**Registration/Diagnosis Data:**

The following data are collected at the time the patient is first seen during Ambulatory (outpatient) visits only for the ImproveCARENow Network (not subsequent visits).

Site ID: __ __ __
Patient ID: __ __ __
Date of Registration: __ __-__ __-__ __ __ __

**Patient Birth-date:** __ __-__ __-__ __ __ __

**Date of Diagnosis:** __ __-__ __-__ __ __ __

Date of diagnosis not available but:
- □ Less than 4 months  □ More than 4 months

**Patient’s Diagnosis:**
- □ Crohn’s Disease  □ Ulcerative Colitis  □ Indeterminate Colitis

**Gender** (check one):
- □ Male  □ Female

**Ethnicity** (check one)
- □ Hispanic  □ Non-Hispanic  □ Not Assessed/Collected

**Race** (check all that apply)
- □ American Indian or Alaska Native
- □ Asian
- □ Black or African American
- □ Native Hawaiian or Other Pacific Islander
- □ White
- □ Other: (specify): ____________________
- □ Not Assessed/Collected

**Parent’s Education**

a. Mother
- □ Did not graduate high school
- □ Graduated high school/GED
- □ Some College
- □ Graduated college
- □ Attended graduate school
- □ Unknown

b. Father
- □ Did not graduate high school
- □ Graduated high school/GED
- □ Some College
- □ Graduated college
- □ Attended graduate school
- □ Unknown

**Health Insurance**
- □ Medicaid
- □ Commercial
- □ Both Medicaid and Commercial
- □ No Insurance
- □ Don’t know

**Recent Height** from at least 6 months prior to this visit *(to the nearest tenth)* __ __ __ cm/in  □ Not Assessed

Date the height was measured __ __ - __ __- __ __ __ __

**Recent Past Weight** from 4 months prior to this visit *(to the nearest tenth)* __ __ __ kg/lb  □ Not Assessed

Date the weight was measured __ __ - __ __- __ __ __ __

**Extent of Disease**: *Crohn’s Disease/Indeterminate Colitis Patients Only* (select one for each category):

a. Macroscopic Lower GI Disease
   - □ None
   - □ Ileal only
   - □ Colonic only
   - □ Ileocolonic
   - □ Not Assessed
   - □ Don’t know

b. Macroscopic Upper GI Disease proximal to the ligament of Treitz
   - □ Yes
   - □ No
   - □ Not Assessed
   - □ Don’t know

c. Macroscopic Upper GI Disease distal to the ligament of Treitz
   - □ Yes
   - □ No
   - □ Not Assessed
   - □ Don’t know

**What is the Crohn’s Disease Phenotype?** (select one):
- □ Inflammatory, non-penetrating, non-stricturing
- □ Strictureing only
- □ Penetrating only
- □ Both stricturing and penetrating
- □ Don’t know

**Perianal Phenotype**
- □ Yes  □ No  □ Don’t know

**Extent of Disease**: *Ulcerative Colitis patients only*

- □ Ulcerative Proctitis (rectum only)
- □ Left sided Ulcerative Colitis (distal to the splenic flexure only)
- □ Extensive Ulcerative Colitis (extends proximal to the splenic flexure)
- □ Pancolitis (the entire colon)
- □ Not Assessed completely (colonoscopy incomplete)
- □ Don’t know

**Ulcerative Colitis Behavior**: Has the patient ever had severe disease (defined as PUCAI >65 or severe disease determined by PGA) as an inpatient or outpatient?
- □ Yes  □ No  □ Don’t know
Visit Data

Site ID: __ __ __
Patient ID: __ __ __ __
Date of Assessment: __ __-__ __-__ __ __ __
Location of assessment
☐ In-person ☐ Telehealth (video and audio) ☐ Phone (audio only)

Assessment

Since the last visit documented in the registry, were there any visits that were not captured? (select one)
☐ Yes ☐ No ☐ Don’t know If YES, How many? __ __ __ __

