NIHR | BioResource

# IBD Health and Lifestyle Questionnaire

*This form will be scanned. Please answer ALL questions by using BLOCK CAPITALS in the spaces provided or crossing the box(es).*
*E.g.* A B 1 2 ☒ *Yes* ☐ *No*

Attach barcode

*Participant ID:* ☐☐☐☐☐☐☐☐

*(For recruiting staff use) Please write site name and code below, before providing participant with this questionnaire, thank you.*

Site code: ☐☐☐☐☐ Site name: ______

## 1. DEMOGRAPHICS - Details about you

NHS number ☐☐☐☐☐☐☐☐☐☐ Date of birth ☐☐ / ☐☐ / ☐☐☐☐

Height (metres / centimetres ☐.☐☐ OR feet / inches) ☐.☐☐ Weight (kilograms ☐☐☐.☐☐ OR stones / lbs) ☐☐.☐☐

Are you right or left handed? (Please cross ONE) ☐ Right ☐ Left ☐ Both ☐ Prefer not to say

Do you have a specific diet? (Please cross ONE) ☐ None ☐ Vegetarian ☐ Pescetarian ☐ Vegan ☐ Other

What was your **biological sex** at birth? ☐ Male ☐ Female ☐ Neutral ☐ Prefer not to say

What **gender** do you identify with? ☐ Male ☐ Female ☐ Neutral ☐ Prefer not to say

## 2. IBD SPECIFIC HEALTH QUESTIONS

What type of inflammatory bowel disease are you affected by? ☐ Crohn's disease ☐ IBD unclassified (IBDU) ☐ Ulcerative colitis

Approximate month and year of first symptoms ☐☐ / ☐☐☐☐

Approximate month and year of first diagnosis ☐☐ / ☐☐☐☐

Have you ever been admitted to hospital for treatment of Crohn's / Ulcerative colitis / IBDU? ☐ Yes ☐ No ☐ Don't know

Have you ever had perianal abscess or fistula? (an abscess next to your anus requiring antibiotics or surgery) ☐ Yes ☐ No ☐ Don't know

## 3. REGARDING YOUR PARTICIPATION IN FUTURE RESEARCH

Are you willing to provide blood samples? ☐ Yes ☐ No

Would you be willing to be invited to studies with life science industries? (e.g. pharmaceutical companies) ☐ Yes ☐ No

Are you willing to travel to your nearest clinical research facility? (travel costs will be reimbursed) ☐ Yes ☐ No

## 4. QUALITY OF LIFE - how you would describe your quality of life

How would you rate your overall quality of life?

☐ *Very poor* ☐ *Poor* ☐ *Neither good nor bad* ☐ *Good* ☐ *Very good*

How happy are you with your general health?

☐ *Very unhappy* ☐ *Unhappy* ☐ *Neither happy nor unhappy* ☐ *Happy* ☐ *Very happy*

Do you have enough energy for everyday life?

☐ *Not at all* ☐ *A little* ☐ *Moderately* ☐ *Mostly* ☐ *Completely*

Do you have the opportunity for leisure activities?

☐ *Not at all* ☐ *A little* ☐ *Moderately* ☐ *Mostly* ☐ *Completely*

Do you have enough money for day to day needs?

☐ *Not at all* ☐ *A little* ☐ *Moderately* ☐ *Mostly* ☐ *Completely*

What is your employment status?

☐ *Unemployed* ☐ *Student* ☐ *Retired* ☐ *Part time* ☐ *Full time*

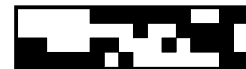
If you would like some help please contact https://www.samaritans.org/ Freephone 116 123

