7%)	107 (8.2%)
White	10,136 (71.6%)	5,277 (70.1%)	4,513 (70.6%)	871 (66.8%)
Multiracial	98 (0.7%)	40 (0.5%)	31 (0.5%)	7 (0.5%)
Other or Unknown	676 (4.8%)	434 (5.8%)	368 (5.8%)	80 (6.1%)
Missing	1,540 (10.9%)	850 (11.3%)	664 (10.4%)	179 (13.7%)
Ethnicity				
Hispanic	1,382 (9.8%)	852 (11.3%)	712 (11.1%)	178 (13.7%)
Non-Hispanic	9,288 (65.6%)	5,505 (73.1%)	4,778 (74.7%)	971 (74.5%)
Missing	3,489 (24.6%)	1,175 (15.6%)	906 (14.2%)	155 (11.9%)

DEMOGRAPHICS

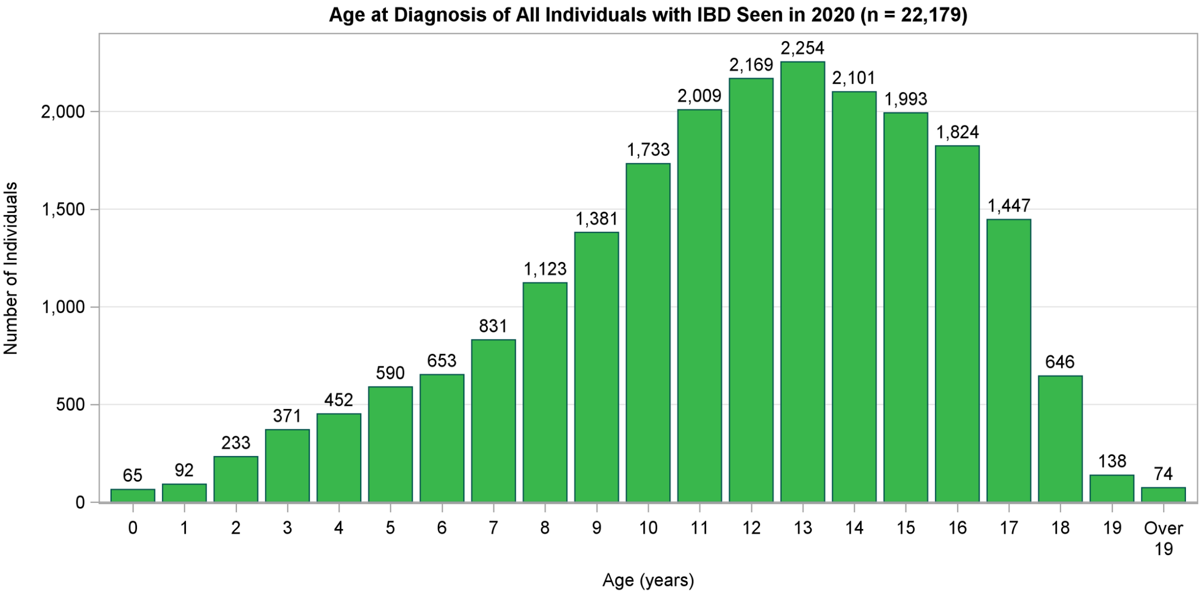
YEAR AND AGE OF DIAGNOSIS

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

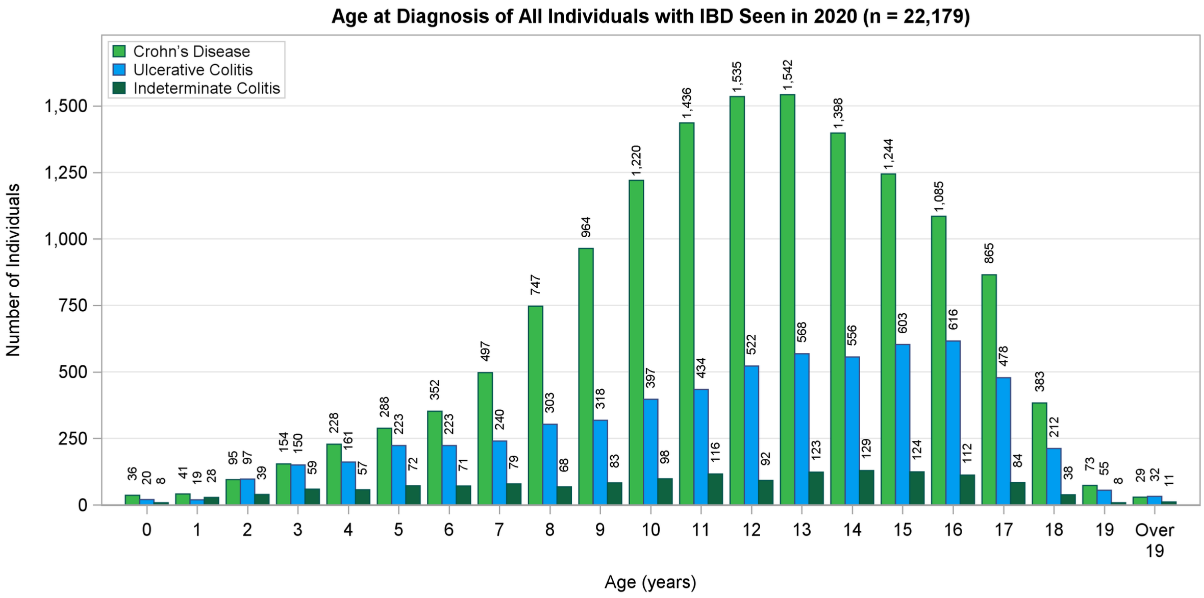
The graph below demonstrates the **age of diagnosis** for all patients who were included in the ICN Registry and had an outpatient clinic visit entered into the registry in 2020.



