

**NIDDK IBD Genetics Consortium
Affected Registration and Demographics Form**

Version 2.5
23-Jun-10

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Registration Information

Affix red Rutgers sample label here (repository subjects only)	Affix Fisher sample label here (repository subjects only)
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Consented for data sharing:

Initials: Gender: Male Female

Date of birth: / /

Local Sample ID: _____

Local Pedigree ID: _____ Consortium ID: _____ - _____

Local Individual ID: _____ Father's Consortium ID: _____ - _____

_____ Mother's Consortium ID: _____ - _____

Disease type: CD UC IC

Inception case: Yes No

If parent, Consortium ID of child: _____ - _____

Demographic and Early Childhood Information

Hispanic: Yes No Unknown

Jewish: Yes No Unknown

Race: White American Indian/Alaskan
 Black/African American Native Hawaiian/^{Native} Pacific Islander
 Asian Unknown
 Other (specify: _____)

	Is grandparent Jewish?			If Jewish, Ashkenazi?			
	Yes	No	Unknown	Yes	No	Unknown	
Paternal grandfather:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Paternal grandmother:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Maternal grandfather:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Maternal grandmother:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	

Birth order: 1st 2nd 3rd 4th
 5th 6th > 6th Unknown

Breast fed: Yes No Unknown

If yes, duration of exclusive breastfeeding: (months) Unknown

Age at weaning: (months) Unknown

Family History of IBD

	CD	UC/IC	IBD affected (type unclear)	Unaffected	Unknown	
Father:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Mother:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
No. siblings:	<input style="width:20px;" type="text"/>	<input style="width:20px;" type="text"/>	<input style="width:20px;" type="text"/>	<input style="width:20px;" type="text"/>	<input style="width:20px;" type="text"/>	(sum of row should equal total no. of siblings)
No. children:	<input style="width:20px;" type="text"/>	<input style="width:20px;" type="text"/>	<input style="width:20px;" type="text"/>	<input style="width:20px;" type="text"/>	<input style="width:20px;" type="text"/>	(sum of row should equal total no. of children)

Family history of IBD in 2nd degree relatives: Yes No Unknown

If family history of IBD, indicate family type:
 CD UC Mixed Unknown

Smoking History Prior to Diagnosis

Smoking at diagnosis: Yes Ex-smoker No Unknown (1 pack = 20 cigarettes)

If yes or ex-smoker: Year started: Year stopped: No. of cigarettes per day: Unknown

Completed by: _____ Date: / /



**NIDDK IBD Genetics Consortium
Unaffected Intake Phenotype Form**

Version 2.5
23-Jun-10

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Registration Information

Affix red Rutgers sample label here (repository subjects only)	Affix Fisher sample label here (repository subjects only)
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Consented for data sharing:

Initials: Gender: Male Female

Date of birth: / /

Local Sample ID: _____
 Local Pedigree ID: _____
 Local Individual ID: _____

Control checklist: No family history of IBD
 Never been diagnosed with IBD
 Never experienced chronic diarrhea, unexplained rectal bleeding, or unexplained weight loss

Relationship to proband: Parent Spouse/Domestic Partner Friend Population Control

If parent, Consortium ID of child: _____ - _____

If spouse, Consortium ID of affected spouse: _____ - _____

Consortium ID: _____ - _____

Demographic Information

Hispanic: Yes No Unknown
 Jewish: Yes No Unknown

Is grandparent Jewish? If Jewish, Ashkenazi?
 Yes No Unknown Yes No Unknown

Paternal grandfather:
 Paternal grandmother:
 Maternal grandfather:
 Maternal grandmother:

Race: White American Indian/Alaskan Native
 Black/African American Native Hawaiian/Pacific Islander
 Asian Unknown
 Other (specify: _____)

Birth order: 1st 2nd 3rd 4th
 5th 6th > 6th Unknown

If spouse/domestic partner, duration of cohabitation: Unknown

Smoking History

Smoking status: Current smoker Ex-smoker Non-smoker Unknown (1 pack = 20 cigarettes)

If current or ex-smoker: Year started: Year stopped: No. of cigarettes per day: Unknown

