This form gathers core data on IBD patients. The clinical fields correspond to information clinicians typically refresh themselves on before seeing a patient in clinic – and once you have this info in your head it shouldn’t take too long to fill in this form. Some fields, such as family history, smoking status at diagnosis and peri-anal involvement are most quickly done by asking the patient (i.e. with the patient in front of you in clinic). You will be able to see all this summary info next time you meet the patient – hence repaying the time you spend helping us with this!

Patient demographics etc… are at the end of the form and hopefully can be filled in by non-clinical staff

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**Clinical Details:**

- **Is the patient NEWLY diagnosed with IBD**
  - □ Yes
  - □ No
  - □ N/K
  - *Is the patient willing to join the more detailed INCEPTION cohort for newly diagnosed patients?*

- **Current IBD Diagnosis:**
  - □ Crohn’s
  - □ UC
  - □ IBD – unspecified (IBDU)
  - □ Other _______________________________

- **Date /year of first IBD diagnosis:**
  - *(can add just year, if exact date not known)*
  - ___________

- **Level of certainty regarding diagnosis of IBD**
  - □ 1
  - □ 2
  - □ 3

- **Certainty of diagnosis CD vs UC vs IBDU**
  - □ 1
  - □ 2
  - □ 3

- **Has IBD diagnosis been confirmed by a hospital specialist?**
  - □ Yes
  - □ No
  - □ N/K

  **Diagnostic methods (indicate all relevant at the time of diagnosis or used subsequently):**
  - □ Endoscopy
  - □ Radiology
  - □ Histology
  - □ Surgery
  - □ Other________________________
  - □ N/K

---
Physician’s global assessment of current IBD inflammatory activity (i.e. on the day of BioResource blood sampling):
- □ Normal
- □ Mild
- □ Moderate
- □ Severe
- □ Unknown

Has the patient ever been admitted to hospital for an IBD flare?
- □ Yes
- □ No
- □ N/K

Have there been any changes in IBD diagnosis (e.g. UC to CD)?
- □ Yes
- □ No

Year of change in IBD diagnosis ____________

Enter change in IBD diagnosis:
- □ UC to CD
- □ IBDU – type unspecified to CD
- □ CD to UC
- □ IBDU – type unspecified to UC
- □ Other
CROHN’s

Macroscopic extent (select all that apply):

**NB** - a frequent mistake is to assume that a patient who has had a right hemicolectomy has had colonic involvement when in fact they just had ileal disease: please be sure about this!

**NB** a bit of ‘spill-over’ inflammation in the caecum does not make it colonic.

☐ Oesophago-gastric  ☐ Duodenal  ☐ Jejunal  ☐ Ileal  ☐ Colonic  ☐ Rectal

Ever had perianal involvement?:
(Often not easy to find in medical notes - you may find it easier to ask the patient!)

☐ Yes  ☐ No  ☐ N/K

What type of perianal lesion has the patient had? *(Select all that apply)*:

☐ Tags / fissures / ulcers
☐ Perianal abscess
☐ Simple fistula (single fistula, little clinical problem)
☐ Complex fistula (more than one or branching or recto-vaginal or major problem)
☐ Other ________________________________

Behaviour:

☐ B1 (inflammatory)  ☐ B2 (stenosing)  ☐ B3 *(internal penetrating*)

*If the only fistulae have been perianal this does not make it B3

If B3, Please specify the nature of the internal perforating / penetrating disease *(Select all that apply)*:

☐ Internal abscess (mesenteric, intra-abdominal, paracolic, pelvic etc)
☐ Entero-enteric or entero-colic fistula
☐ Entero-vesical or colo-vesical fistula
☐ Entero-cutaneous or colo-cutaneous fistula
☐ Other ________________________________

Has the patient had surgery for Crohn’s?

☐ Yes  ☐ No  ☐ N/K

Year  What op? *(Enter number(s) from list below)*  Which hospital?

Op1  ..........  ..........  ...................................................
Op2  ..........  ..........  ...................................................
Others  ..........  ..........  ...................................................

1. Colectomy and ileostomy 8. Partial colectomy
2. Colectomy and ileo-anal pouch 9. Proctectomy
3. Defunctioning ileostomy 10. Strictureplasty
4. Drainage of intra-abdominal abscess 11. Insertion of seton suture
5. Ileal / jejunal resection 12. Drainage of perianal abscess
6. Ileal / jejunal stricturoplasty 13. Perianal fistula repair
7. Ileo-caecal resection (Right hemicolectomy) 14. Other ________________________________

Does the patient currently have a stoma?