DEMOGRAPHICS

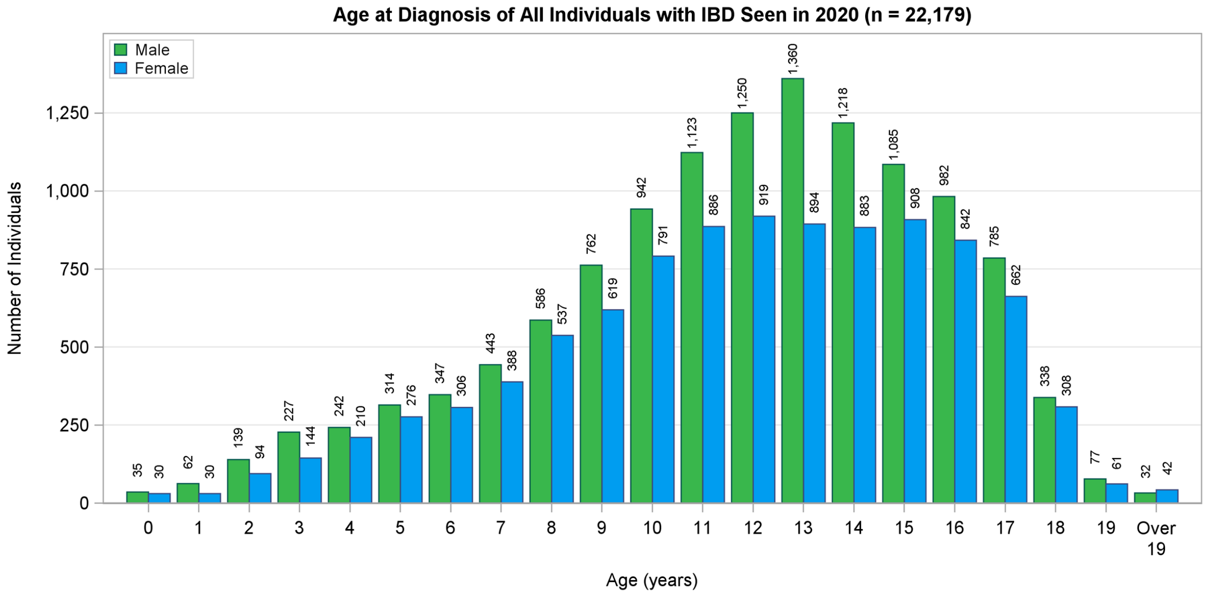
2020 AGE OF DIAGNOSIS

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 2020, **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*).


Age at Diagnosis of All Individuals with IBD Seen in 2020 (n = 22,179)

2020 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 2020, **divided by gender** (*light green bars represent male patients, and blue bars represent female patients*).


Age at Diagnosis of All Individuals with IBD Seen in 2020 (n = 22,179)

CLINICAL CHARACTERISTICS

CROHN'S DISEASE

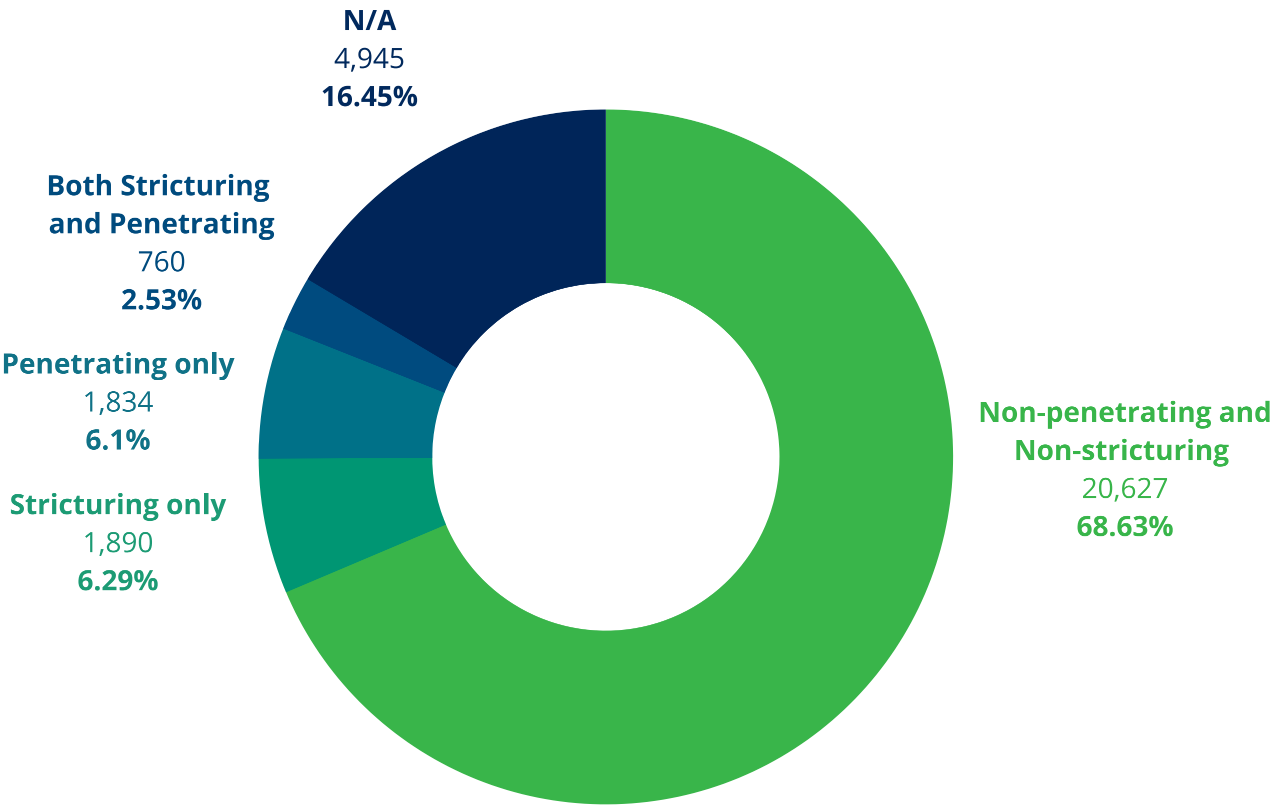
The table below contains clinical characteristics for patients with a diagnosis of **Crohn's disease** in the ICN Registry. The extent and phenotype of Crohn's disease at the time of registration are summarized for all patients ever registered, all newly registered patients in 2020, and all patients 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 = 30,056)	Registered in Report Year (n = 2,503)	Active in Registry (n = 16,918)
Extent of Disease			
CD Extent of Disease			
Macroscopic Lower GI Disease			
None	762 (2.5%)	55 (2.2%)	422 (2.5%)
Ileal Only	4,002 (13.3%)	415 (16.6%)	2518 (14.9%)
Colonic only	4,324 (14.4%)	363 (14.5%)	2667 (15.8%)
Ileocolonic	12,969 (43.1%)	1,265 (50.5%)	10217 (60.4%)
Not Assessed	292 (1.0%)	23 (0.9%)	121 (0.7%)
Don't Know	7,707 (25.6%)	382 (15.3%)	973 (5.8%)
Macroscopic Upper GI Disease proximal to the ligament of Treitz			
No	11,222 (37.3%)	1,171 (46.8%)	8,838 (52.2%)
Yes	9,749 (32.4%)	847 (33.8%)	6,617 (39.1%)
Not Assessed	608 (2.0%)	48 (1.9%)	256 (1.5%)
Don't Know	8,477 (28.2%)	437 (17.5%)	1,207 (7.1%)
Macroscopic Upper GI Disease distal to the ligament of Treitz			
No	12,799 (42.6%)	1,264 (50.5%)	10,506 (62.1%)
Yes	4,992 (16.6%)	522 (20.9%)	3,897 (23.0%)
Not Assessed	3,246 (10.8%)	212 (8.5%)	1,137 (6.7%)
Don't Know	9,019 (30.0%)	505 (20.2%)	1,378 (8.1%)
CD Phenotype			
Inflammatory, non-penetrating, non-stricturing	20,627 (68.6%)	1,651 (66.0%)	11,628 (68.7%)
Stricturing only	1,890 (6.3%)	129 (5.2%)	1,345 (8.0%)
Penetrating only	1,834 (6.1%)	185 (7.4%)	1,070 (6.3%)
Both stricturing and penetrating	760 (2.5%)	70 (2.8%)	542 (3.2%)
Don't Know	4,945 (16.5%)	468 (18.7%)	2,333 (13.8%)
Perianal Disease Phenotype			
No	19,048 (63.4%)	1,544 (61.7%)	11,069 (65.4%)
Yes	5,616 (18.7%)	453 (18.1%)	3,238 (19.1%)
Don't Know	5,392 (17.9%)	506 (20.2%)	2,611 (15.4%)
PGA			
Quiescent		1,436 (57.4%)	13,223 (78.2%)
Mild		527 (21.1%)	2,282 (13.5%)
Moderate		199 (8.0%)	603 (3.6%)
Severe		25 (1.0%)	55 (0.3%)
Missing and No Visit in 2020		264 (10.5%)	695 (4.1%)
Don't Know/Not Assessed		52 (2.1%)	60 (0.4%)
sPCDAI			
Number of Patients		1,705	15,113
Mean (SD)		11.4 (15.05)	7.8 (12.34)
Median [Q1, Q3]		5.0 [0.0, 20.0]	0.0 [0.0, 10.0]
Min - Max		0.0 - 80.0	0.0 - 80.0

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*).