Surgery

Appendectomy: Yes No Unknown If yes, year: Unknown

Completed by: _____ Date: / /



**NIDDK IBD Genetics Consortium
Crohn's Disease Intake Phenotype Form**

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23-Jun-10

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Intake Assessment

Consortium ID: _____ - _____ Local Pedigree ID: _____
 Local Sample ID: _____ Local Individual ID: _____
 Date of diagnosis: / Unknown
 (month optional for non-inception cases) Latest clinical exam/encounter: / /

Macroscopic Disease Location (complete all items)

Upper GI: Esophagus: Yes No Unknown
 Stomach: Yes No Unknown
 Duodenum: Yes No Unknown
 Jejunum: Yes No Unknown
 Ileum: Proximal ileum: Yes No Unknown
 Distal ileum: Yes No Unknown
 Terminal ileum: Yes No Unknown
 Colorectal: Cecum: Yes No Unknown
 Colon: Yes No Unknown
 (not incl. cecum or rectum)
 Rectum: Yes No Unknown
 Perianal/Perineal: Yes No Unknown
 CD disease behavior: B1 B2 B3 Unknown

Surgery

Surgery for complication or treatment of CD: Yes No Unknown
 If yes: Small bowel resection: Yes No Unknown
 Large bowel resection: Yes No Unknown
 Strictureplasty: Yes No Unknown
 Diversion: Yes No Unknown
 Permanent stoma: Yes No Unknown
 Gastroenterostomy: Yes No Unknown
 Abdominal fistula/abscess: Yes No Unknown
 Perineal fistula/abscess: Yes No Unknown
 Surgery for dysplasia/cancer: Yes No Unknown
 Date of first operation: / Unknown
 (for treatment of IBD)
 Date of second operation: / Unknown
 (for treatment of IBD)
 No. of operations for abdominal disease: Unknown
 (i.e., resection, strictureplasty, abscess drainage)
 No. of operations for perineal disease: Unknown
 (including diversions)
 Diagnosis of dysplasia/cancer (colorectal): Yes No Unknown If yes, year: Unknown
 Appendectomy: Yes No Unknown If yes, year: Unknown

Pubertal Stage at Diagnosis (Pediatric Onset Cases Only)

Pediatric onset: Yes No
 If "No", skip to next section
 Height at diagnosis: inches cm Unknown
 Weight at diagnosis: lb kg Unknown
 Pubic hair development: 1 2 3 4 5 Unknown
 Genitalia (males only): 1 2 3 4 5 Unknown
 Breast development (females only): 1 2 3 4 5 Unknown
 (all items refer to pubertal stage at time of diagnosis)

FORM IS CONTINUED ON BACK



**NIDDK IBD Genetics Consortium
Crohn's Disease Intake Phenotype Form**

Disease Activity and Treatment (including Harvey-Bradshaw Index)

- Current disease activity: Normal/Remission
 Mild
 Moderate
 Severe
 Unknown
- Hospitalizations since diagnosis: 0
(for treatment of IBD) 1
 2 or more
 Unknown
- Physician global assessment of disease activity since diagnosis: Continuously quiescent
 Mild with remissions
 Mild but chronically active
 Moderate or severe exacerbations but remissions
 Chronically active moderate/severe disease
 Unknown
- (only if at least one year since diagnosis at intake)
- Less than 1 year since diagnosis

Treatments:	Used since diagnosis?			If yes:	Used within first month?			Used currently?		
	Yes	No	Unk		Yes	No	Unk	Yes	No	Unk
a. Aminosalicylates	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Oral corticosteroids	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. IV corticosteroids	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Antibiotics	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Immunomodulatory drugs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. MTX	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. Anti-TNF	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h. Other biological therapies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(specify: _____)										
i. Enteral nutrition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Note: Items below from Harvey-Bradshaw Index refer to subject's current/most recent condition at the time of ascertainment.

