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CAREGIVER'S EDUCATION

Caregiver 1 Level of Education:

(select only one response)

(Indicate the highest level of education completed)

- Did Not Graduate High School
- Graduated High School/GED
- Some College
- Graduated College
- Attended Graduate School
- Unknown

Caregiver 2 Level of Education:

(select only one response)

(Indicate the highest level of education completed)

- Did Not Graduate High School
- Graduated High School/GED
- Some College
- Graduated College
- Attended Graduate School
- Unknown

HEALTH INSURANCE

Patient's Health Insurance:

(select only one response)

- Medicaid
- Commercial
- Both Medicaid and Commercial
- Tricare
- No Insurance
- Don't Know

RECENT HEIGHT/WEIGHT

	Value <i>(from at least 6 months prior to this visit)</i> <i>(to the nearest tenth)</i>	Date Measured	Not Assessed
Height:	_ _ _ _ . _ cm	_ _ _ _ - _ _ _ _ - _ _ _ _ _ M M M D D Y Y Y Y	<input type="checkbox"/>
Weight:	_ _ _ _ . _ kg	_ _ _ _ - _ _ _ _ - _ _ _ _ _ M M M D D Y Y Y Y	<input type="checkbox"/>

**EXTENT OF DISEASE****CROHN'S DISEASE/INDETERMINATE COLITIS PATIENTS**

- Macroscopic Lower GI Disease:**
(select only one response)
- None
 - Colonic only
 - Ileal only
 - Ileocolonic
 - Not Assessed
 - Don't Know
- Macroscopic Upper GI Disease Proximal to the Ligament of Treitz:**
(select only one response)
- Yes
 - No
 - Not Assessed
 - Don't Know
- Macroscopic Upper GI Disease Distal to the Ligament of Treitz:**
(select only one response)
- Yes
 - No
 - Not Assessed
 - Don't Know
- What is the Crohn's Disease Phenotype:**
(select only one response)
- Inflammatory, non-penetrating, non-stricturing
 - Stricturing only
 - Penetrating only
 - Both stricturing and penetrating
 - Don't Know
- Perianal Phenotype:**
(select only one response)
- Yes
 - No
 - Unknown

ULCERATIVE COLITIS PATIENTS

- Extent of Disease:**
(select only one response)
- 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 \geq 65 or severe disease determined by PGA) as an inpatient or outpatient:
(select only one response)

- Yes
- No
- Unknown

VERIFICATION

***Have you reviewed the data entered on this form in its entirety and verified that it is accurate and complete?**
(select only one response)

- Yes
- No



VISIT

VISIT 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 Previous Visit:

(read only in the registry, pulled forward from previous Visit forms)

				-							
M	M	M			D	D		Y	Y	Y	Y

***Date of Assessment:**

				-							
M	M	M			D	D		Y	Y	Y	Y

Location of Assessment:

(select only one response)

- In Person
- Telehealth (video and audio)
- Phone (audio only)

ASSESSMENT

Current visit entered by: _____

Primary Attending Gastroenterologist:

(dropdown list of providers in the registry)

Secondary Provider:

(dropdown list of providers in the registry)

DIAGNOSIS/COLECTOMY/OSTOMY

What is the patient's current diagnosis?

(select only one response)

- Crohn's Disease
- Ulcerative Colitis
- Indeterminate Colitis

Has the patient had a colectomy?

(select only one response)

- Yes (If yes, and the patient's diagnosis is UC, the patient should be deactivated)
- No
- Unknown

If Yes...

Date of Colectomy:

				-							
M	M	M			D	D		Y	Y	Y	Y



Does the patient currently have an ileostomy or colostomy?

(select only one response)

- Yes
- No
- Unknown

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 only one response)

- Well/Normal
- Fair
- Poor
- Don't Know/Not Assessed

Limitations in daily activities related to IBD:

(select only one response)

- None
- Occasional
- Frequent
- Don't Know/Not Assessed

Abdominal pain due to IBD:

(select only one response)

- None
- Mild
- Moderate to Severe
- Don't Know/Not Assessed

STOOLS (PATIENTS WITHOUT COLECTOMY, ILEOSTOMY, OR COLOSTOMY)

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 only one response)

- 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 only one response)

- Yes
- No
- Don't Know/Not Assessed

If Blood Was Present...