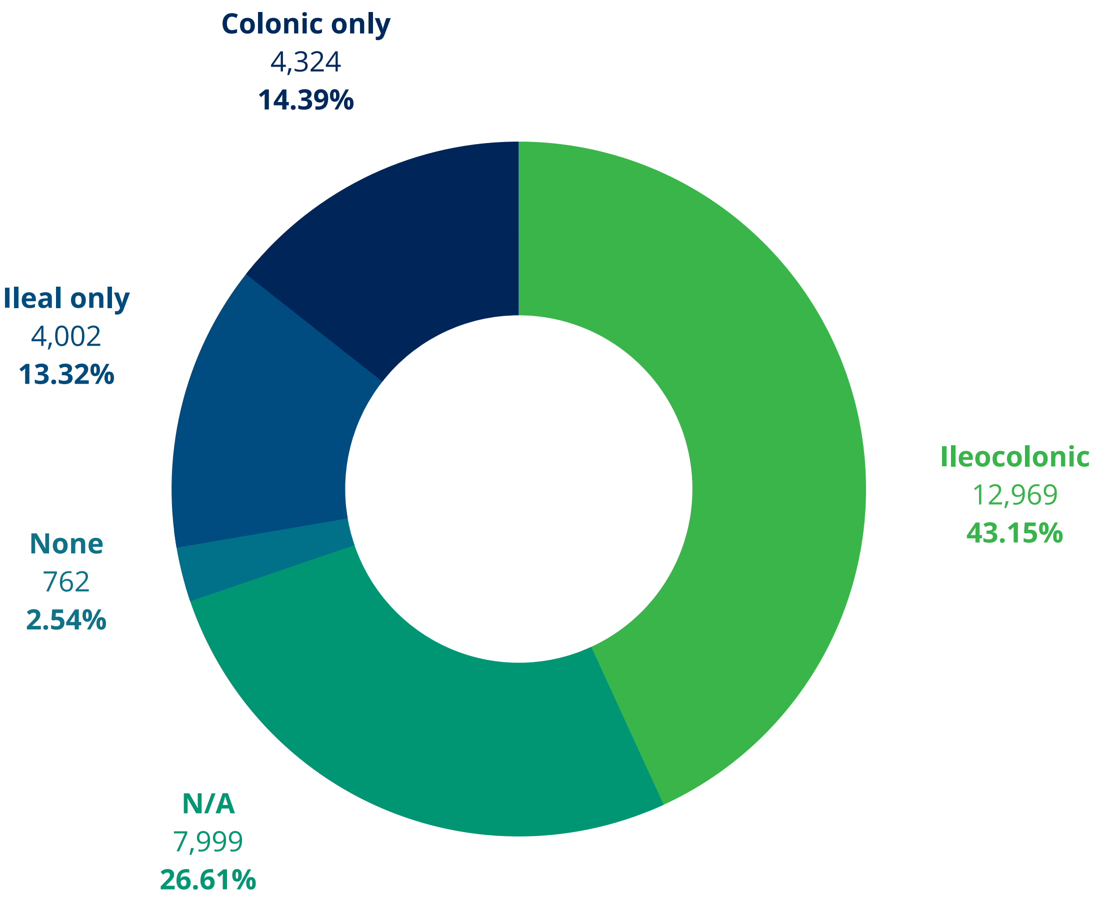
CD Phenotype at Registration
(n = 30,056)

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*).

