

# CCFA PARTNERS: AN INTERNET-BASED COHORT STUDY

## Core Baseline Adult Survey

### Version 5.3

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#### **Funding Source**

Crohn's & Colitis Foundation of America

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## CCFA Partners Dictionary - Welcome Page (v5)

(Report created at: 2014-06-23 12:47:48)

[ [Home - All Versions & Forms](#) ]

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Used in:

- Baseline v5 start from 2014-04-11
- Baseline v5.1 start from 2014-05-07
- Baseline v5.2 start from 2014-05-12
- Baseline v5.3 start from 2014-05-21

[SAS Labels](#)

[SAS Formats](#)

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### Section 1. Welcome Page

Thank you for your interest in CCFA Partners. As you may know, we are actively seeking patients with IBD to join the Partners project.

[Q310](#) - How old are you?

- 1 = Younger than 18 years old
- 2 = Between 18 and 25 years old
- 3 = Older than 25 years old

[Q315](#) - Were you a participant in CCFA Partners Kids & Teens?

- 1 = No
- 2 = Yes

What email address did you use for Partners Kids & Teens?

[Q317](#) - Parent email address:

[Q318](#) - Child email address:

[Q281](#) - How did you hear about CCFA Partners? [Check all that apply]

- Q281\_1 - Email from CCFA
- Q281\_2 - CCFA.org website
- Q281\_3 - Physician
- Q281\_4 - Other healthcare professional
- Q281\_5 - CCFA newsletter
- Q281\_13 - CCFA Information Resource Center (IRC)
- Q281\_6 - CCFA Social media (Facebook, Twitter)
- Q281\_7 - From a friend
- Q281\_8 - Family member
- Q281\_9 - CCFA meeting or event
- Q281\_10 - Internet search
- Q281\_11 - Newspaper or magazine
- Q281\_12 - Radio or TV

Before we begin, we need to ask about YOUR IBD status.

[Q120](#) - Has a doctor EVER told you that YOU have Inflammatory Bowel Disease?

- 1 = Yes, Crohn's disease
- 2 = Yes, ulcerative colitis
- 3 = Yes, indeterminate colitis
- 4 = Yes, other colitis
- 5 = No, I don't have IBD

There are different types of colitis. Have you ever been told that you have any of the following types?

	1 = Yes	2 = No	3 = Don't know
200 - Lymphocytic colitis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
240 - Collagenous colitis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
280 - Microscopic colitis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

[Q282](#) - Your email was on file with the Crohn's & Colitis Foundation of America because: [Check all that apply]

Q282\_1 - I have one or more family members with IBD

Q282\_2 - I have one or more friends with IBD

Q282\_3 - I am a physician

Q282\_4 - I am a nurse

Q282\_5 - I work in the health research field (non-clinician)

Q282\_6 - I work for a media organization interested in IBD

Q282\_7 - I work for a pharmaceutical company

Q282\_8 - For some other reason

[Q283](#) - Are you the parent of a child (younger than 18 years) with IBD?

1 = Yes

2 = No

## CCFA Partners Dictionary - Email Page (v2)

(Report created at: 2014-06-23 12:48:35)

[ [Home - All Versions & Forms](#) ]

Used in:

- Baseline v2 start from 2011-11-22
- Baseline v2.1 start from 2011-12-14
- Baseline v2.2 start from 2012-04-24
- Baseline v2.3 start from 2012-06-22
- Baseline v2.4 start from 2012-08-06
- Baseline v3 start from 2012-12-21
- Baseline v4 start from 2013-07-12
- Baseline v4.1 start from 2013-07-19
- Baseline v4.2 start from 2013-09-17
- Baseline v4.3 start from 2013-10-24
- Baseline v5 start from 2014-04-11
- Baseline v5.1 start from 2014-05-07
- Baseline v5.2 start from 2014-05-12
- Baseline v5.3 start from 2014-05-21

[SAS Labels](#)

[SAS Formats](#)

## Section 1. Email Page

Please confirm the email address you would like us to use to contact you in the future. The address we used to invite you to join CCFA Partners is [[useremail]]

[Q40](#) - Is this the address you would like CCFA Partners to use to contact you in the future?

1 = Yes

2 = No, I want to use a different email address

[Q80](#) - What email address would you like CCFA Partners to use to contact you in the future?

## **CCFA Partners Dictionary - Background Info (v5.3)**

(Report created at: 2014-06-23 12:48:49)

[ [Home - All Versions & Forms](#) ]

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Used in:

- Baseline v5.3 start from 2014-05-21

Section 1. [Demographics](#)

Section 2. [Health Care](#)

Section 3. [Smoking History](#)

Section 4. [Characteristics of your IBD](#)

Section 17. [Extra Intestinal Manifestations](#)

Section 5. [IBD Medications](#)

Section 6. [Use of IBD Medications](#)

Section 7. [Pain Medications](#)

Section 8. [Family History](#)

Section 9. [Colitis History](#)

Section 10. [Crohn's History](#)

Section 11. [Crohn's Activity](#)

Section 12. [Prevention](#)

Section 13. [Exercise – Daily Activity](#)

Section 14. [Health Status – Quality of Life](#)

Section 15. [Health Status – PROMIS](#)

Section 18. [Transitioning](#)

Section 16. [Comments & Feedback](#)

[SAS Labels](#)

[SAS Formats](#)

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### **Section 1. Demographics**

[Q320](#) - How old were you on your last birthday?

[Q360](#) - Are you...?

1 = Male

2 = Female

[Q400](#) - How tall are you?

0 = --- Please choose a unit ---

1 = Feet/Inches

2 = Meters

Qs400\_1\_1 - Specify feet for option 1 (Feet/Inches) of Q400 - How tall are you?

Qs400\_1\_2 - Specify inches for option 1 (Feet/Inches) of Q400 - How tall are you?

Qs400\_2\_1 - Specify meters for option 2 (Meters) of Q400 - How tall are you?

[Q520](#) - How much do you weigh? (enter your weight, then choose the appropriate units)

Qu520 - Unit for Q520 - How much do you weigh? (enter your weight, then choose the appropriate units)

1=pounds (lbs)

2=kilograms (kg)

[Q530](#) - Do you live in the United States (or a U.S. territory)?

1 = Yes

2 = No

**If Q530=1 (live in USA), show Q560 (which US state or territory), else if Q530=2, show Q9790 (which country)**

[Q560](#) - In which U.S. state or territory do you live?

0 = --- Please select a state ---

1 = ALABAMA

2 = ALASKA

60 = AMERICAN SAMOA

4 = ARIZONA

5 = ARKANSAS

6 = CALIFORNIA

8 = COLORADO

9 = CONNECTICUT

10 = DELAWARE

11 = DISTRICT OF COLUMBIA

12 = FLORIDA

13 = GEORGIA

66 = GUAM

15 = HAWAII

16 = IDAHO

17 = ILLINOIS

18 = INDIANA

19 = IOWA

20 = KANSAS

21 = KENTUCKY

22 = LOUISIANA

23 = MAINE

24 = MARYLAND

25 = MASSACHUSETTS

26 = MICHIGAN

27 = MINNESOTA

28 = MISSISSIPPI

29 = MISSOURI

30 = MONTANA

31 = NEBRASKA

32 = NEVADA

33 = NEW HAMPSHIRE

34 = NEW JERSEY

35 = NEW MEXICO

36 = NEW YORK

37 = NORTH CAROLINA

38 = NORTH DAKOTA

39 = OHIO

40 = OKLAHOMA

41 = OREGON

42 = PENNSYLVANIA

72 = PUERTO RICO

44 = RHODE ISLAND

45 = SOUTH CAROLINA

46 = SOUTH DAKOTA

47 = TENNESSEE

48 = TEXAS

49 = UTAH  
50 = VERMONT  
78 = VIRGIN ISLANDS  
51 = VIRGINIA  
53 = WASHINGTON  
54 = WEST VIRGINIA  
55 = WISCONSIN  
56 = WYOMING