The typical amount was:

(select only one response)

- Small amount in <50% of stools
- Small amount in >50% of stools
- Large amount
- Not Available/Assessed



Nocturnal Diarrhea:
(select only one response)

- Yes
- No
- Not Available/Assessed

EXTRAIESTINAL MANIFESTATIONS

Select only one response for each question.

	Yes	No	Not Available/Assessed
Fever 38.5°C (101.3°F) for 3 days of last 7 days?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Definite arthritis?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Uveitis?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Erythema nodosum?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pyoderma gangrenosum?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Does this patient have PSC (Primary Sclerosing Cholangitis)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Does this patient have AIH (Autoimmune Hepatitis)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

EXAM

Abdominal Exam:
(select only one response)

- 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 only one response)

- 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 draining, tenderness, abscess or deep fissure
- Don't Know
- Not Assessed

Current Height: | | | | | . | | | | cm

Not Assessed

Current Weight: | | | | | . | | | | kg

Not Assessed



BMI:
(automatically calculated in the registry)

DISEASE ASSESSMENT

Physician’s Global Assessment of current disease status:
(select only one response)

- Quiescent
- Mild
- Moderate
- Severe
- Don’t Know/Not Assessed

EXTENT OF DISEASE

CROHN’S DISEASE/INDETERMINATE COLITIS PATIENTS

Macroscopic Lower GI Disease:
(select only one response)

- None
- Colonic only
- Ileal only
- Ileocolonic
- Not Assessed
- Don’t Know

Macroscopic Upper GI Disease Proximal to the Ligament of Treitz:
(select only one response)

- Yes
- No
- Not Assessed
- Don’t Know

Macroscopic Upper GI Disease Distal to the Ligament of Treitz:
(select only one response)

- Yes
- No
- Not Assessed
- Don’t Know

What is the Crohn’s Disease Phenotype:
(select only one response)

- Inflammatory, non-penetrating, non-stricturing
- Stricturing only
- Penetrating only
- Both stricturing and penetrating
- Don’t Know

Perianal Phenotype:
(select only one response)

- Yes
- No
- Unknown



ULCERATIVE COLITIS PATIENTS

Extent of Disease:

(select only one response)

- 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:

(select only one response)

- Yes
- No
- Unknown

NUTRITION AND GROWTH STATUS

Nutrition Status:

(select only one response)

- Satisfactory
- At Risk
- In Failure
- Not Assessed

Growth Status:

(select only one response)

- Satisfactory
- At Risk
- In Failure
- Not Assessed

Since the last visit, has the patient been in continuous remission?

(select only one response)

- Yes
- No
- Don't Know

Since the last visit, has the patient has a serious infection (Note: A serious infection is one that requires hospitalization or IV therapy)?

(select only one response)

- 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?

(select only one response)

- Yes
- No
- Don't Know

Was a depression screening completed during today's visit?

(select only one response)

- Yes
- No
- Don't Know

If Yes...

Was the depression screen "positive"?

(select only one response)

- Yes
- No
- Don't Know

ENTERAL NUTRITION

Is the patient currently taking an enteral caloric intake supplement?

(select only one response)

- Yes
- No
- Don't Know

Is the patient currently taking enteral nutrition as primary therapy?

(select only one response)

- Yes
- No
- Don't Know

ENDOSCOPY/IMAGING

Since the last visit, has the patient had an esophagogastroduodenoscopy (EGD)?

(select only one response)

- Yes
- No
- Don't Know

If Yes...

Date of esophagogastroduodenoscopy (EGD):

				-			-					
M	M	M			D	D		Y	Y	Y	Y	

Since the last visit, has the patient had a colonoscopy

(select only one response)

- Yes
- No
- Don't Know

If Yes...