## 5. GENERAL HEALTH QUESTIONS - about you

*Have you been diagnosed with any of the following? If YES, complete additional columns for that condition.*

| CONDITIONS | *Year first diagnosed* | *Cross all that apply* | *Are you taking prescribed medication for this?* |
|---|---|---|---|
| ALLERGY ☐ Yes ☐ No | ☐☐☐☐ | Hay fever / pollen ☐ Yes ☐ No<br>Penicillin ☐ Yes ☐ No<br>Other drug allergy ☐ Yes ☐ No<br>Wheat ☐ Yes ☐ No<br>Nuts ☐ Yes ☐ No<br>Seeds ☐ Yes ☐ No<br>Other food stuffs ☐ Yes ☐ No<br>Other allergy ☐ Yes ☐ No | ☐ Yes ☐ No |
| ANKYLOSING SPONDYLITIS ☐ Yes ☐ No | ☐☐☐☐ | | ☐ Yes ☐ No |
| ARTHRITIS ☐ Yes ☐ No | ☐☐☐☐ | Rheumatoid ☐ Yes ☐ No<br>Osteo ☐ Yes ☐ No<br>Other ☐ Yes ☐ No | ☐ Yes ☐ No |
| ASTHMA ☐ Yes ☐ No | ☐☐☐☐ | | ☐ Yes ☐ No |
| BRAIN TUMOUR ☐ Yes ☐ No | ☐☐☐☐ | Non-cancerous ☐<br>Cancerous ☐ | ☐ Yes ☐ No |

| CONDITIONS | Year first diagnosed | Cross all that apply | Are you taking prescribed medication for this? |
|---|---|---|---|
| CANCER<br>☐ Yes ☐ No | ☐☐☐☐ | Breast ☐ Yes ☐ No<br>Bladder ☐ Yes ☐ No<br>Bowel ☐ Yes ☐ No<br>Rectal ☐ Yes ☐ No<br>Colon ☐ Yes ☐ No<br>Lung ☐ Yes ☐ No<br>Lymphoma ☐ Yes ☐ No<br>Melanoma ☐ Yes ☐ No<br>Skin ☐ Yes ☐ No<br>Ovarian ☐ Yes ☐ No<br>Cervical ☐ Yes ☐ No<br>Prostate ☐ Yes ☐ No<br>Other ☐ Yes ☐ No | ☐ Yes ☐ No |
| CARDIOVASCULAR DISEASE (HEART)<br>☐ Yes ☐ No | ☐☐☐☐ | Heart attack ☐ Yes ☐ No<br>Heart failure ☐ Yes ☐ No<br>Coronary artery disease i.e. angina ☐ Yes ☐ No<br>Atrial fibrillation ☐ Yes ☐ No<br>Vasculitis ☐ Yes ☐ No<br>Other ☐ Yes ☐ No | ☐ Yes ☐ No |
| COPD<br>☐ Yes ☐ No | ☐☐☐☐ | Chronic bronchitis ☐<br>Emphysema ☐ | ☐ Yes ☐ No |
| COELIAC DISEASE<br>☐ Yes ☐ No | ☐☐☐☐ | | ☐ Yes ☐ No |
| DIABETES<br>☐ Yes ☐ No | ☐☐☐☐ | ☐ Type 1<br>☐ Type 2<br>☐ Both<br>☐ Don't know<br>**Taking insulin?** ☐ Yes ☐ No | ☐ Yes ☐ No |
| EPILEPSY<br>☐ Yes ☐ No | ☐☐☐☐ | | ☐ Yes ☐ No |
| ECZEMA<br>☐ Yes ☐ No | ☐☐☐☐ | | ☐ Yes ☐ No |
| GLAUCOMA<br>☐ Yes ☐ No | ☐☐☐☐ | | ☐ Yes ☐ No |
| HIGH BLOOD PRESSURE<br>☐ Yes ☐ No | ☐☐☐☐ | | ☐ Yes ☐ No |
| HIGH CHOLESTEROL<br>☐ Yes ☐ No | ☐☐☐☐ | | ☐ Yes ☐ No |
| MULTIPLE SCLEROSIS<br>☐ Yes ☐ No | ☐☐☐☐ | | ☐ Yes ☐ No |
| MUSCULOSKELETAL DISORDERS<br>☐ Yes ☐ No | ☐☐☐☐ | Lupus ☐ Yes ☐ No<br>Other ☐ Yes ☐ No | ☐ Yes ☐ No |
| PARKINSON'S DISEASE<br>☐ Yes ☐ No | ☐☐☐☐ | | ☐ Yes ☐ No |
| PSORIASIS<br>☐ Yes ☐ No | ☐☐☐☐ | | ☐ Yes ☐ No |