**if Q530=2, show Q9790 (which country)**

**Q9790** - What country do you live in?

0 = --- Please select a country ---

999 = --- Not in this country list ---

16 = Åland Islands

3 = Afghanistan

6 = Albania

61 = Algeria

1 = Andorra

9 = Angola

5 = Anguilla

10 = Antarctica

4 = Antigua and Barbuda

11 = Argentina

7 = Armenia

15 = Aruba

14 = Australia

13 = Austria

17 = Azerbaijan

32 = Bahamas

24 = Bahrain

20 = Bangladesh

19 = Barbados

36 = Belarus

21 = Belgium

37 = Belize

26 = Benin

28 = Bermuda

33 = Bhutan

30 = Bolivia, Plurinational State of

18 = Bosnia and Herzegovina

35 = Botswana

34 = Bouvet Island

31 = Brazil

105 = British Indian Ocean Territory

29 = Brunei Darussalam

23 = Bulgaria

22 = Burkina Faso

25 = Burundi

44 = Côte d'Ivoire

116 = Cambodia

47 = Cameroon

38 = Canada

52 = Cape Verde

123 = Cayman Islands

41 = Central African Republic

212 = Chad

46 = Chile

48 = China

53 = Christmas Island

39 = Cocos (Keeling) Islands  
49 = Colombia  
118 = Comoros  
42 = Congo  
40 = Congo, the Democratic Republic of the  
45 = Cook Islands  
50 = Costa Rica  
97 = Croatia  
51 = Cuba  
54 = Cyprus  
55 = Czech Republic  
58 = Denmark  
57 = Djibouti  
59 = Dominica  
60 = Dominican Republic  
62 = Ecuador  
64 = Egypt  
208 = El Salvador  
87 = Equatorial Guinea  
66 = Eritrea  
63 = Estonia  
68 = Ethiopia  
71 = Falkland Islands (Malvinas)  
73 = Faroe Islands  
70 = Fiji  
69 = Finland  
74 = France  
79 = French Guiana  
174 = French Polynesia  
213 = French Southern Territories  
75 = Gabon  
84 = Gambia  
78 = Georgia  
56 = Germany  
81 = Ghana  
82 = Gibraltar  
88 = Greece  
83 = Greenland  
77 = Grenada  
86 = Guadeloupe  
90 = Guatemala  
80 = Guernsey  
85 = Guinea  
92 = Guinea-Bissau  
93 = Guyana  
98 = Haiti  
95 = Heard Island and McDonald Islands  
233 = Holy See (Vatican City State)  
96 = Honduras  
94 = Hong Kong  
99 = Hungary  
108 = Iceland  
104 = India  
100 = Indonesia  
107 = Iran, Islamic Republic of  
106 = Iraq  
101 = Ireland  
103 = Isle of Man  
102 = Israel

109 = Italy  
111 = Jamaica  
113 = Japan  
110 = Jersey  
112 = Jordan  
124 = Kazakhstan  
114 = Kenya  
117 = Kiribati  
120 = Korea, Democratic Peoples Republic of  
121 = Korea, Republic of  
122 = Kuwait  
115 = Kyrgyzstan  
125 = Lao Peoples Democratic Republic  
134 = Latvia  
126 = Lebanon  
131 = Lesotho  
130 = Liberia  
135 = Libyan Arab Jamahiriya  
128 = Liechtenstein  
132 = Lithuania  
133 = Luxembourg  
147 = Macao  
143 = Macedonia, the former Yugoslav Republic of  
141 = Madagascar  
155 = Malawi  
157 = Malaysia  
154 = Maldives  
144 = Mali  
152 = Malta  
142 = Marshall Islands  
149 = Martinique  
150 = Mauritania  
153 = Mauritius  
243 = Mayotte  
156 = Mexico  
72 = Micronesia, Federated States of  
138 = Moldova, Republic of  
137 = Monaco  
146 = Mongolia  
139 = Montenegro  
151 = Montserrat  
136 = Morocco  
158 = Mozambique  
145 = Myanmar  
159 = Namibia  
168 = Nauru  
167 = Nepal  
165 = Netherlands  
8 = Netherlands Antilles  
160 = New Caledonia  
170 = New Zealand  
164 = Nicaragua  
161 = Niger  
163 = Nigeria  
169 = Niue  
162 = Norfolk Island  
148 = Northern Mariana Islands  
166 = Norway  
171 = Oman



177 = Pakistan  
184 = Palau  
182 = Palestinian Territory, Occupied  
172 = Panama  
175 = Papua New Guinea  
185 = Paraguay  
173 = Peru  
176 = Philippines  
180 = Pitcairn  
178 = Poland  
183 = Portugal  
186 = Qatar  
187 = Réunion  
188 = Romania  
190 = Russian Federation  
191 = Rwanda  
27 = Saint Barthélemy  
198 = Saint Helena, Ascension and Tristan da Cunha  
119 = Saint Kitts and Nevis  
127 = Saint Lucia  
140 = Saint Martin (French part)  
179 = Saint Pierre and Miquelon  
234 = Saint Vincent and the Grenadines  
241 = Samoa  
203 = San Marino  
207 = São Tomé and Príncipe  
192 = Saudi Arabia  
204 = Senegal  
189 = Serbia  
194 = Seychelles  
202 = Sierra Leone  
197 = Singapore  
201 = Slovakia  
199 = Slovenia  
193 = Solomon Islands  
205 = Somalia  
244 = South Africa  
89 = South Georgia and the South Sandwich Islands  
67 = Spain  
129 = Sri Lanka  
195 = Sudan  
206 = Suriname  
200 = Svalbard and Jan Mayen  
210 = Swaziland  
196 = Sweden  
43 = Switzerland  
209 = Syrian Arab Republic  
225 = Taiwan, Province of China  
216 = Tajikistan  
226 = Tanzania, United Republic of  
215 = Thailand  
218 = Timor-Leste  
214 = Togo  
217 = Tokelau  
221 = Tonga  
223 = Trinidad and Tobago  
220 = Tunisia  
222 = Turkey  
219 = Turkmenistan

211 = Turks and Caicos Islands  
 224 = Tuvalu  
 228 = Uganda  
 227 = Ukraine  
 2 = United Arab Emirates  
 76 = United Kingdom  
 231 = Uruguay  
 232 = Uzbekistan  
 239 = Vanuatu  
 235 = Venezuela, Bolivarian Republic of  
 238 = Vietnam  
 236 = Virgin Islands, British  
 240 = Wallis and Futuna  
 65 = Western Sahara  
 242 = Yemen  
 245 = Zambia  
 246 = Zimbabwe

Qs9790\_999\_1 - Specify Country Name: for option 999 (--- Not in this country list ---) of Q9790 - What country do you live in?

[Q600](#) - What is the highest grade of school that you have completed?

1 = Less than 12th grade  
 2 = 12th grade  
 3 = Some college  
 4 = College  
 5 = Graduate school

[Q640](#) - Do you consider yourself to be of Hispanic or Latino ethnicity?

1 = Yes  
 2 = No

[Q680](#) - Which of the following best describes you?

1 = White  
 2 = Black/African American  
 3 = Asian  
 4 = Native Hawaiian or Other Pacific Islander  
 5 = American Indian or Alaskan Native  
 6 = More than one race  
 7 = Other

[Q26690](#) - Do you consider yourself of Jewish ancestry?