Date of esophagogastroduodenoscopy (EGD):

				-			-					
M	M	M			D	D		Y	Y	Y	Y	



Since the last visit, has the patient had a Magnetic Resonance Enterography (MRE) / Computed Tomography Enterography (CTE) / capsule endoscopy?

(select only one response)

- Yes
- No
- Don't Know

If Yes...

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

M	M	M	D	D	Y	Y	Y	Y	

VERIFICATION

***Have you reviewed the data entered on this form in its entirety and verified that it is accurate and complete?**

(select only one response)

- Yes
- No



HOSPITALIZATION

HOSPITALIZATION 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).

***Date of Admission:**

M	M	M	D	D	Y	Y	Y	Y	

Discharge Date:

M	M	M	D	D	Y	Y	Y	Y	

Is hospitalization IBD related?

(select only one response)

- Yes
- No
- Unknown

Was intra-abdominal GI surgery performed during the admission?

(select only one response)

- Yes
- No
- Unknown

Comments:

VERIFICATION

***Have you reviewed the data entered on this form in its entirety and verified that it is accurate and complete?**

(select only one response)

- Yes
- No



MEDICATIONS

MEDICATION RECORD

***Medication Name:**

(select only one response)

- | | | | |
|--|--|--|--|
| <input type="radio"/> 6MP | <input type="radio"/> Entocort | <input type="radio"/> Methylprednisolone | <input type="radio"/> Sirolimus |
| <input type="radio"/> Abrilada | <input type="radio"/> Entyvio | <input type="radio"/> Mirikizumab | <input type="radio"/> Skyrizi |
| <input type="radio"/> Allopurinol | <input type="radio"/> Flagyl | <input type="radio"/> Omvoh | <input type="radio"/> Solu-Medrol |
| <input type="radio"/> Amjevita | <input type="radio"/> Flixabi | <input type="radio"/> Otulfi | <input type="radio"/> Solymbic |
| <input type="radio"/> Apriso | <input type="radio"/> Folic Acid | <input type="radio"/> Ozanimod (Zeposia) | <input type="radio"/> Stelara |
| <input type="radio"/> Asacol | <input type="radio"/> Hadlima | <input type="radio"/> Pentasa | <input type="radio"/> Sulfasalazine |
| <input type="radio"/> Avsola | <input type="radio"/> Hulio | <input type="radio"/> Prednisolone | <input type="radio"/> Tacrolimus |
| <input type="radio"/> Azathioprine | <input type="radio"/> Humira | <input type="radio"/> Prednisone | <input type="radio"/> Tofacitinib |
| <input type="radio"/> Budesonide | <input type="radio"/> Hydrocortisone Enema | <input type="radio"/> Remicade | <input type="radio"/> Tremfya |
| <input type="radio"/> Budesonide Enema | <input type="radio"/> Hydrocortisone Suppository | <input type="radio"/> Remsima | <input type="radio"/> Tysabri |
| <input type="radio"/> Canasa | <input type="radio"/> Hyrimoz | <input type="radio"/> Renflexis | <input type="radio"/> UCERIS |
| <input type="radio"/> Cimzia | <input type="radio"/> Idacio | <input type="radio"/> Refaximin | <input type="radio"/> Upadaitinib (Rinvoq) |
| <input type="radio"/> Cipro | <input type="radio"/> Imraldi | <input type="radio"/> Rowasa | <input type="radio"/> Velsipity |
| <input type="radio"/> Colazal | <input type="radio"/> Inflectra | <input type="radio"/> Ruxolitinib | <input type="radio"/> Wezlana |
| <input type="radio"/> Cyclosporine | <input type="radio"/> Ixifi | <input type="radio"/> Salofalk | <input type="radio"/> Yesintek |
| <input type="radio"/> Cyltezo | <input type="radio"/> Lialda | <input type="radio"/> Selardsi | <input type="radio"/> Yuflyma |
| <input type="radio"/> Delzicol | <input type="radio"/> Mesalamine | <input type="radio"/> Simlandi | <input type="radio"/> Yusimry |
| <input type="radio"/> Dipentum | <input type="radio"/> Methotrexate | <input type="radio"/> Simponi | <input type="radio"/> Zymfentra |

If Biologic...