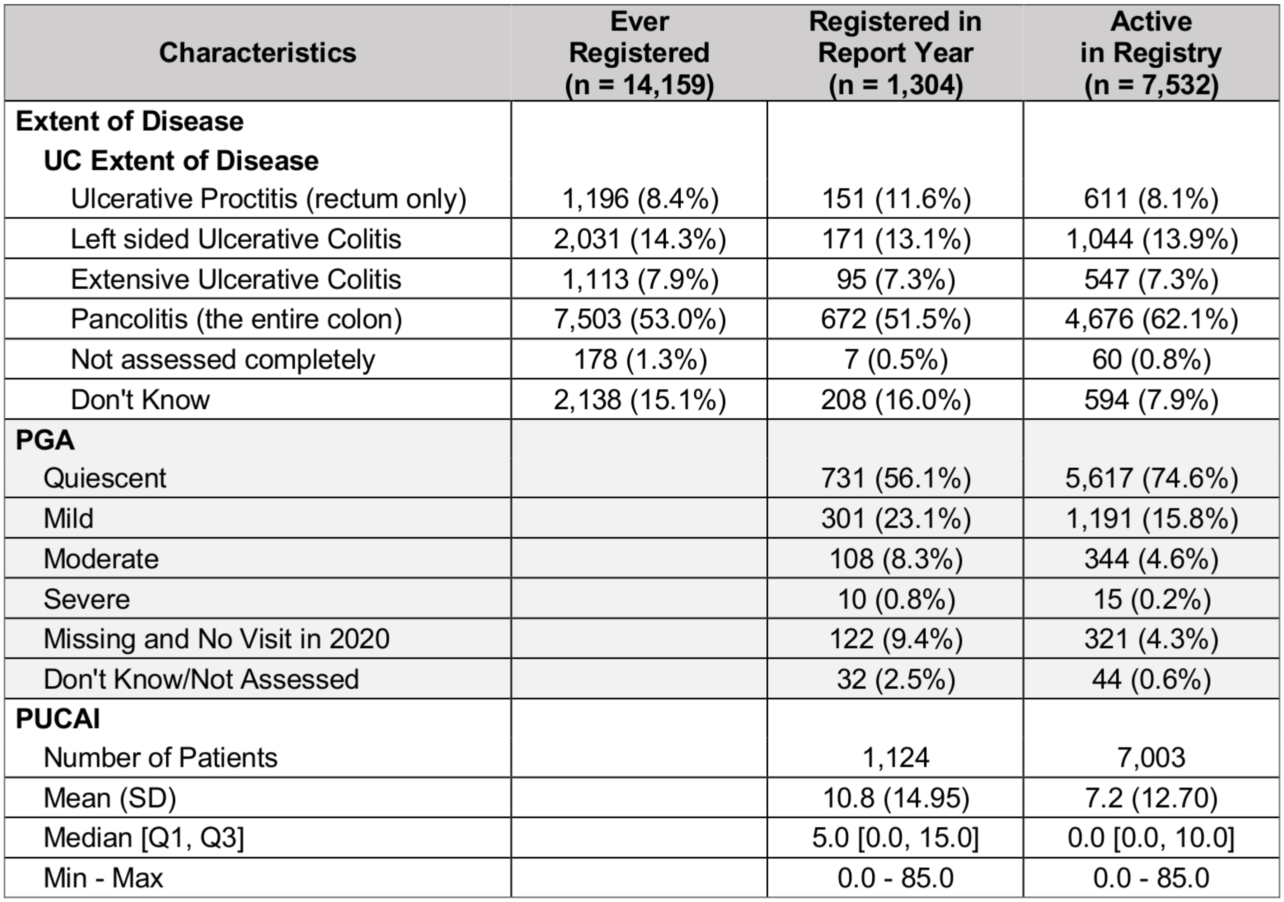


CD Extent of Disease at Registration - Macroscopic Lower GI Disease
(n = 30,056)

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 2020, 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.

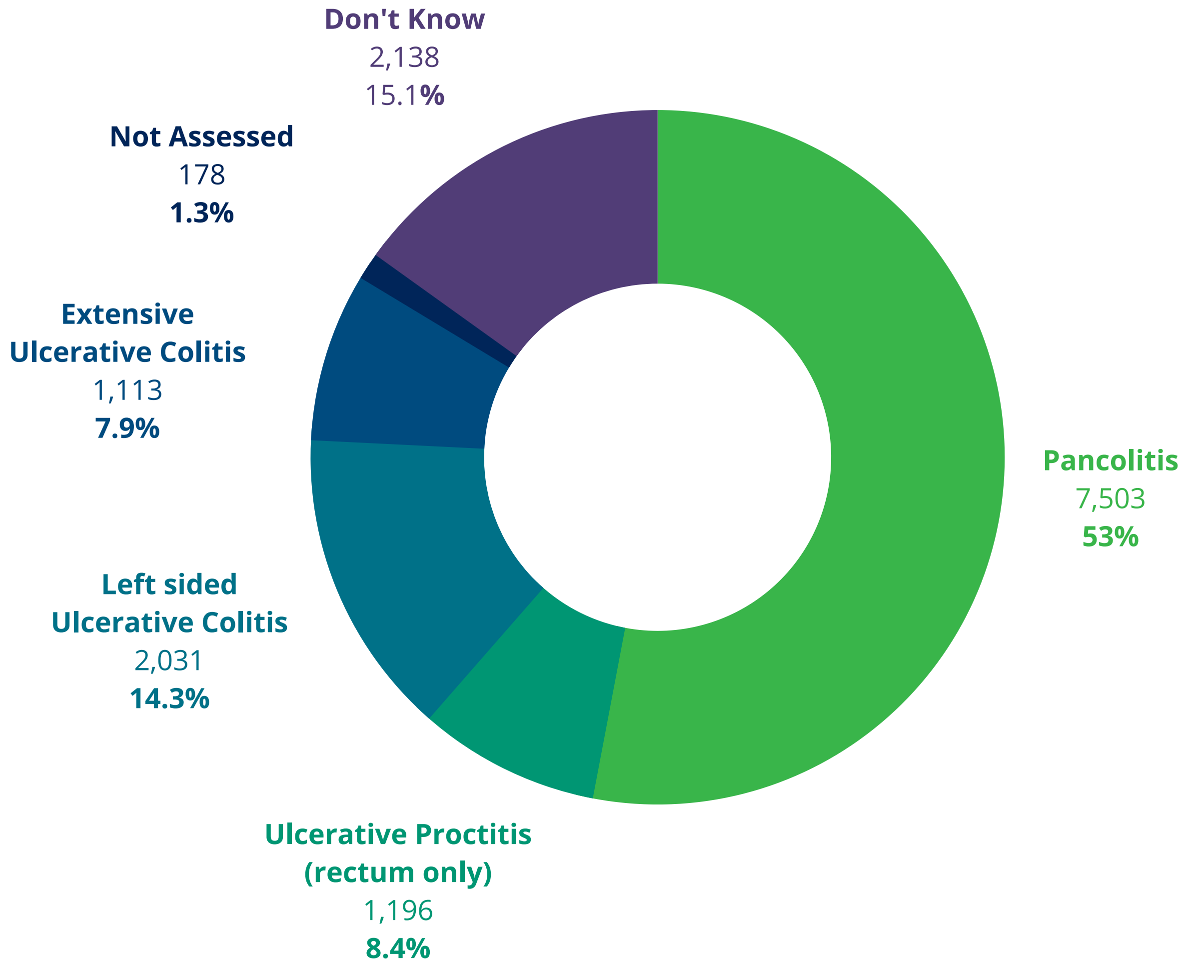


Characteristics	Ever Registered (n = 14,159)	Registered in Report Year (n = 1,304)	Active in Registry (n = 7,532)
Extent of Disease			
UC Extent of Disease			
Ulcerative Proctitis (rectum only)	1,196 (8.4%)	151 (11.6%)	611 (8.1%)
Left sided Ulcerative Colitis	2,031 (14.3%)	171 (13.1%)	1,044 (13.9%)
Extensive Ulcerative Colitis	1,113 (7.9%)	95 (7.3%)	547 (7.3%)
Pancolitis (the entire colon)	7,503 (53.0%)	672 (51.5%)	4,676 (62.1%)
Not assessed completely	178 (1.3%)	7 (0.5%)	60 (0.8%)
Don't Know	2,138 (15.1%)	208 (16.0%)	594 (7.9%)
PGA			
Quiescent		731 (56.1%)	5,617 (74.6%)
Mild		301 (23.1%)	1,191 (15.8%)
Moderate		108 (8.3%)	344 (4.6%)
Severe		10 (0.8%)	15 (0.2%)
Missing and No Visit in 2020		122 (9.4%)	321 (4.3%)
Don't Know/Not Assessed		32 (2.5%)	44 (0.6%)
PUCAI			
Number of Patients		1,124	7,003
Mean (SD)		10.8 (14.95)	7.2 (12.70)
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*).