1 = Yes  
 2 = No  
 3 = Don't know

	Is grandparent Jewish?			If Jewish, Ashkenazi?		
	Yes	No	Unknown	Yes	No	Unknown
Paternal grandfather:	Q26715			Q26718		
	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3
Paternal grandmother:	Q26725			Q26728		
	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3

Maternal grandfather:	Q26735 <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	Q26738 <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3
Maternal grandmother:	Q26745 <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3	Q26748 <input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3

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## Section 2. Health Care

**Q700** - Are you currently pregnant?

- 1 = Yes
- 2 = No
- 3 = Don't know

**Q710** - Are you currently trying to become pregnant or considering pregnancy within the next 12 months?

- 1 = Yes
- 2 = No
- 3 = Don't know

**Q720** - Do you currently have a primary care physician?

- 1 = Yes
- 2 = No
- 3 = Don't know

**If Q720=1 (have a primary care physician), show Q760 (how many times ... over the past year)**

**Q760** - How many times have you seen this physician over the past year?

- 1 = Never
- 2 = 1 or 2 times
- 3 = 3 or 4 times
- 4 = 5 or more times
- 5 = Don't know

**Q800** - Do you currently have a gastroenterologist who helps you treat your IBD?

- 1 = Yes
- 2 = No
- 3 = Don't know

**If Q800=1 (have a gastroenterologist), show Q840 (how many times ... over the past year) and Q880 (where)**

**Q840** - How many times have you seen this gastroenterologist over the past year?

- 1 = Never
- 2 = 1 or 2 times
- 3 = 3 or 4 times
- 4 = 5 or more times
- 5 = Don't know

**Q880** - Where do you usually see this gastroenterologist?

- 1 = University/academic setting
- 2 = Private practice
- 3 = Veterans Administration
- 4 = Other
- 5 = Don't know setting

**Q890** - Do you have any health condition(s) - unrelated to IBD - that have greatly affected your diet, exercise, digestion, lifestyle, or mental health over the past month? Examples might be recent major surgery (non-IBD) or acute health problem, injury, other significant illness, etc.

- 1 = Yes

2 = No  
3 = Don't know

**If Q890=1 (have any health condition(s) - unrelated to IBD), show Q900 (what health condition)**

Q900 - What are the health condition(s)? (Check all that apply.)

Q900\_1 - Stroke

Q900\_2 - Heart attack

Q900\_4 - Major non-IBD surgery

Q900\_5 - Fracture or other injury

Q900\_6 - Other

Qs900\_6 - Specify for option 6 (Other) of Q900 - What are the health condition(s)? (Check all that apply.)

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### Section 3. Smoking History

Q920 - Have you smoked at least 100 cigarettes in your life?

1 = Yes

2 = No

**If smoked at least 100 cigarettes (Q920=1), show Q1000.**

Q1000 - Do you currently smoke cigarettes?

1 = Yes

2 = No

**If currently smoking (Q1000=1), show Q1040.**

Q1040 - In the past year have you been advised by your doctor to quit smoking or has your doctor offered you cessation medications, methods or strategies to quit smoking?

1 = Yes

2 = No

3 = Don't know

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### Section 4. Characteristics of your IBD

Q1080 - At what age were you first diagnosed with IBD?

Q1120 - Have you ever been hospitalized for your IBD?

1 = Yes

2 = No

3 = Don't know

**If Q1120=1 (hospitalized), show Q1160 (how many times) and Q1200 (when was the last time)**

Q1160 - How many times have you been hospitalized for your IBD?

1 = 1 time

2 = 2 times

3 = 3 times

4 = 4 times

5 = 5 times

6 = More than 5 times

7 = Don't know

Q1200 - When was the last time you were hospitalized for IBD?

1 = Less than 1 year ago

2 = 1-2 years ago

3 = 3-10 years ago

4 = More than 10 years ago

5 = Don't know

Q1240 - Have you had any surgeries on your bowels?

1 = Yes

2 = No  
3 = Don't know

**If Q1240=1 (have surgeries on bowels), show Q1280 (how many operations), Q1320 (pouch) and Q1360 (ostomy)**

**Q1280** - How many operations have you had on your bowels?

1 = 1  
2 = 2  
3 = 3 or more  
4 = Don't know

**Q1320** - Do you have an ileal pouch or Koch pouch?

1 = Yes - ileal pouch anal anastomosis (such as J pouch or restorative proctocolectomy)  
2 = Yes - Koch pouch  
4 = Yes - unsure what type  
3 = No  
5 = Don't know

**If Q1320=1,2,4 (have pouch), show Q1330 (how long had pouch).**

**Q1330** - For how long have you had your pouch?

1 = Less than 6 months  
2 = Between 6 months and 1 year  
3 = Between 1 and 5 years  
4 = More than 5 years  
5 = Don't know

**Q1360** - Do you currently have an ostomy?

1 = Yes - ileostomy  
2 = Yes - colostomy  
3 = Yes - unsure what type  
4 = No  
5 = Don't know

**Q10010** - In the past 6 months my disease has been

1 = Constantly active, giving me symptoms every day  
2 = Often active, giving me symptoms most days  
3 = Sometimes active, giving me symptoms on some days (for instance 1-2 days/week)  
4 = Occasionally active, giving me symptoms 1-2 days/month  
5 = Rarely active, giving me symptoms on a few days in the past 6 months  
6 = I was well in the past 6 months, what I consider a remission or absence of symptoms

**If UC/IC patient (Q120=2,3) and Q1320=1,4 (have ileal pouch or unsure type) and no ostomy (Q1360!=1,2,3), show Q26005.**

**Q26005** - Have you ever had symptoms of pouchitis? Symptoms include abdominal pain, cramping and urgent and frequent bowel movements.

1 = Yes  
2 = No  
3 = Don't know

**If Q26005=1, show Q26010.**

**Q26010** - In the past 6 months, have you had symptoms of pouchitis?

1 = Yes  
2 = No  
3 = Don't know

**If UC/IC patient (Q120=2,3) and Q1320=1,4 (have ileal pouch or unsure type) and no ostomy (Q1360!=1,2,3), show Q26015.**

**Q26015** - Have you ever been diagnosed with cuffitis?

1 = Yes  
2 = No

3 = Don't know

**If Q26015=1, show Q26020.**

[Q26020](#) - In the past 6 months, have you been diagnosed with cuffitis?

1 = Yes

2 = No

3 = Don't know

**If UC/IC patient (Q120=2,3) and Q1320=1,4 (have ileal pouch or unsure type) and no ostomy (Q1360!=1,2,3), show Q26025.**

[Q26025](#) - Have you ever been diagnosed with irritable pouch syndrome?

1 = Yes

2 = No

3 = Don't know

**If Q26025=1, show Q26030.**

[Q26030](#) - In the past 6 months, have you been diagnosed with irritable pouch syndrome?

1 = Yes

2 = No

3 = Don't know

[Q10200](#) - After you were diagnosed with IBD has a doctor ever told you that you had Irritable Bowel Syndrome (IBS).

1 = Yes

2 = No

3 = Don't know

[Q19000](#) - Have you ever been diagnosed with any types of cancers?

1 = Yes

2 = No

3 = Don't know

**If Q19000=1, show Q19050.**

[Q19050](#) - What type of cancer? (Check all that apply.)