| CONDITIONS | *Year first diagnosed* | *Cross all that apply* | *Are you taking prescribed medication for this?* |
|---|---|---|---|
| STROKE ☐ Yes ☐ No | | Ischaemic (blood clot) ☐ Yes ☐ No<br>Haemorrhagic (burst vessel) ☐ Yes ☐ No<br>TIA (transient ischaemic attack) ☐ Yes ☐ No | ☐ Yes ☐ No |
| THYROID DISEASE ☐ Yes ☐ No | | | ☐ Yes ☐ No |
| VITILIGO ☐ Yes ☐ No | | | ☐ Yes ☐ No |

| PSYCHOLOGICAL CONDITIONS | | Are you taking prescribed medication for this? |
|---|---|---|
| Agoraphobia | ☐ Yes ☐ No | ☐ Yes ☐ No |
| Anorexia nervosa | ☐ Yes ☐ No | ☐ Yes ☐ No |
| Attention deficit or attention deficit and hyperactivity disorder (ADD/ADHD) | ☐ Yes ☐ No | ☐ Yes ☐ No |
| Autism spectrum disorder | ☐ Yes ☐ No | ☐ Yes ☐ No |
| Bulimia nervosa | ☐ Yes ☐ No | ☐ Yes ☐ No |
| Depression - that needs treatment | ☐ Yes ☐ No | ☐ Yes ☐ No |
| Depression - related to pregnancy | ☐ Yes ☐ No | ☐ Yes ☐ No |
| Mania / hypomania / bipolar / manic depression | ☐ Yes ☐ No | ☐ Yes ☐ No |
| Obsessive compulsive disorder (OCD) | ☐ Yes ☐ No | ☐ Yes ☐ No |
| Panic attacks | ☐ Yes ☐ No | ☐ Yes ☐ No |
| Personality disorder | ☐ Yes ☐ No | ☐ Yes ☐ No |
| Psychological over eating or binge eating | ☐ Yes ☐ No | ☐ Yes ☐ No |
| Psychosis/other psychotic illness | ☐ Yes ☐ No | ☐ Yes ☐ No |
| Schizophrenia | ☐ Yes ☐ No | ☐ Yes ☐ No |
| Social anxiety / social phobia / other related conditions | ☐ Yes ☐ No | ☐ Yes ☐ No |

Do you suffer from any clinically diagnosed chronic medical condition? ☐ Yes ☐ No

Do you take any long term prescription medication? ☐ Yes ☐ No

Do you take long term medication in any of the following categories :

| | | | |
|---|---|---|---|
| Non-steroidal anti-inflammatory drugs | ☐ Yes ☐ No | Hormone replacement therapy | ☐ Yes ☐ No |
| Steroids | ☐ Yes ☐ No | Thyroid hormones | ☐ Yes ☐ No |
| Immunosuppressants | ☐ Yes ☐ No | Contraceptive pill | ☐ Yes ☐ No |
| | | Bronchodilators | ☐ Yes ☐ No |

## 6. METAL IMPLANTS

Have you got any metal implants (excluding normal dental fillings) or had an injury which left you with metal fragments in your body?

(e.g. pacemakers, aneurysm clips, cochlear implants, shrapnel)

☐ Yes ☐ No

## 7. ALCOHOL

Do you drink alcohol? ☐ Yes ☐ No ☐ Prefer not to say

If yes, how many units per week (approx)? ☐ 0-5 ☐ 6-15 ☐ 16-25 ☐ >25

**Drinks and units:** Guide to how many units are in common drinks

| Pint : beer/cider/lager (lower strength) | 2 units | Single small shot of spirits | 1 unit |
|---|---|---|---|
| Pint : beer/cider/lager (higher strength) | 3 units | 750ml bottle of wine | 10 units |

## 8. SMOKING

Do you smoke? ☐ Yes ☐ No ☐ Prefer not to say

*if Yes*

How many cigarettes per day?