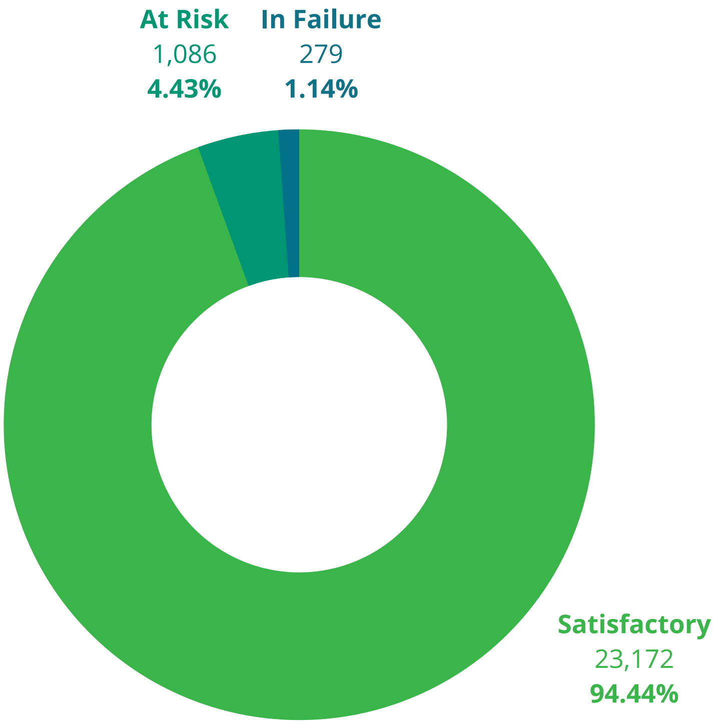


UC Extent of Disease at Registration
(n = 14,159)

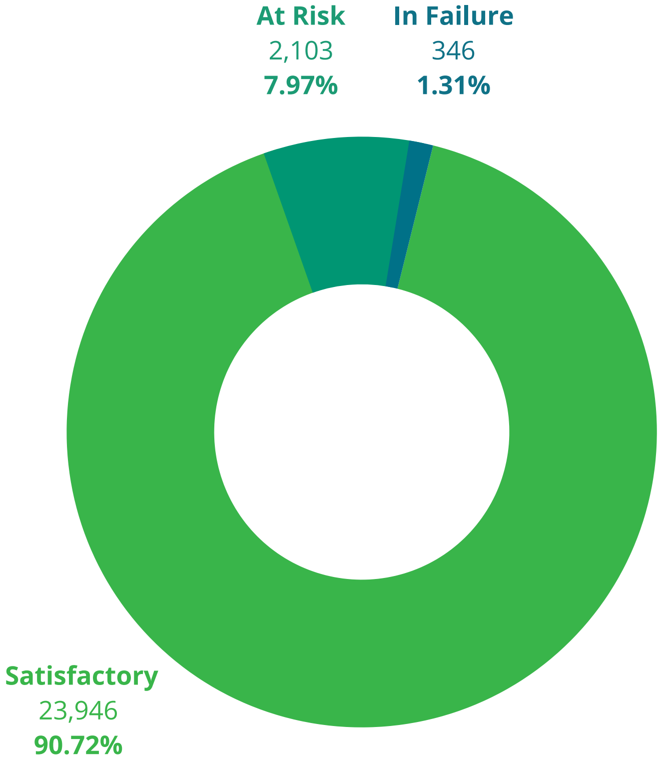
GROWTH & NUTRITION

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 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.



Growth Status at Most Recent Visit
(n = 24,537)

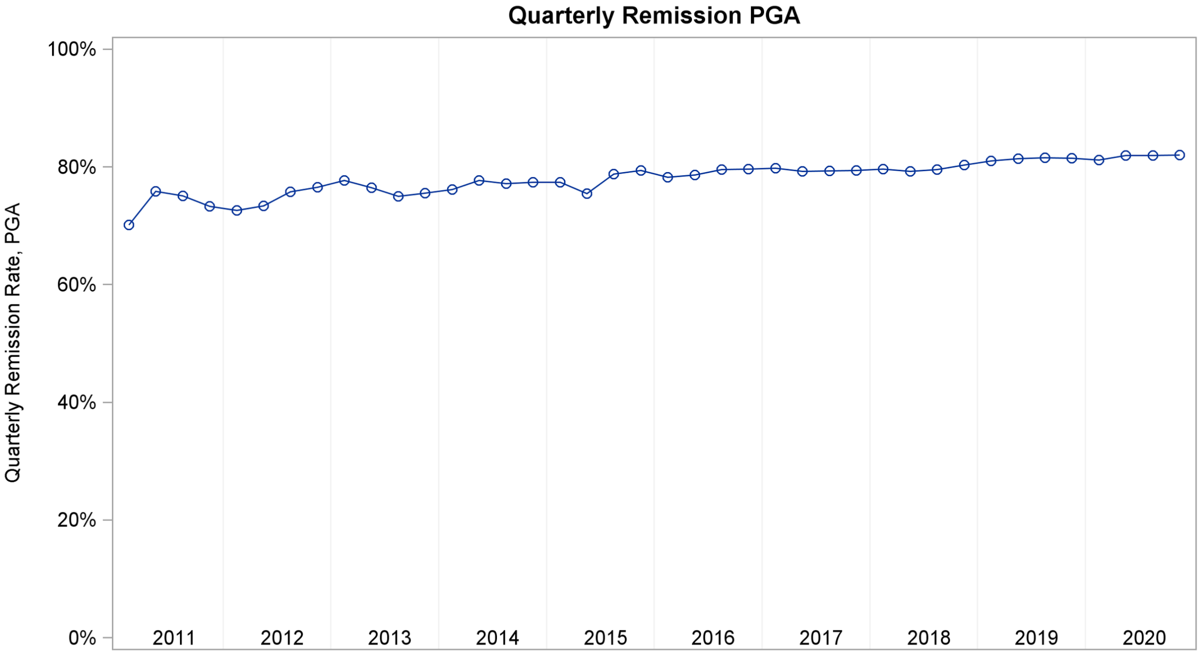


Nutrition Status at Most Recent Visit
(n = 26,395)

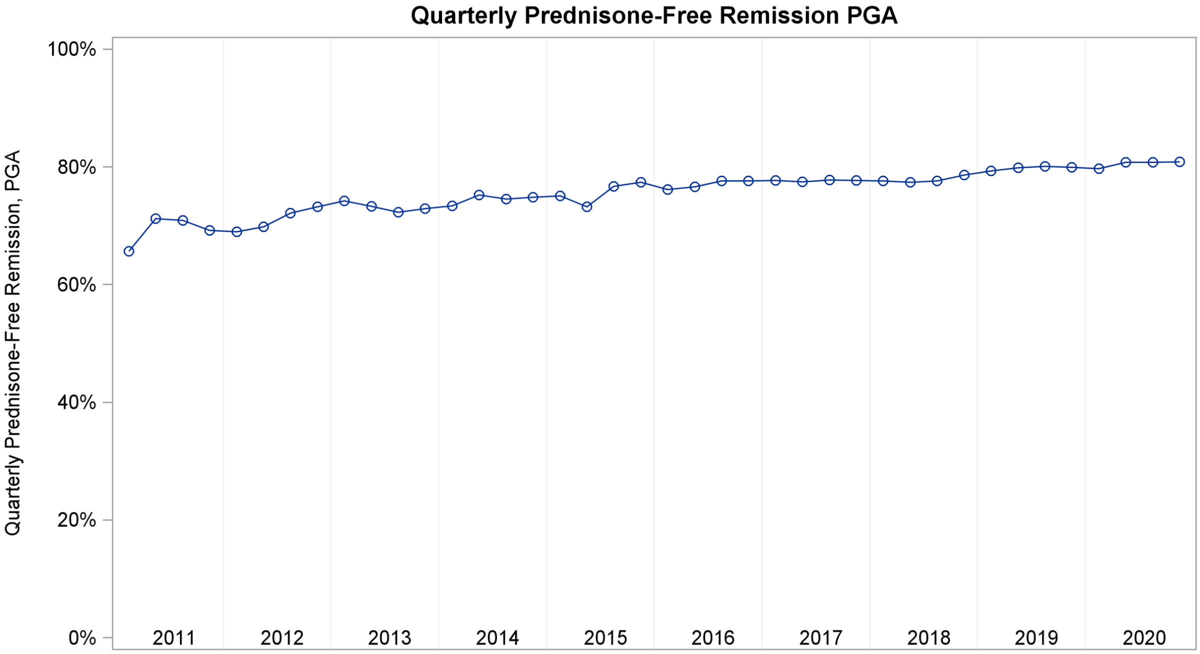
At each outpatient visit, a patient's **nutritional status** is classified as satisfactory, at risk, or in failure. Failure is defined as weight loss ≥10% or body mass index <3rd percentile for age or weight percentile changed lower by two isobars. At risk is defined as weight stable (no gain) or 1-9%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