Current visit data entered by: __ __ __ __ __ __ __ __ __ __ __
Primary attending gastroenterologist: __ __ __
Secondary Provider: __ __ __

Diagnosis/Colecotomy/Ostomy

What is the patient’s current diagnosis? (select one)
☐ Crohn’s Disease ☐ Ulcerative Colitis ☐ Indeterminate Colitis

Has the patient had a colectomy? (If yes, and the patient’s diagnosis is UC, the patient should be deactivated) (select one)
☐ Yes ☐ No ☐ Don’t know
Date of Colectomy __ __ / __ __ / __ __ __ __

Does the patient currently have an ileostomy or a colostomy? (Select one): ☐ Yes ☐ No ☐ Don’t know

Symptoms

In the following set of questions, describe the symptoms on the worst day in the last 7 days.

General well-being related to IBD (select one):
☐ Well/Normal ☐ Fair ☐ Poor ☐ Don’t know/Not assessed

Limitations in daily activities related to IBD (select one):
☐ None ☐ Occasional ☐ Frequent ☐ Don’t know/Not assessed

Abdominal pain due to IBD (select one):
☐ None ☐ Mild ☐ Moderate to Severe ☐ Don’t know/Not assessed

Stools

In the following set of questions, describe the stools on the worst day in the last 7 days.

Total number of stools per day (enter 0 if none):
___ ___ .___ ☐ Not assessed

Most stools were (select one):
☐ Formed ☐ Partially formed ☐ Liquid ☐ Don’t know/ Not assessed

Number of liquid watery stools per day (enter 0 if none):
___ ___ .___ ☐ Not assessed

Did the patient report bloody stools? (select one)
☐ Yes ☐ No ☐ Don’t know/ Not assessed

If blood was present, the typical amount was (select one)
☐ Small amount in <50% of stools ☐ Large amount ☐ Small amount in >50% of stools ☐ Not available/assessed

Nocturnal diarrhea (select one):
☐ Yes ☐ No ☐ Not available/assessed

Extraintestinal Manifestations

Fever 38.5°C (101.3 degrees F) for 3 of last 7 days? (select one)
☐ Yes ☐ No ☐ Not available/assessed

Definite arthritis? (select one) ☐ Yes ☐ No ☐ Not available/assessed

Uveitis? (select one) ☐ Yes ☐ No ☐ Not available/assessed

Erythema nodosum? (select one) ☐ Yes ☐ No ☐ Not available/assessed

Pyoderma gangrenosum? (select one) ☐ Yes ☐ No ☐ Not available/assessed

Exam

Abdominal Exam (select one)
☐ No tenderness, no mass
☐ Mild tenderness or questionable mass without tenderness
☐ Moderate to severe tenderness, involuntary guarding, definite mass
☐ Don’t Know
☐ Not Assessed

Perirectal disease at current exam (select one)
☐ Normal or asymptomatic tag, non-draining fistula without tenderness, no deep fissuring or abscess
☐ Mildly inflamed skin tag(s), 1 to 2 indolent fistulas with scant drainage (NO tenderness, deep fissure, or abscess)
☐ Severely inflamed skin tag(s), active fistula with drainage, tenderness, abscess or deep fissure
☐ Don’t Know
☐ Not Assessed

Current Height: __________ cm/in

Current Weight: __________ kg/lb

For patients less than 18 years old, have height, weight and BMI been plotted on a growth chart (select one)?
☐ Yes ☐ No ☐ Don’t know
### Disease Assessment

**Physician’s Global Assessment of current disease status (select one):**
- □ Quiescent
- □ Mild
- □ Moderate
- □ Severe
- □ Don’t know/Not assessed

### Extent of Disease: Crohn’s Disease/Indeterminate Colitis patients only (select one for each category)

**Macroscopic Lower GI Disease**
- □ None
- □ Ileal only
- □ Colonic only
- □ Ileocolonic
- □ Not Assessed
- □ Don’t know