- Subject's general well-being: Very well
 Slightly below par
 Poor
 Very poor
 Terrible
 Unknown
- Abdominal pain: None
 Mild
 Moderate
 Severe
 Unknown
- No. of liquid stools per day: Unk
- Abdominal mass: None
 Dubious
 Definite
 Definite and tender
 Unknown
- Complications: Aphthous ulcers: Yes No Unknown
Anal fissure: Yes No Unknown
New fistula: Yes No Unknown
Abscess: Yes No Unknown
- (HBI complications arthralgia, uveitis, erythema nodosum and pyoderma gangrenosum recorded in Extra-Intestinal Manifestations section below)

Extra-Intestinal Manifestations

- Joints: Large joint related to disease activity: Yes No Unknown
Small joint unrelated to disease activity: Yes No Unknown
Ankylosing spondylitis: Yes No Unknown
Sacro-iliitis: Yes No Unknown
Non-specific joint inflammation: Yes No Unknown
- Eyes: Uveitis: Yes No Unknown
Episcleritis: Yes No Unknown
Undiagnosed ocular inflammation: Yes No Unknown
- Liver: Primary sclerosing cholangitis: Yes No Unknown
- Skin: Erythema nodosum: Yes No Unknown
Pyoderma: Yes No Unknown

Completed by: _____

Date: / /



NIDDK IBD Genetics Consortium
UC/IC Intake Phenotype Form

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23-Jun-10

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Intake Assessment

Consortium ID: _____ - _____ Local Pedigree ID: _____
Local Sample ID: _____ Local Individual ID: _____
Date of diagnosis: / Unknown Latest clinical exam/encounter: / /
(month optional for non-inception cases) Disease type: UC IC

Macroscopic Disease Location (complete all items)

Proctitis: Yes No Unknown Terminal ileum visualized: Yes No Unknown
Left-sided (to splenic flexure): Yes No Unknown If yes, biopsied: Yes No Unknown
Extensive (beyond splenic flexure): Yes No Unknown If biopsied: Normal
Pancolitis: Yes No Unknown Non-specific inflammation
Periappendiceal inflammation: Yes No Unknown Unknown

Surgery

Surgery for complication or treatment of UC/IC: Yes No Unknown Date of surgery (colectomy): / Unk
If yes: Surgery for dysplasia/cancer: Yes No Unknown
Surgery for chronic continuous disease: Yes No Unknown
Surgery for acute or fulminant disease: Yes No Unknown

Pouchitis: Yes No Unknown

Diagnosis of dysplasia/cancer (colorectal): Yes No Unknown If yes, year: Unknown

Appendectomy: Yes No Unknown If yes, year: Unknown

Pubertal Stage at Diagnosis (Pediatric Onset Cases Only)

Pediatric onset: Yes No Height at diagnosis: inches cm Unknown
If "No", skip to next section Weight at diagnosis: lb kg Unknown

Pubic hair development: 1 2 3 4 5 Unknown
Genitalia (males only): 1 2 3 4 5 Unknown (all items refer to pubertal stage at time of diagnosis)

Breast development (females only): 1 2 3 4 5 Unknown

FORM IS CONTINUED ON BACK



**NIDDK IBD Genetics Consortium
UC/IC Intake Phenotype Form**

Disease Activity and Treatment (including Partial Mayo Index)

- Current disease activity: Normal/Remission
 Mild
 Moderate
 Severe
 Unknown
- Hospitalizations since diagnosis: 0
 (for treatment of IBD) 1
 2 or more
 Unknown
- Physician global assessment of disease activity since diagnosis: Continuously quiescent
 Mild with remissions
 Mild but chronically active
 Moderate or severe exacerbations but remissions
 Chronically active moderate/severe disease
 Unknown
- (only if at least one year since diagnosis at intake)
 Less than 1 year since diagnosis

Treatments:	Used since diagnosis?			If yes:	Used within first month?			Used currently?		
	Yes	No	Unk		Yes	No	Unk	Yes	No	Unk
a. Aminosalicylates	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Oral corticosteroids	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. IV corticosteroids	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Antibiotics	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Immunomodulatory drugs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. MTX	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. Anti-TNF	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h. Other biological therapies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(specify: _____)										
i. Enteral nutrition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Note: Items below from Partial Mayo Index refer to subject's current/most recent condition at the time of ascertainment.