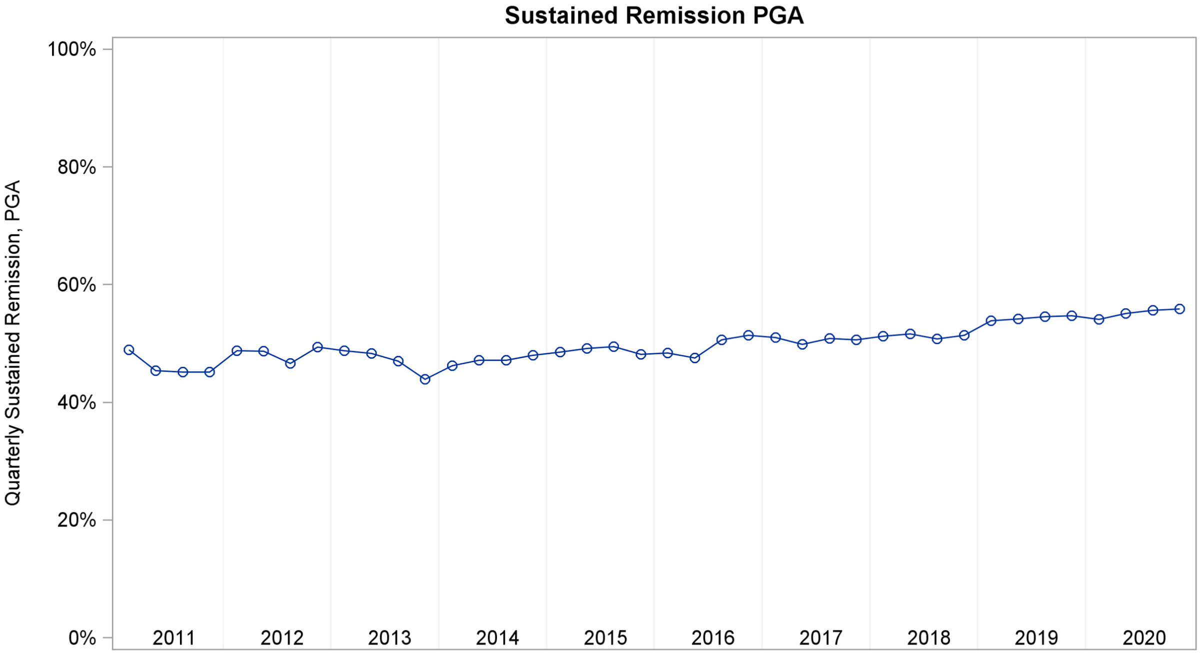


Prednisone-free remission is also determined by the percentage of patients whose PGA is marked as “quiescent” by the pediatric gastroenterology provider at the time of the patient’s most recent outpatient clinic visit, with the additional criterion of having no planned steroid exposure at the time of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