**Macroscopic Upper GI Disease proximal to the ligament of Treitz**
- □ Yes
- □ No
- □ Not Assessed
- □ Don’t know

**Macroscopic Upper GI Disease distal to the ligament of Treitz**
- □ Yes
- □ No
- □ Not Assessed
- □ Don’t know

### For CD/IC patients only

**Current Crohn’s Disease Phenotype** (select one):
- □ Inflammatory, non-penetrating, non-stricturing
- □ Stricture
- □ Penetrating only
- □ Both penetrating and stricturing
- □ Don’t know

**Perianal Phenotype** (select one):
- □ Yes
- □ No
- □ Don’t know

### Ulcerative Colitis patients only

**Extent of Disease** (select one):
- □ Ulcerative Proctitis (rectum only)
- □ Left sided Ulcerative Colitis
- □ Extensive Ulcerative Colitis
- □ Pancolitis (the entire colon)
- □ Not assessed completely
- □ Don’t know

**Ulcerative Colitis Behavior: Has the patient ever had severe disease?**
- □ Yes
- □ No
- □ Don’t know

### Nutritional and Growth Status

**Nutritional Status** (select one):
- □ Satisfactory
- □ At risk
- □ In failure
- □ Not Assessed

**For patients less than 18 years old: Growth Status** (select one):
- □ Satisfactory
- □ At risk
- □ In failure
- □ Not Assessed

Since the previous visit, has the patient been in continuous remission? (select one):
- □ Yes
- □ No
- □ Don’t know

Since the last visit, has the patient had a serious infection? (Note: A serious infection is one that requires hospitalization or IV therapy)
- □ Yes
- □ No
- □ Don’t know

If Yes, indicate infection: ________________________________

### Psychosocial Risks

Are there psychosocial factors that are felt to significantly impact the patient’s medical care?
- □ Yes
- □ No
- □ Don’t know

### Laboratory Analysis

**Was a blood sample drawn for laboratory analysis?** (select one)
- □ Yes
- □ No
- □ Don’t know

**Date of Lab Sample:** __ __-__ __-__ __ __ __

**C-Reactive Protein (CRP)**
- □ Not Done
- □ Done on same date as above
- □ Done on different date than above

**Date of sample:** __ __-__ __-__ __ __ __

**Result** __ __ __

If result is outside the quantifiable range, select one
- □ Above level of quantification
- □ Below level of quantification

**Lab (select one):** □ Lab Corp □ Quest □ In-house □ Other

**Hematocrit:**
- □ Not Done
- □ Done on same date as above
- □ Done on different date than above

**Date of sample:** __ __-__ __-__ __ __ __

**Result** __ __ __

**Erythrocyte Sedimentation Rate (ESR):**
- □ Not Done
- □ Done on same date as above
- □ Done on different date than above

**Date of sample:** __ __-__ __-__ __ __ __

**Result** __ __ __

**Albumin:**
- □ Not Done
- □ Done on same date as above
- □ Done on different date than above

**Date of sample:** __ __-__ __-__ __ __ __

**Result** __ __ __

**Was a stool sample drawn for laboratory analysis?** (select one)
- □ Yes
- □ No
- □ Don’t know

**Date of Stool Lab Sample:** __ __-__ __-__ __ __ __

**Fecal Calprotectin**
- □ Not Done
- □ Done on same date as above
- □ Done on different date than above

**Date of sample:** __ __-__ __-__ __ __ __

**Result** __ __ __

If result is outside the quantifiable range, select one
- □ Above level of quantification
- □ Below level of quantification

**Lab (select one):** □ Lab Corp □ Quest □ In-house □ Other

**Lactoferrin**
- □ Not Done
- □ Done on same date as above
- □ Done on different date than above

**Date of sample:** __ __-__ __-__ __ __ __

**Numerical Result** __ __ __

If result is outside the quantifiable range, select one
- □ Above level of quantification
- □ Below level of quantification