☐ Yes  ☐ No  ☐ N/K
## Ulcerative Colitis or IBD-Unclassified (Indeterminate Colitis)

### Maximum macroscopic extent ever:
- Rectum
- Recto-sigmoid
- < Splenic
- < Hepatic
- Total
- Unknown

### Maximum macroscopic extent at last assessment:
- Rectum
- Recto-sigmoid
- < Splenic
- < Hepatic
- Total
- Unknown

### Has the patient undergone surgical colectomy?
- Yes
- No
- N/K

  **Date** ________________

  **Indication for colectomy:**
  - Acute severe UC
  - Chronic continuous UC
  - Dysplasia
  - Colorectal Cancer
  - N/K

  **Does the patient still have a rectal stump in situ?**
  - Yes
  - No
  - N/K

### Has the patient undergone reconstructive surgery with an ileo-anal pouch?
- Yes
- No
- N/K

  **Is the pouch still in place?**
  - Yes
  - No
  - N/K
Extra intestinal manifestations and co-morbidities

For EACH please tick YES (Y) or No (N) – Do tick ‘no’ if patient has not been diagnosed with and has no symptoms of the listed conditions! If equivocal, please tick ‘not known’

**If No for all please tick here**: □ No for all

<table>
<thead>
<tr>
<th>Condition</th>
<th>Y</th>
<th>N</th>
<th>N/K</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary Sclerosing Cholangitis (incl PSC / AIH overlap, small duct PSC)</td>
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<tr>
<td>Enteropathic arthritis</td>
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<tr>
<td>Erythema Nodosum</td>
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<tr>
<td>Iritis / uveitis (confirmed by Ophthalmology)</td>
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<tr>
<td>Orofacial Granulomatosis (oral Crohn’s)</td>
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<tr>
<td>Psoriasis</td>
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<tr>
<td>Ankylosing Spondylitis</td>
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<tr>
<td>Multiple Sclerosis</td>
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<tr>
<td>Lymphoma</td>
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<td>Type of malignancy:</td>
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<td>Date of diagnosis:</td>
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<td>Other malignancy</td>
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<td>Type of malignancy:</td>
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<td>Date of diagnosis:</td>
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<tr>
<td>Serious infections</td>
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<tr>
<td>Infection type: (specify e.g. TB, pneumonia)</td>
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<tr>
<td>Date of diagnosis:</td>
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<tr>
<td>Other (extra-intestinal manifestations of IBD or other inflammatory/auto-immune diseases) (separate with a comma):</td>
<td></td>
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</tr>
</tbody>
</table>
### Treatment history – Please indicate which of these drugs the patient has taken

(Complete all that apply)

<table>
<thead>
<tr>
<th>Treatment for IBD</th>
<th>Year of starting</th>
<th>Currently on it? Y / N / NK</th>
<th>Year of stopping</th>
<th>Was the treatment effective?</th>
<th>Significant adverse events requiring Rx cessation or dose reduction? Y / N / NK</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>specify number(s) from chart below</td>
</tr>
<tr>
<td>(example)</td>
<td>2011</td>
<td>N</td>
<td>2011</td>
<td>2</td>
<td>Y – 13 (ALT=450), 16</td>
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<tr>
<td>Azathioprine</td>
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<tr>
<td>Mercaptopurine</td>
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<tr>
<td>Methotrexate</td>
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</tbody>
</table>

Has the patient ever been tried on low dose thiopurine and allopurinol  □Yes □No □N/K

(for example if developed side effects)

<table>
<thead>
<tr>
<th>Year of starting</th>
<th>Currently on it?</th>
<th>Year of stopping</th>
<th>Was the treatment effective?</th>
<th>Significant adverse events? Y / N / NK</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<td></td>
<td>specify number(s) from chart below</td>
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<tr>
<td>Ciclosporin</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Year of starting</th>
<th>Currently on it?</th>
<th>Year of stopping</th>
<th>Was the treatment effective?</th>
<th>Significant adverse events? Y / N / NK</th>
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<tr>
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<td></td>
<td>specify number(s) from list below</td>
</tr>
<tr>
<td>Infliximab</td>
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<tr>
<td>Adalimumab</td>
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<tr>
<td>Golimumab</td>
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<tr>
<td>Vedolizumab</td>
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<tr>
<td>Ustekinumab</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Year of starting</th>
<th>Currently on it?</th>
<th>Year of stopping</th>
<th>Was the treatment effective?</th>
<th>Significant adverse events? Y / N / NK</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<td>specify number(s) from list below</td>
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<tr>
<td>Mesalazine (5 ASA)</td>
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<tr>
<td>Adverse Event</td>
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<tr>
<td>3. Anaphylaxis or anaphylactoid</td>
<td>15. Interstitial nephritis</td>
<td>26. Psoriasis</td>
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<tr>
<td>reaction</td>
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<tr>
<td>5. Demyelination or other neurological</td>
<td>17. Leucopaenia</td>
<td>28. Rash</td>
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<tr>
<td>symptoms</td>
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<tr>
<td>a) Maximum ALT</td>
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<tr>
<td>b) Maximum ALP</td>
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<tr>
<td>c) Maximum bilirubin</td>
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<tr>
<td>8. Exacerbation of IBD symptoms</td>
<td>20. Nausea / vomiting</td>
<td>31. Thrombocytopenia</td>
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<td></td>
<td>a) Minimum white cell count</td>
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<td></td>
<td>b) Minimum neutrophil count</td>
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<tr>
<td>10. Flu-like symptoms</td>
<td>22. None</td>
<td>33. Not known</td>
<td></td>
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<tr>
<td>11. Hypertension</td>
<td>23. Osteopaenia</td>
<td>34. Information not available</td>
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<tr>
<td>12. Hypotension</td>
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</tbody>
</table>