(Abrilada, Amjevita, Avsola, Cimzia, Cyltezo, Entyvio, Flixabi, Hadlima, Hulio, Humira, Hyrimoz, Idacio, Imraldi, Inflectra, Ixifi, Mirikizumab, Omvoh, Otulfi, Remicade, Remsima, Renflexis, Selardsi, Simlandi, Simponi, Skyrizi, Solymbic, Stelara, Tremfya, Tysabri, Wezlana, Yesintek, Yuflyma, Yusimry, Zymfentra)

***Dose Type:**

(select only one response)

- Induction
- Maintenance

***Start Date:**

M	M	M	D	D	Y	Y	Y	Y	Y

Ongoing

If Not Ongoing...

***End Date:**

M	M	M	D	D	Y	Y	Y	Y	Y

Dose:

Units:

- Milligram
- Milligram per 24 hours
- Milligram per kilogram



Biologics Maintenance Dose

Interval: _____ Week(s)

Non-Biologics

Frequency:

- As Needed
- Daily
- Every Other Day
- Once
- Three Times Daily
- Twice Daily
- Week(s)
- Weekly

Route:

- Intramuscular
- Intravenous
- Oral
- Rectal
- Subcutaneous



LABS

LAB RESULTS

*Lab Date:

M	M	M	D	D	Y	Y	Y	Y	Y

LABORATORY ANALYSIS

BLOOD LABS

	Result	Unit <i>(select only one response)</i>	Range Min	Range Max
CRP (C-Reactive Protein Test):	_____	<input type="radio"/> mg/L <input type="radio"/> mg/dL	_____	_____
Hematocrit:	_____	%		
ESR (Erythrocyte Sedimentation Rate):	_____	mm/h		
Albumin:	_____	g/dL		
ALT (Alanine Aminotransferase):	_____	U/L		
AST (Aspartate Aminotransferase):	_____	U/L		
GGT (Gamma-Glutamyl Transpeptidase):	_____	U/L		

STOOL LABS

	Result	Unit
Fecal Calprotectin:	_____	ug/g
Lactoferrin:	_____	

THERAPEUTIC DRUG MONITORING



INFLIXIMAB

	Result	Unit
Trough:	_____	ug/mL
Antibody:	_____	ng/mL

ADALIMUMAB

	Result	Unit
Trough:	_____	ug/mL
Antibody:	_____	ng/mL

USTEKINUMAB

	Result	Unit
Trough:	_____	ug/mL
Antibody:	_____	ng/mL

VEDOLIZUMAB

	Result	Unit
Trough:	_____	ug/mL
Antibody:	_____	ng/mL

TPMT

TMPT Genotype:

- Wild type
- Heterozygous
- Homozygous



MRN / Patient ID: _____

TMPT Phenotype:

- Normal Metabolizer
- Intermediate Metabolizer
- Poor Metabolizer
- Rapid Metabolizer
- Ultrarapid Metabolizer

6MP/AZA

THOPURINE METABOLITES

	Result	Unit
6MP:	_____	pmol/8x 10E8
6-TGN	_____	pmol/8x 10E8



ACTIVATION

ACTIVATION STATUS

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).

***Status:**
(select only one response)

- Activated
- Deactivated
- Removed

***Date of Status Change:**

M	M	M	D	D	Y	Y	Y	Y	Y

If Deactivated...

Reason for deactivation on this patient:
(select only one response)

- 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: _____

If Removed...

Reason for removal:
(select only one response)

- Data entry error
- Thought to have never had IBD
- Withdraw of consent
- Other, specify: _____

VERIFICATION

***Have you reviewed the data entered on this form in its entirety and verified that it is accurate and complete?**
(select only one response)

- Yes
- No