**Lab (select one):** □ Lab Corp □ Quest □ In-house □ Other
### Medications

**Is the patient currently taking any non-biologic prescription medications for IBD?** (select one)
- □ Yes
- □ No
- □ Don’t know

**Aminosalicylates**
**Is the patient taking any oral aminosalicylates?**
- □ Yes
- □ No
  - □ Mesazaline (oral) Dose __________ mg/day
  - □ Sulfasalazine Dose __________ mg/day
  - □ Pentasa Dose __________ mg/day
  - □ Asacol Dose __________ mg/day
  - □ Apriso Dose __________ mg/day
  - □ Lialda Dose __________ mg/day
  - □ Colazal Dose __________ mg/day
  - □ Delzicol Dose __________ mg/day
  - □ Salofalk Dose __________ mg/day

**Rectal Therapy**
**Is the patient taking any rectal therapy?**
- □ Yes
- □ No
  - □ Rowasa Dose __ __ __ __ mg/day
  - □ Canasa Dose __ __ __ __ mg/day
  - □ Mesalazine Dose __ __ __ __ mg/day
  - □ Hydrocortisone enema/suppository Dose __ __ __ mg/day

**Corticosteroids**
**Is the patient taking any corticosteroids?**
- □ Yes
- □ No
  - □ Prednisone Dose __ __ __ mg/day
  - □ Budesonide Dose __ __ __ mg/day
  - □ Methylprednisolone Dose __ __ __ mg/day

**Immunomodulators**
**Is the patient taking any immunomodulators?**
- □ Yes
- □ No
  - □ 6MP Dose __ __ __ __ mg/day
  - □ Azathioprine Dose __ __ __ __ mg/day
  - □ Allopurinol Dose __ __ __ __ mg/day
  - □ Tofacitinib Dose __ __ __ __ mg/wk
  - □ Methotrexate Dose __ __ __ __ mg/wk
  - □ Methotrexate Route (select one):
    - □ Subcutaneous
    - □ PO
    - □ IM
    - □ Don’t know
  - □ Folic Acid Dose __ __ __ __ mg/day

**Other Immune Suppressants**
**Is the patient taking cyclosporine, tacrolimus or sirolimus?**
- □ Yes
- □ No
  - □ Cyclosporine Dose __ __ __ __ mg/day
  - □ Tacrolimus Dose __ __ __ __ mg/day
  - □ Sirolimus Dose __________ mg/day

**Antibiotics for IBD**
**Is the patient taking any antibiotics for IBD?**
- □ Yes
- □ No
  - □ Cipro Dose __ __ __ __ mg/day
  - □ Flagyl Dose __ __ __ __ mg/day
  - □ Rifaximin Dose __ __ __ __ mg/day

**Enteral Nutrition**
**Is the patient currently taking the following?**
**An enteral caloric intake supplement?** (select one)
- □ Yes
- □ No
- □ Don’t know

**Enteral nutrition as primary therapy?** (select one)
- □ Yes
- □ No
- □ Don’t know

**Other Medication**
**Other prescription medications for IBD (per site discretion)**
- Rx: __________________
  - Dose/Unit/Interval __________________
- Rx: __________________
  - Dose/Unit/Interval __________________
**Biologics Information**

**Infliximab**
- □ Remicade Dose __ __ __mg
  - Treatment Period: □ Maintenance □ Induction
  - Dosing Interval (maintenance only): ____________ weeks
- □ Remsima Dose __ __ __mg
  - Treatment Period: □ Maintenance □ Induction
  - Dosing Interval (maintenance only): ____________ weeks
- □ Inflectra Dose __ __ __mg
  - Treatment Period: □ Maintenance □ Induction
  - Dosing Interval (maintenance only): ____________ weeks
- □ Renflexis/Flixabi Dose __ __ __mg
  - Treatment Period: □ Maintenance □ Induction
  - Dosing Interval (maintenance only): ____________ weeks
- □ Ixifi Dose __ __ __mg
  - Treatment Period: □ Maintenance □ Induction
  - Dosing Interval (maintenance only): ____________ weeks