Please use the numbers in this table to complete the significant adverse events column in the treatment history tables above.
Demographics *(Section to be completed by research staff)*

Smoking status at **DIAGNOSIS** *(please tick one option):*
- [ ] Never smoked
- [ ] Not known
- [ ] Smoking at diagnosis:
  - Roughly how many cigarettes was the patient smoking at the time of diagnosis?
    - [ ] Less than 5
    - [ ] 5+
    - [ ] Pipe only
    - [ ] N/K
- [ ] Had quit before diagnosis:
  - Roughly how long before diagnosis did patient quit smoking?
    - [ ] Less than 1 month
    - [ ] 1-6 months
    - [ ] More than 6 months
    - [ ] N/K

**CURRENT** smoking status:
- [ ] Not smoking
- [ ] Smoking
- [ ] Other
- [ ] Not known

Family history of IBD?
- [ ] Yes
- [ ] No
- [ ] N/K

Which relative? Which type of IBD? Relative name *(if participant willing to share)*?
- ……………………..  ………………………………  ……………………………………………………
- ……………………..  ………………………………  ……………………………………………………
- ……………………..  ………………………………  ……………………………………………………

**IBD BioResource number *(taken from barcode)*:**
*This section is vital*

IBD_________________
## Patient Contact details

Ideally, please ask the patient to complete the separate Data Collection Sheet. Accurate and up-to-date details are vitally important for the aims of the study.

<table>
<thead>
<tr>
<th>Gender</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>Title: (please circle)</td>
<td>Mr/Mrs/Ms/Miss/Dr/Prof/Mx</td>
<td></td>
</tr>
<tr>
<td>First Name:</td>
<td>Surname:</td>
<td></td>
</tr>
<tr>
<td>Address:</td>
<td></td>
<td></td>
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<tr>
<td>Postcode:</td>
<td></td>
<td></td>
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<tr>
<td>Phone Number – Home</td>
<td>Phone Number - Work</td>
<td></td>
</tr>
<tr>
<td>Phone Number – Mobile</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Email</strong> <strong>VERY important - electronic questionnaire will be via this email, unless you indicate on REDCap that a paper questionnaire has been given instead to the patient</strong>:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Preferred contact: (please circle)</td>
<td>Phone call</td>
<td>Phone text</td>
</tr>
<tr>
<td>NHS no.</td>
<td></td>
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</tr>
<tr>
<td>DOB:</td>
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</tr>
</tbody>
</table>

### Ethnicity

#### 2001 census ethnicity classification

**Tick one box only**

- **White**
  - A British
  - B Irish
  - C Any other white background

- **Black or Black British**
  - M Caribbean
  - N African
  - P Any other Black background

- **Mixed**
  - D White and Black Caribbean
  - E White and Black African
  - F White and Asian
  - G Any other mixed background

- **Other ethnic category**
  - R Chinese
  - S Any other ethnic category
  - Z Not stated

- **Asian or Asian British**
  - H Indian
  - J Pakistani
  - K Bangladeshi
  - L Any other Asian background
Alongside IBD BioResource there are two parallel projects with overlapping objectives – please identify which of these parallel projects the patient has signed consent for:

☐ PrediCCt  ☐ IBD Registry

Has the IBD BioResource consent been signed?
**This section is a vital field for NIHR accrual data**:

☐ Y  ☐ N

Date of consent: _______________

Which version of consent form has been used?:

☐ 1  ☐ 2  ☐ 2.1  ☐ 3  ☐ N/K

Date of most recent clinic review (i.e. when were data re clinical features last updated?): _______________

Please enter the patient’s UK IBD Genetics Consortium identifier number (if known): If entering multiple numbers, please separate with a comma in REDCap
__________________________

Has the patient withdrawn from the IBD BioResource study?

☐ Y  ☐ N  ☐ N/K

 Withdrawal status?

☐ Withdrawn with no participation

☐ Withdrawn with no participation and data removed

☐ Deceased

☐ Other

Date withdrawal requested: _______________

Date of actual withdrawal: _______________

Withdrawal form ID number: _______________

Withdrawn by: _______________

Other studies notified (IBD Registry, PrediCCt):

☐ Y  ☐ N  ☐ N/K