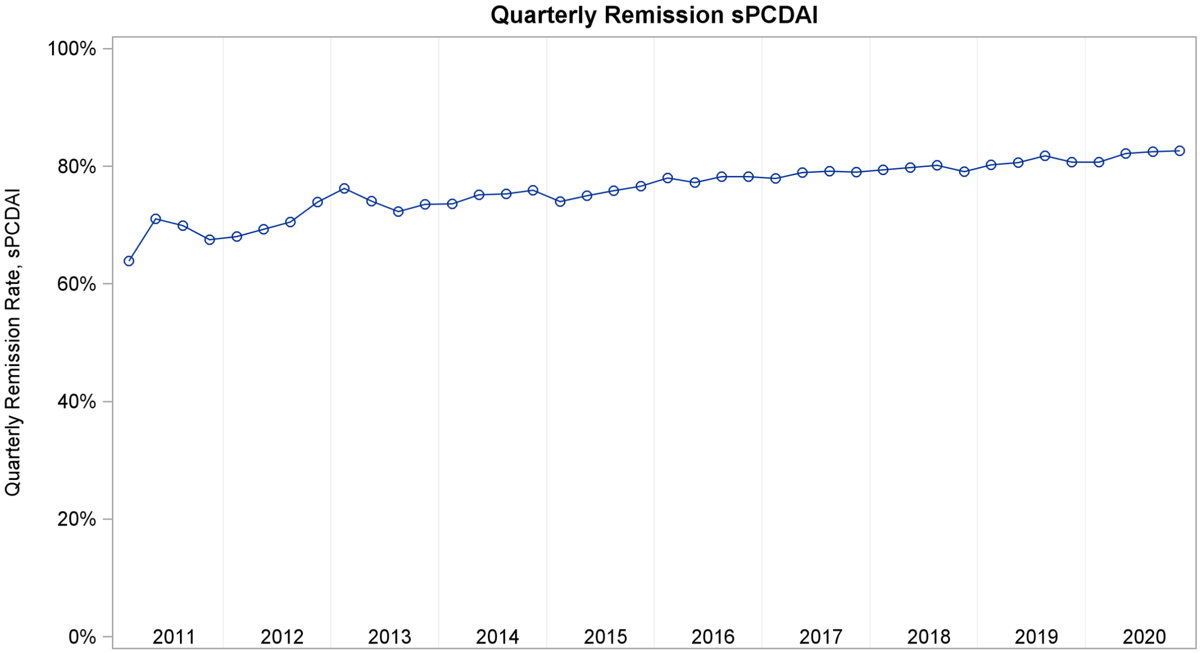
QI MEASURES: REMISSION

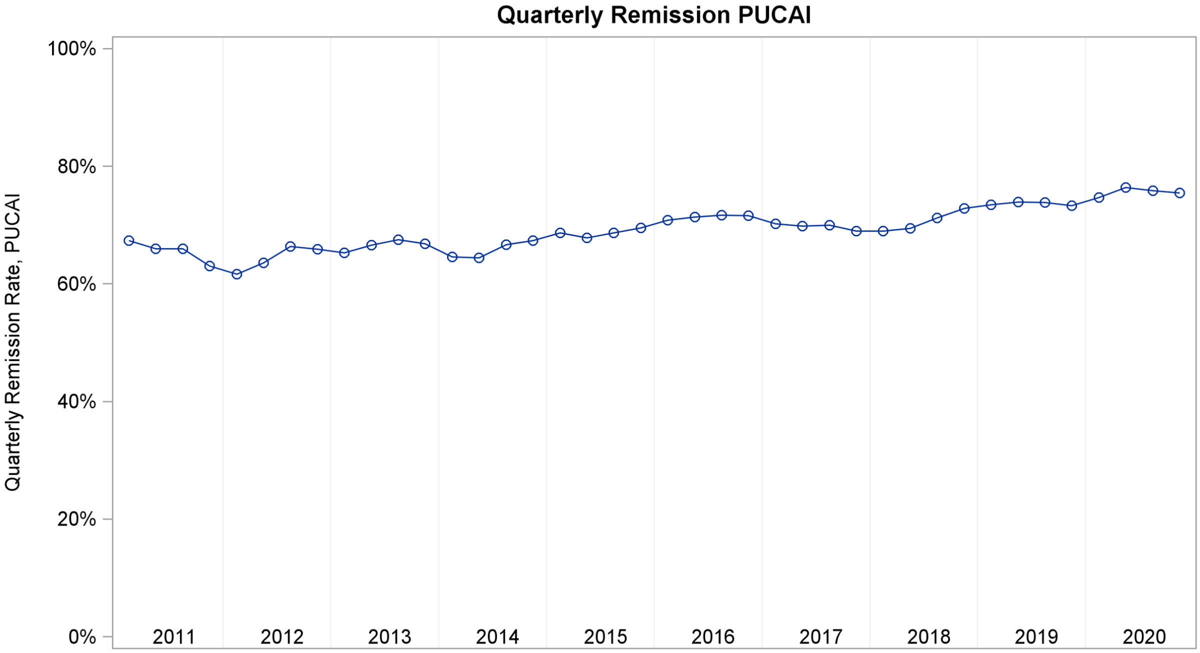
Sustained remission is calculated based on two criteria at all visits in the last one year: the pediatric gastroenterology provider marked the PGA as "quiescent", and the pediatric gastroenterology provider marked "yes" to the question of whether the patient had been in continuous remission since the 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*)**[1] or **PUCAI (*Pediatric Ulcerative Colitis Activity Index*)**[2] 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.

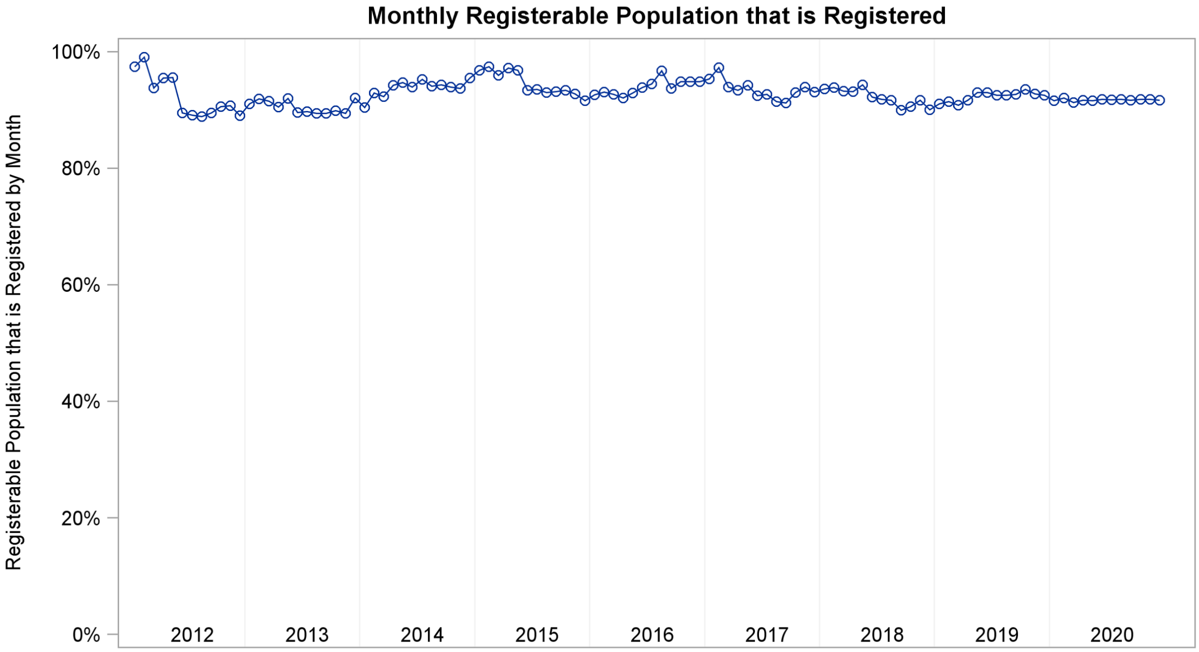




NETWORK DATA QUALITY

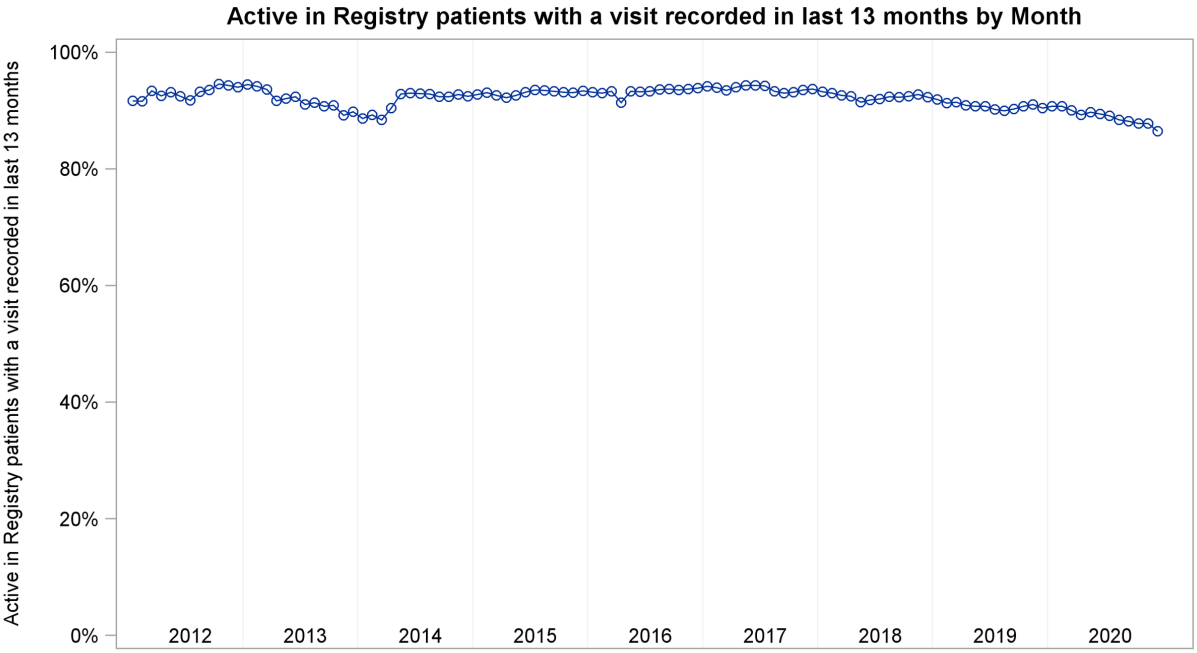
The ICN Registry captures data on centers' performance in registering their eligible IBD patient population, seeing patients in outpatient clinic on a regular basis, and several components of data quality, which measure the completeness, accuracy, and timeliness of the data that are captured during outpatient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