Q19050\_1 - Colorectal

Q19050\_2 - Lung

Q19050\_3 - Breast

Q19050\_4 - Prostate

Q19050\_18 - Bile duct

Q19050\_5 - Bladder

Q19050\_6 - Brain

Q19050\_7 - Cervical

Q19050\_8 - Kidney

Q19050\_9 - Leukemia/lymphoma

Q19050\_19 - Liver

Q19050\_10 - Oral

Q19050\_11 - Ovarian

Q19050\_12 - Pancreatic

Q19050\_20 - Small bowel

Q19050\_13 - Stomach

Q19050\_14 - Uterine

Q19050\_15 - Skin

Q19050\_16 - Other

Q19050\_17 - Don't know

**if Q19050=1, show Q19110 and Q19115**

**if Q19050=2, show Q19120 and Q19125**

**if Q19050=3, show Q19130 and Q19135**

**if Q19050=4, show Q19140 and Q19145**

**if Q19050=5, show Q19150 and Q19155**

if Q19050=6, show Q19160 and Q19165  
if Q19050=7, show Q19170 and Q19175  
if Q19050=8, show Q19180 and Q19185  
if Q19050=9, show Q19190 and Q19195  
if Q19050=10, show Q19200 and Q19205  
if Q19050=11, show Q19210 and Q19215  
if Q19050=12, show Q19220 and Q19225  
if Q19050=13, show Q19230 and Q19235  
if Q19050=14, show Q19240 and Q19245  
if Q19050=15, show Q19250, Q19255, and Q19257  
if Q19050=16, show Q19260 and Q19265  
if Q19050=18, show Q19146 and Q19147  
if Q19050=19, show Q19196 and Q19197  
if Q19050=20, show Q19228 and Q19229

[Q19110](#) - How old were you when you were first diagnosed with colorectal cancer?

[Q19115](#) - What treatment(s) did you receive for colorectal cancer? (Check all that apply.)

Q19115\_1 - Surgery  
Q19115\_2 - Chemotherapy  
Q19115\_3 - Radiation  
Q19115\_4 - Other  
Q19115\_5 - None  
Q19115\_6 - Don't know

Qs19115\_4 - Specify for option 4 (Other) of Q19115 - What treatment(s) did you receive for colorectal cancer? (Check all that apply.)

[Q19120](#) - How old were you when you were first diagnosed with lung cancer?

[Q19125](#) - What treatment(s) did you receive for lung cancer? (Check all that apply.)

Q19125\_1 - Surgery  
Q19125\_2 - Chemotherapy  
Q19125\_3 - Radiation  
Q19125\_4 - Other  
Q19125\_5 - None  
Q19125\_6 - Don't know

Qs19125\_4 - Specify for option 4 (Other) of Q19125 - What treatment(s) did you receive for lung cancer? (Check all that apply.)

[Q19130](#) - How old were you when you were first diagnosed with breast cancer?

[Q19135](#) - What treatment(s) did you receive for breast cancer? (Check all that apply.)

Q19135\_1 - Surgery  
Q19135\_2 - Chemotherapy  
Q19135\_3 - Radiation  
Q19135\_4 - Other  
Q19135\_5 - None  
Q19135\_6 - Don't know

Qs19135\_4 - Specify for option 4 (Other) of Q19135 - What treatment(s) did you receive for breast cancer? (Check all that apply.)

[Q19140](#) - How old were you when you were first diagnosed with prostate cancer?

[Q19145](#) - What treatment(s) did you receive for prostate cancer? (Check all that apply.)

Q19145\_1 - Surgery  
Q19145\_2 - Chemotherapy

Q19145\_3 - Radiation  
Q19145\_4 - Other  
Q19145\_5 - None  
Q19145\_6 - Don't know

Qs19145\_4 - Specify for option 4 (Other) of Q19145 - What treatment(s) did you receive for prostate cancer? (Check all that apply.)

[Q19146](#) - How old were you when you were first diagnosed with bile duct cancer?

[Q19147](#) - What treatment(s) did you receive for bile duct cancer? (Check all that apply.)

Q19147\_1 - Surgery  
Q19147\_2 - Chemotherapy  
Q19147\_3 - Radiation  
Q19147\_4 - Other  
Q19147\_5 - None  
Q19147\_6 - Don't know

Qs19147\_4 - Specify for option 4 (Other) of Q19147 - What treatment(s) did you receive for bile duct cancer? (Check all that apply.)

[Q19150](#) - How old were you when you were first diagnosed with bladder cancer?

[Q19155](#) - What treatment(s) did you receive for bladder cancer? (Check all that apply.)

Q19155\_1 - Surgery  
Q19155\_2 - Chemotherapy  
Q19155\_3 - Radiation  
Q19155\_4 - Other  
Q19155\_5 - None  
Q19155\_6 - Don't know

Qs19155\_4 - Specify for option 4 (Other) of Q19155 - What treatment(s) did you receive for bladder cancer? (Check all that apply.)

[Q19160](#) - How old were you when you were first diagnosed with brain cancer?

[Q19165](#) - What treatment(s) did you receive for brain cancer? (Check all that apply.)

Q19165\_1 - Surgery  
Q19165\_2 - Chemotherapy  
Q19165\_3 - Radiation  
Q19165\_4 - Other  
Q19165\_5 - None  
Q19165\_6 - Don't know

Qs19165\_4 - Specify for option 4 (Other) of Q19165 - What treatment(s) did you receive for brain cancer? (Check all that apply.)

[Q19170](#) - How old were you when you were first diagnosed with cervical cancer?

[Q19175](#) - What treatment(s) did you receive for cervical cancer? (Check all that apply.)

Q19175\_1 - Surgery  
Q19175\_2 - Chemotherapy  
Q19175\_3 - Radiation  
Q19175\_4 - Other  
Q19175\_5 - None  
Q19175\_6 - Don't know

Qs19175\_4 - Specify for option 4 (Other) of Q19175 - What treatment(s) did you receive for cervical cancer? (Check all that apply.)



[Q19180](#) - How old were you when you were first diagnosed with kidney cancer?

[Q19185](#) - What treatment(s) did you receive for kidney cancer? (Check all that apply.)

Q19185\_1 - Surgery

Q19185\_2 - Chemotherapy

Q19185\_3 - Radiation

Q19185\_4 - Other

Q19185\_5 - None

Q19185\_6 - Don't know

Qs19185\_4 - Specify for option 4 (Other) of Q19185 - What treatment(s) did you receive for kidney cancer? (Check all that apply.)

[Q19190](#) - How old were you when you were first diagnosed with leukemia/lymphoma?

[Q19195](#) - What treatment(s) did you receive for leukemia/lymphoma? (Check all that apply.)

Q19195\_1 - Surgery

Q19195\_2 - Chemotherapy

Q19195\_3 - Radiation

Q19195\_4 - Other

Q19195\_5 - None

Q19195\_6 - Don't know

Qs19195\_4 - Specify for option 4 (Other) of Q19195 - What treatment(s) did you receive for leukemia/lymphoma? (Check all that apply.)

[Q19196](#) - How old were you when you were first diagnosed with liver cancer?

[Q19197](#) - What treatment(s) did you receive for liver cancer? (Check all that apply.)

Q19197\_1 - Surgery

Q19197\_2 - Chemotherapy

Q19197\_3 - Radiation

Q19197\_4 - Other

Q19197\_5 - None

Q19197\_6 - Don't know

Qs19197\_4 - Specify for option 4 (Other) of Q19197 - What treatment(s) did you receive for liver cancer? (Check all that apply.)

[Q19200](#) - How old were you when you were first diagnosed with oral cancer?

[Q19205](#) - What treatment(s) did you receive for oral cancer? (Check all that apply.)

Q19205\_1 - Surgery

Q19205\_2 - Chemotherapy

Q19205\_3 - Radiation

Q19205\_4 - Other

Q19205\_5 - None

Q19205\_6 - Don't know

Qs19205\_4 - Specify for option 4 (Other) of Q19205 - What treatment(s) did you receive for oral cancer? (Check all that apply.)

[Q19210](#) - How old were you when you were first diagnosed with ovarian cancer?

[Q19215](#) - What treatment(s) did you receive for ovarian cancer? (Check all that apply.)

Q19215\_1 - Surgery

Q19215\_2 - Chemotherapy

Q19215\_3 - Radiation

Q19215\_4 - Other  
Q19215\_5 - None  
Q19215\_6 - Don't know

Qs19215\_4 - Specify for option 4 (Other) of Q19215 - What treatment(s) did you receive for ovarian cancer? (Check all that apply.)

[Q19220](#) - How old were you when you were first diagnosed with pancreatic cancer?