- Stool frequency: Normal
 1-2 stools/day more than normal
 3-4 stools/day more than normal
 > 4 stools/day more than normal
 Unknown
- Rectal bleeding: None
 Visible blood with stool less than half the time
 Visible blood with stool half the time or more
 Passing blood alone
 Unknown

Extra-Intestinal Manifestations

- Joints: Large joint related to disease activity: Yes No Unknown
 Small joint unrelated to disease activity: Yes No Unknown
 Ankylosing spondylitis: Yes No Unknown
 Sacro-iliitis: Yes No Unknown
 Non-specific joint inflammation: Yes No Unknown
- Eyes: Uveitis: Yes No Unknown
 Episcleritis: Yes No Unknown
 Undiagnosed ocular inflammation: Yes No Unknown
- Liver: Primary sclerosing cholangitis: Yes No Unknown
- Skin: Erythema nodosum: Yes No Unknown
 Pyoderma: Yes No Unknown

Completed by: _____

Date: / /



**NIDDK IBD Genetics Consortium
Disease Activity and Update Form (Crohn's Disease)**

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23-Jun-10

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Assessment Date

Consortium ID: _____ - _____

Local Pedigree ID: _____

Local Sample ID: _____

Local Individual ID: _____

Previous assessment:

M	M
---	---

 /

D	D
---	---

 /

Y	Y	Y	Y
---	---	---	---

(corresponds to "Latest clinical exam/encounter" from previous form)

Latest clinical exam/encounter:

M	M
---	---

 /

D	D
---	---

 /

Y	Y	Y	Y
---	---	---	---

 Disease type: Unchanged (CD) Changed to CD from UC/IC

Family History Update

Family history changed since last assessment: Yes No Unknown *(if "Yes," complete all items below)*

	CD	UC/IC	IBD affected (type unclear)	Unaffected	Unknown											
Father:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>											
Mother:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>											
No. siblings:	<table border="1" style="display: inline-table; border-collapse: collapse;"><tr><td> </td><td> </td></tr></table>			<table border="1" style="display: inline-table; border-collapse: collapse;"><tr><td> </td><td> </td></tr></table>			<table border="1" style="display: inline-table; border-collapse: collapse;"><tr><td> </td><td> </td></tr></table>			<table border="1" style="display: inline-table; border-collapse: collapse;"><tr><td> </td><td> </td></tr></table>			<table border="1" style="display: inline-table; border-collapse: collapse;"><tr><td> </td><td> </td></tr></table>			<i>(sum of row should equal total no. of siblings)</i>
No. children:	<table border="1" style="display: inline-table; border-collapse: collapse;"><tr><td> </td><td> </td></tr></table>			<table border="1" style="display: inline-table; border-collapse: collapse;"><tr><td> </td><td> </td></tr></table>			<table border="1" style="display: inline-table; border-collapse: collapse;"><tr><td> </td><td> </td></tr></table>			<table border="1" style="display: inline-table; border-collapse: collapse;"><tr><td> </td><td> </td></tr></table>			<table border="1" style="display: inline-table; border-collapse: collapse;"><tr><td> </td><td> </td></tr></table>			<i>(sum of row should equal total no. of children)</i>

Family history of IBD in 2nd degree relatives: Yes No Unknown If family history of IBD, indicate family type:
 CD Mixed Unknown

Current Smoking Status

Smoking status: Current smoker Ex-smoker Non-smoker Unknown *(1 pack = 20 cigarettes)*
If yes or ex-smoker: Year started:

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 Year stopped:

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 No. of cigarettes per day:

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 Unknown

Macroscopic Disease Location (complete all items)

Upper GI: Esophagus: <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown	Colorectal: Cecum: <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown
Stomach: <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown	Colon: <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown <i>(not incl. cecum or rectum)</i>
Duodenum: <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown	Rectum: <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown
Jejunum: <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown	Perianal/Perineal: <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown
Ileum: Proximal ileum: <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown	-----
Distal ileum: <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown	CD disease behavior: <input type="radio"/> B1 <input type="radio"/> B2 <input type="radio"/> B3 <input type="radio"/> Unknown
Terminal ileum: <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown	