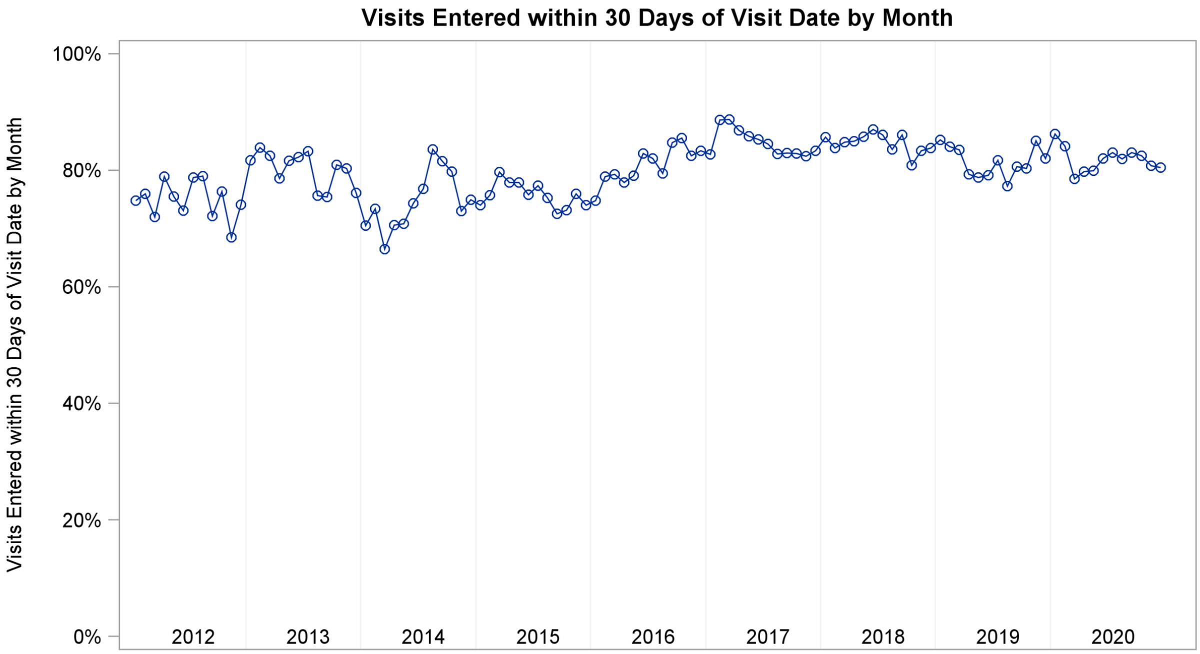
NETWORK DATA QUALITY

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.

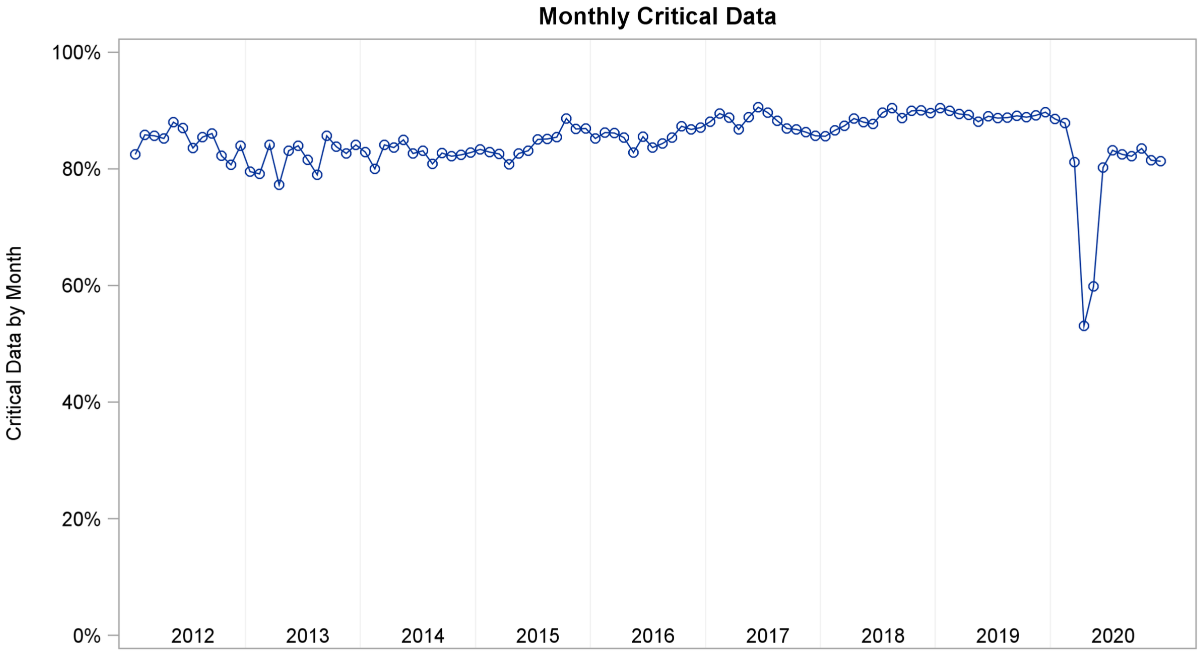


NETWORK DATA QUALITY

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. If the visit was defined as "telehealth" or "phone" visit, then all critical data points except for height, weight, and abdominal examination must be entered.



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CITATION

To cite this report, please use the following information:
Steiner SJ, Samson CM, Howe KM, Saeed S, Duganiero TM. ImproveCareNow Network 2020 Annual Data Report. June 2021. Retrieved from ImproveCareNow website: https://www.improvecarenow.org/

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To request use of charts and data provided in this report, contact ImproveCareNow by email at info@improvecarenow.org.

BETTER TOGETHER

The year 2020 presented challenges never seen before by the ICN community: telemedicine, virtual meetings, quarantines, testing, and eventually vaccines. The entire ICN community adapted and persevered. Without the support of the entire community, the ICN Registry could not exist. We would like to thank the team members at the participating ICN centers who are responsible for collecting and entering a large amount of high-quality clinical data into the ICN Registry, and the members of the ICN Data Management Team who are responsible for maintaining the ICN Registry, answering questions from participating centers, and assembling the data to make this report possible. And lastly, special thanks to all of the patients and families whose data are included in the ICN Registry: you are our inspiration and motivation to improve outcomes. We hope this Annual Data Report helps demonstrate how ICN continues to grow and improve - how we are better together.

Thank You!

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Co-Physician Leader, ICN Data Management Team

> When we all work together, **we can reshape chronic illness care** with improvements and research that are driven by the needs of folks who access these services.

CHRIS K

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2020 Annual Data Report