[Q19225](#) - What treatment(s) did you receive for pancreatic cancer? (Check all that apply.)

Q19225\_1 - Surgery  
Q19225\_2 - Chemotherapy  
Q19225\_3 - Radiation  
Q19225\_4 - Other  
Q19225\_5 - None  
Q19225\_6 - Don't know

Qs19225\_4 - Specify for option 4 (Other) of Q19225 - What treatment(s) did you receive for pancreatic cancer? (Check all that apply.)

[Q19228](#) - How old were you when you were first diagnosed with small bowel cancer?

[Q19229](#) - What treatment(s) did you receive for small bowel cancer? (Check all that apply.)

Q19229\_1 - Surgery  
Q19229\_2 - Chemotherapy  
Q19229\_3 - Radiation  
Q19229\_4 - Other  
Q19229\_5 - None  
Q19229\_6 - Don't know

Qs19229\_4 - Specify for option 4 (Other) of Q19229 - What treatment(s) did you receive for small bowel cancer? (Check all that apply.)

[Q19230](#) - How old were you when you were first diagnosed with stomach cancer?

[Q19235](#) - What treatment(s) did you receive for stomach cancer? (Check all that apply.)

Q19235\_1 - Surgery  
Q19235\_2 - Chemotherapy  
Q19235\_3 - Radiation  
Q19235\_4 - Other  
Q19235\_5 - None  
Q19235\_6 - Don't know

Qs19235\_4 - Specify for option 4 (Other) of Q19235 - What treatment(s) did you receive for stomach cancer? (Check all that apply.)

[Q19240](#) - How old were you when you were first diagnosed with uterine cancer?

[Q19245](#) - What treatment(s) did you receive for uterine cancer? (Check all that apply.)

Q19245\_1 - Surgery  
Q19245\_2 - Chemotherapy  
Q19245\_3 - Radiation  
Q19245\_4 - Other  
Q19245\_5 - None  
Q19245\_6 - Don't know

Qs19245\_4 - Specify for option 4 (Other) of Q19245 - What treatment(s) did you receive for uterine cancer? (Check all that apply.)

[Q19250](#) - How old were you when you were first diagnosed with skin cancer?

[Q19255](#) - What treatment(s) did you receive for skin cancer? (Check all that apply.)

Q19255\_1 - Surgery

Q19255\_2 - Chemotherapy

Q19255\_3 - Radiation

Q19255\_4 - Other

Q19255\_5 - None

Q19255\_6 - Don't know

Qs19255\_4 - Specify for option 4 (Other) of Q19255 - What treatment(s) did you receive for skin cancer? (Check all that apply.)

[Q19257](#) - What type of skin cancer? (Check all that apply.)

Q19257\_1 - Melanoma

Q19257\_2 - Other skin cancer

**If 19257=2, show Q19258**

[Q19258](#) - What type of other skin cancer? (Check all that apply.)

Q19258\_1 - Squamous Cell carcinoma (SCC)

Q19258\_2 - Basal Cell carcinoma (BCC)

[Q19260](#) - How old were you when you were first diagnosed with other cancers?

[Q19265](#) - What treatment(s) did you receive for other cancers? (Check all that apply.)

Q19265\_1 - Surgery

Q19265\_2 - Chemotherapy

Q19265\_3 - Radiation

Q19265\_4 - Other

Q19265\_5 - None

Q19265\_6 - Don't know

Qs19265\_4 - Specify for option 4 (Other) of Q19265 - What treatment(s) did you receive for other cancers? (Check all that apply.)

---

## Section 17. Extra Intestinal Manifestations

**If UC/IC (Q120=2,3), show following past week table Q2800~Q3000**

**Over the past week**, have you experienced any of the following?

	1 = Yes	2 = No	3 = Don't know
2800 - Painful joints	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2840 - Erythema nodosum - painful red skin lesions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2880 - Pyoderma gangrenosum - painful ulcerated skin lesions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2920 - Eye inflammation/redness (Uveitis, Scleritis or Episcleritis)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2960 - Aphthous ulcerations in your mouth	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3000 - Primary sclerosing cholangitis (a kind of liver disease associated with inflammatory bowel disease)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Show following ever or since last survey table to all patients Q2805~Q3005**

Have you **ever** experienced any of the following related to your IBD?

	1 = Yes	2 = No	3 = Don't know
2805 - Painful joints	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2845 - Erythema nodosum - painful red skin lesions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2885 - Pyoderma gangrenosum - painful ulcerated skin lesions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2925 - Eye inflammation/redness (Uveitis, Scleritis or Episcleritis)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2965 - Aphthous ulcerations in your mouth	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3005 - Primary sclerosing cholangitis (a kind of liver disease associated with inflammatory bowel disease)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Section 5. IBD Medications

Many medications and supplements can be used to treat Crohn's and colitis or complications of these diseases. For each medication or supplement, we want to know if you have ever used it, and whether you are currently using it.

	1 = I have never used, or I don't know if I have ever used	2 = I have used, but I am not currently using	3 = I am currently using
1520 - Rectal Steroids (Cortenema, Cortifoam (hydrocortisone rectal), etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
1440 - Oral/IV steroids (prednisone, prednisolone, methylprednisolone)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
1480 - Budesonide (Entocort, Uceris)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
1560 - Oral 5-ASA (Lialda, Asacol, Delzicol, Pentasa, Apriso (mesalamine), Colazal, Giazol (balsalazide), Dipentum (olsalazine))	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
1640 - Rectal 5-ASA (Rowasa, Canasa (mesalamine rectal))	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
1600 - Azulfidine (sulfasalazine)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
1680 - Ciprofloxacin	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
1720 - Flagyl (metronidazole)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
1760 - Other antibiotics prescribed for IBD	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
1800 - Purethanol (6MP) /Imuran (Azathioprine)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
1840 - Methotrexate (oral)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

1860 - Methotrexate (subcutaneous injection)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
1880 - Remicade (infliximab)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
1920 - Humira (adalimumab)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
1960 - Cimzia (certolizumab pegol)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
1980 - Simponi (golimumab)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2000 - Neoral (cyclosporine)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2040 - Prograf (Tacrolimus)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2080 - Tysabri (natalizumab)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2100 - Entyvio (vedolizumab)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4600 - Calcium	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4640 - Vitamin D	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10040 - Vitamin B-12	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4680 - Bisphosphonate (medications like Fosamax (alendronate), Actonel (risedronate), Boniva (ibandronate), Zometa or Reclast (Zoledronate), Didronel (etidronate))	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2120 - Narcotic pain medicine (examples might include Percocet (oxycodone/acetaminophen), Vicodin, Codeine (hydrocodone/acetaminophen), etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2160 - Experimental therapies in clinical trials	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2240 - Probiotics (VSL-3 or other)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2200 - Other complementary or alternative therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10050 - Total parenteral nutrition (TPN; receiving nutrition intravenously)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
30160 - Supplemental enteral nutrition (high calorie formula such as Ensure added to current diet for weight gain)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Section 6. Use of IBD Medications

**Skip this section if taking any injection or infusion medication(s).**

**Otherwise if taking the oral medications Q1440, Q1480, Q1500, Q1520, Q1560, Q1600, Q1680, Q1720, Q1760, Q1800, Q1840, Q2000, Q2040, show this section.**

© Morisky Medication Adherence Scale.

You indicated that you are taking medication for your IBD. Individuals have identified several issues regarding their medication-taking behavior and we are interested in your experiences. There is no right or wrong answer. Please answer each question based on your personal experience with your IBD.

[Q7960](#) - Do you sometimes forget to take your IBD pills?

1 = Yes

2 = No

[Q8000](#) - People sometimes miss taking their medications for reasons other than forgetting. Thinking over the past 2 weeks, were there any days when you did not take your medication?