Surgical History Update

Surgery for complication or treatment of CD since last assessment: Yes No Unknown Unknown

If yes: Small bowel resection: <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown	Date of first operation: <table border="1" style="display: inline-table; border-collapse: collapse;"><tr><td>M</td><td>M</td></tr></table> / <table border="1" style="display: inline-table; border-collapse: collapse;"><tr><td>Y</td><td>Y</td><td>Y</td><td>Y</td></tr></table> <input type="radio"/>	M	M	Y	Y	Y	Y
M	M						
Y	Y	Y	Y				
Large bowel resection: <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown	<i>(for treatment of IBD)</i>						
Strictureplasty: <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown	Date of second operation: <table border="1" style="display: inline-table; border-collapse: collapse;"><tr><td>M</td><td>M</td></tr></table> / <table border="1" style="display: inline-table; border-collapse: collapse;"><tr><td>Y</td><td>Y</td><td>Y</td><td>Y</td></tr></table> <input type="radio"/>	M	M	Y	Y	Y	Y
M	M						
Y	Y	Y	Y				
Diversion: <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown	<i>(for treatment of IBD)</i>						
Permanent stoma: <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown	No. of operations for abdominal disease: <table border="1" style="display: inline-table; border-collapse: collapse;"><tr><td> </td><td> </td></tr></table> <input type="radio"/>						
Gastroenterostomy: <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown	<i>(i.e., resection, strictureplasty, abscess drainage)</i>						
Abdominal fistula/abscess: <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown	No. of operations for perineal disease: <table border="1" style="display: inline-table; border-collapse: collapse;"><tr><td> </td><td> </td></tr></table> <input type="radio"/>						
Perineal fistula/abscess: <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown	<i>(including diversions)</i>						
Surgery for dysplasia/cancer: <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown							

Diagnosis of dysplasia/cancer (colorectal): Yes No Unknown If yes, year:

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 Unknown

Appendectomy: Yes No Unknown If yes, year:

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 Unknown

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**NIDDK IBD Genetics Consortium
Disease Activity and Update Form (UC/IC)**

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Intake Assessment

Consortium ID: _____ - _____

Local Pedigree ID: _____

Local Sample ID: _____

Local Individual ID: _____

Previous assessment:

M	M
---	---

 /

D	D
---	---

 /

Y	Y	Y	Y
---	---	---	---

(corresponds to "Latest clinical exam/encounter" from previous form)

Latest clinical exam/encounter:

M	M
---	---

 /

D	D
---	---

 /

Y	Y	Y	Y
---	---	---	---

 Disease type: Unchanged (UC) Changed to UC
 Unchanged (IC) Changed to IC

Family History Update

Family history changed since last assessment: Yes No Unknown *(if "Yes," complete all items below)*

	CD	UC/IC	IBD affected (type unclear)	Unaffected	Unknown											
Father:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>											
Mother:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>											
No. siblings:	<table border="1" style="display: inline-table; border-collapse: collapse;"><tr><td> </td><td> </td></tr></table>			<table border="1" style="display: inline-table; border-collapse: collapse;"><tr><td> </td><td> </td></tr></table>			<table border="1" style="display: inline-table; border-collapse: collapse;"><tr><td> </td><td> </td></tr></table>			<table border="1" style="display: inline-table; border-collapse: collapse;"><tr><td> </td><td> </td></tr></table>			<table border="1" style="display: inline-table; border-collapse: collapse;"><tr><td> </td><td> </td></tr></table>			<i>(sum of row should equal total no. of siblings)</i>
No. children:	<table border="1" style="display: inline-table; border-collapse: collapse;"><tr><td> </td><td> </td></tr></table>			<table border="1" style="display: inline-table; border-collapse: collapse;"><tr><td> </td><td> </td></tr></table>			<table border="1" style="display: inline-table; border-collapse: collapse;"><tr><td> </td><td> </td></tr></table>			<table border="1" style="display: inline-table; border-collapse: collapse;"><tr><td> </td><td> </td></tr></table>			<table border="1" style="display: inline-table; border-collapse: collapse;"><tr><td> </td><td> </td></tr></table>			<i>(sum of row should equal total no. of children)</i>