**Cerolizumab**
- □ Cimzia Dose __ __ __mg
  - Treatment Period: □ Maintenance □ Induction
  - Dosing Interval (maintenance only): ____________ weeks

**Adalimumab**
- □ Humira Dose __ __ __mg
  - Treatment Period: □ Maintenance □ Induction
  - Dosing Interval (maintenance only): ____________ weeks
- □ Amjevita/Solymbic Dose __ __ __mg
  - Treatment Period: □ Maintenance □ Induction
  - Dosing Interval (maintenance only): ____________ weeks
- □ Cyltezo Dose __ __ __mg
  - Treatment Period: □ Maintenance □ Induction
  - Dosing Interval (maintenance only): ____________ weeks
- □ Imraldi Dose __ __ __mg
  - Treatment Period: □ Maintenance □ Induction
  - Dosing Interval (maintenance only): ____________ weeks

**Natalizumab**
- □ Tysabri Dose __ __ __mg
  - Treatment Period: □ Maintenance □ Induction
  - Dosing Interval (maintenance only): ____________ weeks

**Golimumab**
- □ Simponi Dose __ __ __mg
  - Treatment Period: □ Maintenance □ Induction
  - Dosing Interval (maintenance only): ____________ weeks

**Ustekinumab**
- □ Stelara Dose __ __ __mg
  - Treatment Period: □ Maintenance □ Induction
  - Dosing Interval (maintenance only): ____________ weeks

**Vedolizumab**
- □ Entyvio Dose __ __ __mg
  - Treatment Period: □ Maintenance □ Induction
  - Dosing Interval (maintenance only): ____________ weeks

**TPMT**
- Has the TPMT been measured? (select one)
  - □ Yes □ No
- TPMT Genotype: (select one)
  - □ Normal □ Heterozygous □ Homozygous Recessive □ Not Done
  - TPMT Genotype Date: __ __-__ __-__ __ __ __
- TPMT Phenotype (enzyme activity):
  - □ Normal/High □ Intermediate □ Low □ Not Done
  - TPMT Phenotype Date: __ __-__ __-__ __ __ __

**6MP/AZA**
- Has the patient had 6MP metabolites measured more recently than the test indicated above? (select one)
  - □ Yes □ No □ Don’t know
- If Yes, most recent measurement date: __ __-__ __-__ __ __ __
- Most recent 6-TGN level: ____________
  - □ Outside Quantifiable Range
  - If result is outside the quantifiable range, select one
    - □ Above level of quantification □ Below level of quantification
- Most recent 6-MMPN: ____________
  - □ Outside Quantifiable Range
  - If result is outside the quantifiable range, select one
    - □ Above level of quantification □ Below level of quantification

**Therapy**

**Infliximab Patients only**
- Has the patient had infliximab trough level measured more recently than the test above? (select one)
  - □ Yes □ No □ Don’t know
- If yes infliximab trough level: ____________
- If result is outside the quantifiable range, select one:
  - □ Below level of quantification □ Above level of quantification
- Date of infliximab trough level measurement: __ __-__ __-__ __ __ __
  - Infliximab trough lab?
    - □ LabCorp □ Prometheus □ Mayo □ ARUP

**Infliximab antibody level**
- Has the patient had infliximab antibody levels measured more recently than the test above? (select one)
  - □ Yes □ No □ Don’t know
- Infliximab antibody level: ____________
- If result is outside the quantifiable range, select one:
  - □ Below level of quantification □ Above level of quantification
- Date of Infliximab antibody level measurement: __ __-__ __-__ __ __ __
Adalimumab Patients only
Has the patient had adalimumab trough level measured more recently than the test above? (select one)
□ Yes □ No □ Don’t know

If yes adalimumab trough level: __________________
If result is outside the quantifiable range, select one:
□ Below level of quantification □ Above level of quantification