1 = Yes

2 = No

[Q8040](#) - Have you ever cut back or stopped taking your medication without telling your doctor because you felt worse when you took it?

1 = Yes

2 = No

[Q8080](#) - When you travel or leave home, do you sometimes forget to bring along your IBD medication?

1 = Yes

2 = No

[Q8120](#) - Did you take your IBD medicine yesterday?

1 = Yes

2 = No

[Q8160](#) - When you feel like your IBD symptoms are under control, do you sometimes stop taking your medication?

1 = Yes

2 = No

[Q8200](#) - Taking medication every day is a real inconvenience for some people. Do you ever feel hassled about sticking to your IBD treatment plan?

1 = Yes

2 = No

[Q8240](#) - How often do you have difficulty remembering to take all your IBD medications?

1 = Rarely/Never

2 = Once in a while

3 = Sometimes

4 = Usually

5 = Always

---

## Section 7. Pain Medications

We are now interested in obtaining information on certain medications that you may have taken during the past month.

These include medicines that you have obtained anywhere including a doctor's prescription, a hospital or neighborhood clinic, pharmacy, supermarket, store, friends, neighbors and relatives.

During the past month did you ever take any of the following medications, for abdominal pain, headache, backache, arthritis, bursitis, rheumatism, joint pain, injury, accident, operation, migraine, sinus trouble or (women) menstrual cramps, or for other reasons?

[Q11010](#) - During the past month, did you ever take any prescription aspirin-type pain medications (called "[prescription NSAIDs](#)")? Examples include Daypro, Celebrex, Lodine, Feldene, Mobic.

1 = Yes

2 = No

3 = Don't know

**If Q11010=1, show Q11015. If Q11010=2, show Q11016**

[Q11015](#) - About how often, on average during the past month, did you take ANY of these medications? Please tell us the average number of times per day, per week, or per month you took ANY 1 or MORE of these medications?

Qu11015 - Unit for Q11015 - About how often, on average during the past month, did you take ANY of these medications? Please tell us the average number of times per day, per week, or per month you took ANY 1 or MORE of these medications?

1=per day

2=per week

3=per month

4=Don't know

[Q11016](#) - Why did you NOT take these pain medications? (Check all that apply.)

Q11016\_4 - Did not need these medications

Q11016\_1 - Advised by physician NOT to take these medications due to my IBD

Q11016\_2 - Allergy to these medications

Q11016\_3 - These types of medications don't work for my pain

Q11016\_5 - Other

Qs11016\_5 - Specify for option 5 (Other) of Q11016 - Why did you NOT take these pain medications? (Check all that apply.)

[Q11020](#) - During the past month, did you ever take any over the counter aspirin-type pain medications (called "[OTC NSAIDS](#)")? Examples include aspirin, ibuprofen, Aleve, Advil, BC or Goody's powders, Excedrin or Alka-seltzer.

1 = Yes

2 = No

3 = Don't know

**If Q11020=1, show Q11025. If Q11020=2, show Q11026**

[Q11025](#) - About how often, on average during the past month, did you take ANY of these medications? Please tell us the average number of times per day, per week, or per month you took ANY 1 or MORE of these medications?

Qu11025 - Unit for Q11025 - About how often, on average during the past month, did you take ANY of these medications? Please tell us the average number of times per day, per week, or per month you took ANY 1 or MORE of these medications?

1=per day

2=per week

3=per month

4=Don't know

[Q11026](#) - Why did you NOT take these pain medications? (Check all that apply.)

Q11026\_4 - Did not need these medications

Q11026\_1 - Advised by physician NOT to take these medications due to my IBD

Q11026\_2 - Allergy to these medications

Q11026\_3 - These types of medications don't work for my pain

Q11026\_5 - Other

Qs11026\_5 - Specify for option 5 (Other) of Q11026 - Why did you NOT take these pain medications? (Check all that apply.)

[Q11030](#) - Do you feel that taking ANY aspirin-type pain medications ([NSAIDS](#)) worsens your bowel symptoms?

1 = Yes

2 = No

3 = Don't know

4 = Never use these medications

[Q11040](#) - During the past month, did you ever take any over the counter [non-aspirin pain medications](#)? Examples include Tylenol, Datril, aspirin-free pain formula, aspirin-free Excedrin and acetaminophen.

1 = Yes

2 = No

3 = Don't know

**If Q11040=1, show Q11045. If Q11040=2, show Q11046**

[Q11045](#) - About how often, on average during the past month, did you take ANY of these medications? Please tell us the average number of times per day, per week, or per month you took ANY 1 or MORE of these medications?

Qu11045 - Unit for Q11045 - About how often, on average during the past month, did you take ANY of these medications? Please tell us the average number of times per day, per week, or per month you took ANY 1 or MORE of these medications?

1=per day

2=per week

3=per month

4=Don't know

[Q11046](#) - Why did you NOT take these pain medications? (Check all that apply.)

Q11046\_4 - Did not need these medications

Q11046\_1 - Advised by physician NOT to take these medications due to my IBD

Q11046\_2 - Allergy to these medications

Q11046\_3 - These types of medications don't work for my pain

Q11046\_5 - Other

Qs11046\_5 - Specify for option 5 (Other) of Q11046 - Why did you NOT take these pain medications? (Check all that apply.)

[Q11070](#) - Do you feel that taking [non-aspirin pain medications](#) worsens your bowel symptoms?

1 = Yes

2 = No

3 = Don't know

4 = Never use these medications

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## Section 8. Family History

[Q2320](#) - Have any of your immediate biological family members (biological parents, brothers or sisters, children) ever been diagnosed with Crohn's disease, ulcerative colitis, or indeterminate colitis?

1 = Yes

2 = No

3 = Don't know

**If Q2320=1, show the following text and table.**

In the chart below, please enter the number of immediate biological family members who have Crohn's Disease (CD), ulcerative colitis (UC)? [Enter numbers only 0,1,2, 3, etc]

	Number with CD	Number with UC	Don't know
Biological Mother	Q2342	Q2343	<input type="checkbox"/> Q2346
Biological Father	Q2352	Q2353	<input type="checkbox"/> Q2356
Biological Siblings	Q2362	Q2363	<input type="checkbox"/> Q2366
Biological Children	Q2372	Q2373	<input type="checkbox"/> Q2376



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## Section 9. Colitis History

**Only show this section to UC/IC patients (Q120=2,3).**

**Only show this question to patients without pouch (Q1320!=1,2,4).**

Q2520 - Ulcerative colitis can involve all of the colon or only part of the colon. Which part(s) of your colon have been involved at any point in your life?

- 1 = Just the rectum
- 2 = The rectum and sigmoid colon
- 3 = The rectum, sigmoid colon, and descending colon (sometimes referred to as left side of colon or left-sided disease)
- 4 = The rectum, sigmoid colon, descending colon and transverse colon
- 5 = The entire colon (sometimes referred to as pancolitis)
- 6 = Don't know

**Only show this section to UC/IC patients (Q120=2,3).**

**For the rest of the questions in this section, please answer for an average 24-hour period over the past week.**

Q2560 - What has been your bowel frequency during the day?

- 1 = 0 times
- 2 = 1-3 times
- 3 = 4-6 times
- 4 = 7-9 times
- 5 = More than 9 times

Q2600 - What has been your bowel frequency during the night?

- 1 = 0 times
- 2 = 1-3 times
- 3 = 4-6 times
- 4 = 7 or more times

Q2640 - What has been your urgency of defecation?

- 1 = No urgency
- 2 = Hurry
- 3 = Immediately
- 4 = Incontinence

Q2680 - Have you seen blood in your bowel movements?

- 1 = No blood
- 2 = A little blood
- 3 = Occasionally a lot of blood
- 4 = Usually a lot of blood

Q2720 - How would you describe your general well being?