Family history of IBD in 2nd degree relatives: Yes No Unknown

If family history of IBD, indicate family type:
 UC Mixed Unknown

Current Smoking Status

Smoking status: Current smoker Ex-smoker Non-smoker Unknown *(1 pack = 20 cigarettes)*

If yes or ex-smoker: Year started:

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 Year stopped:

--	--	--	--

 No. of cigarettes per day:

--	--

 Unknown

Macroscopic Disease Location (complete all items)

Proctitis: <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown	Terminal ileum visualized: <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown
Left-sided (to splenic flexure): <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown	If yes, biopsied: <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown
Extensive (beyond splenic flexure): <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown	If biopsied: <input type="radio"/> Normal
Pancolitis: <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown	<input type="radio"/> Non-specific inflammation
Periappendiceal inflammation: <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown	<input type="radio"/> Unknown

Surgical History Update

Surgery for complication or treatment of UC/IC since last assessment: Yes No Unknown

If yes: Surgery for dysplasia/cancer: Yes No Unknown Date of surgery (colectomy):

M	M
---	---

 /

Y	Y	Y	Y
---	---	---	---

 Unknown
Surgery for chronic continuous disease: Yes No Unknown
Surgery for acute or fulminant disease: Yes No Unknown

Pouchitis: Yes No Unknown

Diagnosis of dysplasia/cancer (colorectal): Yes No Unknown If yes, year:

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 Unknown

Appendectomy: Yes No Unknown If yes, year:

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 Unknown

FORM IS CONTINUED ON BACK



**NIDDK IBD Genetics Consortium
Disease Activity and Update Form (UC/IC)**

Current Pubertal Stage (Pediatric Subjects Only)

Pediatric subject: Yes No
If "No", skip to next section

Pubic hair development: 1 2 3 4 5 Unknown

Genitalia (males only): 1 2 3 4 5 Unknown

Breast development (females only): 1 2 3 4 5 Unknown

Height: inches cm Unknown

Weight: lb kg Unknown

Disease Activity and Treatment Since Last Assessment (including Partial Mayo Index)

Hospitalizations since last assessment: 0 1 2 or more Unknown
(for treatment of IBD)

Physician global appraisal of disease activity since last assessment: Continuously quiescent Mild with remissions Mild but chronically active Moderate or severe exacerbations but remissions Chronically active moderate/severe disease Unknown

Current disease activity: Normal/Remission Mild Moderate Severe Unknown

Note: Items below from Partial Mayo Index refer to subject's current condition.

Stool frequency: <input type="radio"/> Normal <input type="radio"/> 1-2 stools/day more than normal <input type="radio"/> 3-4 stools/day more than normal <input type="radio"/> > 4 stools/day more than normal <input type="radio"/> Unknown	Treatments:	Used since last assessment?			If yes: Used currently?		
		Yes	No	Unk	Yes	No	Unk
Rectal bleeding: <input type="radio"/> None <input type="radio"/> Visible blood with stool less than half the time <input type="radio"/> Visible blood with stool half the time or more <input type="radio"/> Passing blood alone <input type="radio"/> Unknown	a. Aminosalicylates	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	b. Oral corticosteroids	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	c. IV corticosteroids	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	d. Antibiotics	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	e. Immunomodulatory drugs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	f. MTX	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	g. Anti-TNF	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	h. Other biological therapies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	(specify: _____)						
i. Enteral nutrition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	

Extra-Intestinal Manifestations

Joints: Large joint related to disease activity: <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown Small joint unrelated to disease activity: <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown Ankylosing spondylitis: <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown Sacro-iliitis: <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown Non-specific joint inflammation: <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown	Eyes: Uveitis: <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown Episcleritis: <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown Undiagnosed ocular inflammation: <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown
Skin: Erythema nodosum: <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown Pyoderma: <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown	Liver: Primary sclerosing cholangitis: <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown

Completed by: _____ Date: / /