Date of adalimumab trough level measurement: __ __-__ __-__ __ __ __ __ __ __

Adalimumab trough lab?
□ LabCorp □ Prometheus □ Mayo □ ARUP

Has the patient had adalimumab antibody levels measured more recently than the test above? (select one)
□ Yes □ No □ Don’t know

Adalimumab antibody level: __________________
If result is outside the quantifiable range, select one:
□ Below level of quantification □ Above level of quantification

Date of adalimumab antibody level measurement: __ __-__ __-__ __ __ __ __ __ __

Ustekinumab Patients only
Has the patient had ustekinumab trough level measured more recently than the test above? (select one)
□ Yes □ No □ Don’t know

If yes ustekinumab trough level: __________________
If result is outside the quantifiable range, select one:
□ Below level of quantification □ Above level of quantification

Date of ustekinumab trough level measurement: __ __-__ __-__ __ __ __ __ __ __

Ustekinumab trough lab?
□ LabCorp □ Prometheus □ Mayo □ ARUP

Has the patient had ustekinumab antibody levels measured more recently than the test above? (select one)
□ Yes □ No □ Don’t know

Ustekinumab antibody level: __________________
If result is outside the quantifiable range, select one:
□ Below level of quantification □ Above level of quantification

Date of ustekinumab antibody level measurement: __ __-__ __-__ __ __ __ __ __ __

Vedolizumab Patients only
Has the patient had vedolizumab trough level measured more recently than the test above? (select one)
□ Yes □ No □ Don’t know

If yes vedolizumab trough level: _________________
If result is outside the quantifiable range, select one:
□ Below level of quantification □ Above level of quantification

Date of vedolizumab trough level measurement: __ __-__ __-__ __ __ __ __ __ __

Vedolizumab trough lab?
□ LabCorp □ Prometheus □ Mayo □ ARUP

Has the patient had vedolizumab antibody levels measured more recently than the test above? (select one)
□ Yes □ No □ Don’t know

Vedolizumab antibody level: _________________
If result is outside the quantifiable range, select one:
□ Below level of quantification □ Above level of quantification

Date of vedolizumab antibody level measurement: __ __-__ __-__ __ __ __ __ __ __

Endoscopy/ Imaging
Since the last visit, has the patient had an esophagogastroduodenoscopy (EGD)? (select one)
□ Yes □ No □ Don’t know

Date of esophagogastroduodenoscopy (EGD): __ __-__ __-__ __ __ __ __ __ __

Since the last visit, has the patient had a colonoscopy? (select one)
□ Yes □ No □ Don’t know

Date of colonoscopy: __ __-__ __-__ __ __ __ __ __ __

Since the last visit, has the patient had a Magnetic Resonance Enterography (MRE) /Computed Tomography Enterography (CTE)/capsule endoscopy (select one)
□ Yes □ No □ Don’t know

Date of Magnetic Resonance Enterography (MRE) /Computed Tomography Enterography (CTE)/capsule endoscopy: __ __-__ __-__ __ __ __ __ __ __

Activation Status
Status: □ Activated □ Deactivated □ Removed

Date of status change: __ __-__ __-__ __ __ __ __ __ __

Reason for deactivation of this patient:
□ Transferred to an adult gastroenterologist
□ Transferred to another pediatric gastroenterology practice
□ Transferred to another physician who is not a gastroenterologist
□ Colectomy for ulcerative colitis
□ Moved to another city
□ Lost to follow-up
□ Death
□ Other, specify: _________________________________________

Reason for removal:
□ Data Entry Error □ Thought to never have had IBD
□ Withdraw of consent □ Other, specify: _____________________
Hospitalization Data

| Date of admission: ___-___-___-___-___-___ |
| Discharge Date: ___-___-___-___-___-___ |

Is hospitalization IBD related?  □ Yes  □ No  □ Not Sure

Was intra-abdominal GI surgery performed during the admission?  □ Yes  □ No  □ Not Sure

Comments:

_________________________________________________________________
_________________________________________________________________
_________________________________________________________________