- 1 = Very well
- 2 = Slightly below par
- 3 = Poor
- 4 = Very poor
- 5 = Terrible

---

## Section 10. Crohn's History

**If Q120=1 (Crohn's Disease), show section 10 (Crohn's History).**

Crohn's disease can involve any part of the gastrointestinal tract starting at the mouth all the way to the anal canal. What parts have you ever been told are involved?

	1 = Yes	2 = No	3 = Don't know
3081 - Upper GI (Esophagus, stomach, first part of small bowel)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

3083 - Terminal ileum (the very last part of the small intestine, right before the colon or large intestine starts)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3085 - Colon (large intestine)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Q3120** - Have you ever been told that you have a stricture (a narrowing of the intestine that can sometimes lead to obstruction)?

1 = Yes

2 = No

3 = Don't know

**Q3160** - Have you ever been told that you have a fistula (a connection between the small or large intestine and another part of the body, such as the skin or perianal area)?

1 = Yes

2 = No

3 = Don't know

**If Q3160=1 (had fistula), show Q3200 (which type) to Q3480 (have now)**

Which types of fistula have you had?

	1 = Yes	2 = No	3 = Don't know
3240 - to the skin near the anus	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3280 - to the skin of the abdominal wall	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>If female (Q360=2) show Q3320.</b> 3320 - to the vagina	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3360 - to the bladder	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3400 - from one part of the intestines to another part of the intestines	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3440 - Other	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Q3480** - Do you have a fistula now?

1 = Yes

2 = No

3 = Don't know

**Q10120** - Have you ever had an abscess? (An abscess is a collection of pus in any part of the body that, in most cases, causes swelling and inflammation around it.)

1 = Yes

2 = No

3 = Don't know

**If Q10120=1 (had an abscess), show Q10130 (where) and Q10140 (now)**

**Q10130** - Was your abscess in your:

1 = Abdomen only

2 = Near the rectum only

3 = Both abdomen and rectum

4 = Other

5 = Don't know

Qs10130\_4 - Specify for option 4 (Other) of Q10130 - Was your abscess in your:

Qs10130\_5 - Specify for option 5 (Don't know) of Q10130 - Was your abscess in your:

[Q10140](#) - Do you have an abscess now?

1 = Yes

2 = No

3 = Don't know

---

## Section 11. Crohn's Activity

**If Q120=1 (Crohn's Disease), show section 11 (Crohn's Activity)**

[Q3520](#) - How would you describe your general well being over the past week?

1 = Generally well

2 = Slightly below par

3 = Poor

4 = Very poor

5 = Terrible

[Q3560](#) - On average, over the past week, would you rate your abdominal pain as:

1 = None

2 = Mild

3 = Moderate

4 = Severe

**If has ostomy (Q1360=1,2,3) or has Koch pouch (Q1320=2)**

[Q3600](#) - On average, over the past week, how many liquid or very soft stools have you had per day?

---

## Section 12. Prevention

Which of the following adult vaccines have you ever had:

	1 = Yes	2 = No	3 = Don't know
4120 - Hepatitis B	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4160 - Hepatitis A	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4240 - Varicella (chicken pox)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4320 - Pneumococcal (pneumonia)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4360 - Influenza (regular flu or swine flu)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4400 - Meningococcal (meningitis)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Ask only for female or no gender.</b> 4200 - HPV (cervical cancer & genital warts)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4280 - Zoster (Shingles)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10060 - Tetanus	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

[Q4440](#) - In the past 12 months, did you receive a flu shot or flu mist (nasal vaccine)?

1 = Yes

2 = No

4 = Not currently due  
3 = Don't know

**If Q4440=2 (not had flu shot in 12 months), show Q4480 (why not receive)**

[Q4480](#) - Why did you not receive a flu shot? (Check all that apply.)

Q4480\_1 - Never offered flu shot  
Q4480\_2 - Allergy to eggs/vaccines  
Q4480\_3 - Did not think I needed it  
Q4480\_4 - Too expensive  
Q4480\_5 - Vaccine not available  
Q4480\_6 - Too busy/forgot  
Q4480\_7 - Concerned about side effects from the vaccine  
Q4480\_8 - Concerned that the vaccine would worsen my IBD  
Q4480\_9 - My doctor advised against a flu shot  
Q4480\_10 - Other reason  
Q4480\_11 - Don't know

Qs4480\_10 - Specify for option 10 (Other reason) of Q4480 - Why did you not receive a flu shot? (Check all that apply.)

[Q4520](#) - With regard to bone health, have you ever been told by a doctor that you have weak bones or osteoporosis/osteopenia?

1 = Yes  
2 = No  
3 = Don't know

[Q4720](#) - Have you ever had a bone density study?

1 = Yes  
2 = No  
3 = Don't know

[Q4760](#) - Have you ever had a Pap smear (a test for cervical cancer)?

1 = Yes  
2 = No  
3 = Don't know

[Q4800](#) - How many years ago was your last Pap smear?

1 = Within the last year  
2 = Between 1-3 years  
3 = Between 4-5 years  
4 = More than 5 years  
5 = Don't know

[Q4840](#) - Do you wear sunscreen during outdoor activities?

1 = Yes, always  
2 = Yes, most of the time  
3 = Yes, some of the time  
4 = No, never  
5 = Don't know

[Q4880](#) - Have you ever had a screening skin examination by a dermatologist?

1 = Yes  
2 = No  
3 = Don't know

**If Q4880=1 (had a screening skin examination), show Q4920 (when).**

[Q4920](#) - When was your last screening skin examination by a dermatologist?

1 = Within the last year  
2 = Between 1-3 years  
3 = Between 4-5 years

4 = More than 5 years  
5 = Don't know

[Q4960](#) - Have you ever had a skin test for tuberculosis?

1 = Yes  
2 = No  
3 = Don't know

**If Q4960=1 (had a skin test for tuberculosis), show Q5000 (when).**

[Q5000](#) - When was your last test for tuberculosis?

1 = Within the last year  
2 = Between 1-3 years  
3 = Between 4-5 years  
4 = More than 5 years  
5 = Don't know

[Q5040](#) - Have you ever had a colonoscopy?

1 = Yes  
2 = No  
3 = Don't know

[Q5080](#) - How long ago was your last colonoscopy?

1 = Within the last year  
2 = Between 1-2 years  
3 = Between 3-5 years  
4 = Between 6-10 years  
5 = More than 10 years  
6 = Don't know

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### Section 13. Exercise – Daily Activity

[Q10110](#) - How often did you participate in 1 or more physical activities of 20-30 minutes duration per session during your leisure time within the past 6 months?

1 = Not at all  
2 = Less than once a month  
3 = About once a month  
4 = About 2 or 3 times a month  
5 = About 1 to 2 times a week  
6 = 3 times or more a week

Considering a 7-day period (a week), how many times on average do you do the following kinds of exercise for more than 15 minutes during your free time?

[Q5160](#) - How many times per week do you do strenuous exercise (heart beats rapidly) (e.g. running, jogging, hockey, football, soccer, squash, basketball, cross country skiing, judo, roller skating, vigorous swimming, vigorous long-distance bicycling)?

[Q5200](#) - How many times per week do you do moderate exercise (not exhausting) (e.g. fast walking, baseball, tennis, easy bicycling, volleyball, badminton, easy swimming, alpine skiing, popular and folk dancing)?

[Q5240](#) - How many times per week do you do mild exercise (minimal effort) (e.g. yoga, archery, fishing from a river bank, bowling, horseshoes, golf, snowmobiling, easy walking)?

[Q5280](#) - Considering a 7-day period (a week), during your leisure-time, how often do you engage in any regular activity long enough to work up a sweat wherein your heart beats rapidly)?

1 = Often  
2 = Sometimes  
3 = Never/Rarely

## Section 14. Health Status – Quality of Life

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**Q8280** - How often has the feeling of fatigue, or of being tired and worn out, been a problem for you during the last 2 weeks?

- 1 = All of the time
- 2 = Most of the time
- 3 = A good bit of the time
- 4 = Some of the time
- 5 = A little of the time
- 6 = Hardly any of the time
- 7 = None of the time

**Q8320** - How often during the last 2 weeks have you had to delay or cancel a social engagement because of your bowel problem?

- 1 = All of the time
- 2 = Most of the time
- 3 = A good bit of the time
- 4 = Some of the time
- 5 = A little of the time
- 6 = Hardly any of the time
- 7 = None of the time

**Q8360** - How much difficulty have you had, as a result of your bowel problems, doing leisure or sports activities you would have liked to have done during the last 2 weeks?

- 1 = A great deal of difficulty, activities made impossible
- 2 = A lot of difficulty
- 3 = A fair bit of difficulty
- 4 = Some difficulty
- 5 = A little difficulty
- 6 = Hardly any difficulty
- 7 = No difficulty; the bowel problems did not limit sports or leisure activities

**Q8400** - How often during the last 2 weeks have you been troubled by pain in the abdomen?

- 1 = All of the time
- 2 = Most of the time
- 3 = A good bit of the time
- 4 = Some of the time
- 5 = A little of the time
- 6 = Hardly any of the time
- 7 = None of the time

**Q8440** - How often during the last 2 weeks have you felt depressed or discouraged?

- 1 = All of the time
- 2 = Most of the time
- 3 = A good bit of the time
- 4 = Some of the time
- 5 = A little of the time
- 6 = Hardly any of the time
- 7 = None of the time

**Q8480** - Overall, in the last 2 weeks, how much of a problem have you had with passing large amounts of gas?

- 1 = A major problem
- 2 = A big problem
- 3 = A significant problem

- 4 = Some trouble
- 5 = A little trouble
- 6 = Hardly any trouble
- 7 = No trouble

**Q8520** - Overall, in the last 2 weeks, how much of a problem have you had maintaining or getting to the weight you would like to be?

- 1 = A major problem
- 2 = A big problem
- 3 = A significant problem
- 4 = Some trouble
- 5 = A little trouble
- 6 = Hardly any trouble
- 7 = No trouble

**Q8560** - How often during the last 2 weeks have you felt relaxed and free of tension?

- 1 = None of the time
- 2 = A little of the time
- 3 = Some of the time
- 4 = A good bit of the time
- 5 = Most of the time
- 6 = Almost all of the time
- 7 = All of the time

**Q8600** - How much of the time during the last 2 weeks have you been troubled by a feeling of having to go to the bathroom even though your bowels were empty?

- 1 = All of the time
- 2 = Most of the time
- 3 = A good bit of the time
- 4 = Some of the time
- 5 = A little of the time
- 6 = Hardly any of the time
- 7 = None of the time

**Q8640** - How much of the time during the last 2 weeks have you felt angry as a result of your bowel problem?

- 1 = All of the time
- 2 = Most of the time
- 3 = A good bit of the time
- 4 = Some of the time
- 5 = A little of the time
- 6 = Hardly any of the time
- 7 = None of the time

## Section 15. Health Status – PROMIS

In the past 7 days...

	1 = Never	2 = Rarely	3 = Sometimes	4 = Often	5 = Always
8720 - I felt fearful	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8760 - I found it hard to focus on anything other than my anxiety	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8800 - My worries overwhelmed me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8840 - I felt uneasy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

8880 - I felt worthless	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8920 - I felt helpless	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8960 - I felt depressed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9000 - I felt hopeless	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

In the past 7 days...

	1 = Not at all	2 = A little bit	3 = Somewhat	4 = Quite a bit	5 = Very much
9080 - I feel fatigued	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9120 - I have trouble starting things because I am tired	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9160 - How run-down did you feel on average	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9200 - How fatigued were you on average	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

In the past 7 days...

[Q9280](#) - My sleep quality was

- 1 = Very poor
- 2 = Poor
- 3 = Fair
- 4 = Good
- 5 = Very good

In the past 7 days...

	1 = Not at all	2 = A little bit	3 = Somewhat	4 = Quite a bit	5 = Very much
9360 - My sleep was refreshing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9400 - I had a problem with my sleep	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9440 - I had difficulty falling asleep	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9480 - I am satisfied with my ability to do things for fun with others	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9520 - I am satisfied with my ability to do things for my family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9560 - I am satisfied with my ability to meet the needs of my friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9600 - I am satisfied with my ability to do the work that is really important to me (include work at home)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



10070 - How much did pain interfere with your day-to-day activities?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10080 - How much did pain interfere with work around the home?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10090 - How much did pain interfere with your ability to participate in social activities?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10100 - How much did pain interfere with your household chores?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

[Q9640](#) - In general, my health is...

- 1 = Excellent
- 2 = Very good
- 3 = Good
- 4 = Fair
- 5 = Poor

[Q2280](#) - During the past week, how would you rate your IBD activity?

- 1 = Remission (no symptoms)
- 2 = Minimal symptoms
- 3 = Mildly active
- 4 = Moderately active
- 5 = Severely active

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### Section 18. Transition Readiness Assessment Questionnaire 5.0

This section contains questions for patients who were diagnosed with IBD as a child. If you were not diagnosed with IBD as a child or do not want to answer these questions, it is okay to skip this section.

Please choose the option that best describes your skill level in the following areas that are important for transition to adult health care. There is no right or wrong answer and your answers will remain confidential and private.

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#### Managing Medications

	1 = No, I do not know how	2 = No, but I want to learn	3 = Yes, I am learning to do this	4 = Yes, I started doing this	5 = Yes, I always do this when I need to
30330 - Do you fill a prescription if you need to?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
30340 - Do you know what to do if you are having a bad reaction to your medications?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
30350 - Do you take medications correctly and on your own?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
30360 - Do you reorder medications before they run out?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

#### Appointment Keeping

	1 = No,	2 = No,	3 = Yes,	4 = Yes,	5 = Yes,
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	I do not know how	but I want to learn	I am learning to do this	I started doing this	I always do this when I need to
30380 - Do you call the doctor's office to make an appointment?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
30390 - Do you follow-up on any referral for tests or check-ups or labs?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
30400 - Do you arrange for your ride to medical appointments?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
30410 - Do you call the doctor about unusual changes in your health (For example: Allergic reactions)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
30420 - Do you apply for health insurance if you lose your current coverage?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
30430 - Do you know what your health insurance covers?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
30440 - Do you manage your money & budget household expenses (For example: use checking/debit card)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

#### Tracking Health Issues

	1 = No, I do not know how	2 = No, but I want to learn	3 = Yes, I am learning to do this	4 = Yes, I started doing this	5 = Yes, I always do this when I need to
30460 - Do you fill out the medical history form, including a list of your allergies?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
30470 - Do you keep a calendar or list of medical and other appointments?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
30480 - Do you make a list of questions before the doctor's visit?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
30490 - Do you get financial help with school or work?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

#### Talking with Providers

	1 = No, I do not know how	2 = No, but I want to learn	3 = Yes, I am learning to do this	4 = Yes, I started doing this	5 = Yes, I always do this when I need to
30510 - Do you tell the doctor or nurse what you are feeling?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
30520 - Do you answer questions that are	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

asked by the doctor, nurse, or clinic staff?					
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### Managing Daily Activities

	1 = No, I do not know how	2 = No, but I want to learn	3 = Yes, I am learning to do this	4 = Yes, I started doing this	5 = Yes, I always do this when I need to
30540 - Do you help plan or prepare meals/food?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
30550 - Do you keep home/room clean or clean-up after meals?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
30560 - Do you use neighborhood stores and services (For example: Grocery stores and pharmacy stores)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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### Section 16. Comments & Feedback

[Q11080](#) - If you have any feedback, please submit your comments in the following box. Thank you.