☐ 1-10 ☐ 11-30 ☐ >30 ☐ Prefer not to say

How many years have you been smoking? ☐☐

*IBD-SPECIFIC*

What was your smoking status at the time of IBD diagnosis?

☐ Smoker ☐ Had quit smoking ☐ Had never smoked

*if No*

Did you smoke in the past?

☐ Yes ☐ No ☐ Prefer not to say

How many cigarettes per day?

☐ 1-10 ☐ 11-30 ☐ >30 ☐ Prefer not to say

How many years did you smoke? ☐☐

What year did you give up? (yyyy) ☐☐☐☐

## 9. IBD SPECIFIC MEDICATION

Please tell us if you are currently on any medication listed below:

| Medication | | | |
|---|---|---|---|
| Azathioprine | ☐ Yes | ☐ No | ☐ Don't know |
| Mercaptopurine (6-MP) | ☐ Yes | ☐ No | ☐ Don't know |
| Methotrexate | ☐ Yes | ☐ No | ☐ Don't know |
| Ciclosporin | ☐ Yes | ☐ No | ☐ Don't know |
| Infliximab (e.g. Remicade, Inflectra, Remsima) - hospital infusions/home injections | ☐ Yes | ☐ No | ☐ Don't know |
| Adalimumab (e.g. Humira, Imraldi, Amjevita) - home injection | ☐ Yes | ☐ No | ☐ Don't know |
| Vedolizumab (Entyvio) - hospital infusions/home injections | ☐ Yes | ☐ No | ☐ Don't know |
| Mesalazine - rectal | ☐ Yes | ☐ No | ☐ Don't know |
| Mesalazine - oral | ☐ Yes | ☐ No | ☐ Don't know |
| Sulfasalazine (Salazopyrin) | ☐ Yes | ☐ No | ☐ Don't know |
| Steroids - oral (prednisolone or budesonide e.g. Entocort, Budenofalk, Cortiment) | ☐ Yes | ☐ No | ☐ Don't know |
| Steroids - rectal | ☐ Yes | ☐ No | ☐ Don't know |
| Tioguanine | ☐ Yes | ☐ No | ☐ Don't know |
| Allopurinol | ☐ Yes | ☐ No | ☐ Don't know |
| Tacrolimus | ☐ Yes | ☐ No | ☐ Don't know |
| Ustekinumab (Stelara) - hospital infusions/home injections | ☐ Yes | ☐ No | ☐ Don't know |
| Tofacitinib | ☐ Yes | ☐ No | ☐ Don't know |

## 10. FAMILY HISTORY

Are you aware of any close members of your family who have the same or similar conditions as you? ☐ Yes ☐ No *if yes, please complete section 11 & 12*

## 11. FAMILY - Please include all blood relatives both living and deceased - but not adopted relatives, step children etc.

How many children do you have? ☐☐ Son(s) ☐☐ Daughter(s)

How many brothers and sisters do you have?

☐☐ Brother(s) ☐☐ Sister(s) ☐☐ Half-brother(s) ☐☐ Half-sister(s)

Do you have a twin brother or sister? ☐ Yes ☐ No - *if no, continue to 12.*

If yes, is your twin? ☐ Identical ☐ Non-identical ☐ Not known

Does your twin have IBD? ☐ Yes ☐ No ☐ Unknown

## 12. FAMILY HISTORY OF INFLAMMATORY BOWEL DISEASE

How many people do you currently live with who **do not** have Crohn's or Ulcerative colitis or IBDU?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4+ ☐ Unknown

How many unaffected brothers and sisters do you have? (who **do not** have Crohn's or Ulcerative colitis or IBDU)

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4+ ☐ Unknown

Have any of your first/second degree blood relatives (*parents, brothers, sisters, children, uncles, aunts, cousins, grandparents*) ever been diagnosed with:

| | | | |
|---|---|---|---|
| Crohn's | ☐ Yes - *specify below* | ☐ No | ☐ Don't know |
| Ulcerative colitis | ☐ Yes - *specify below* | ☐ No | ☐ Don't know |
| IBDU | ☐ Yes - *specify below* | ☐ No | ☐ Don't know |

| | | | | |
|---|---|---|---|---|
| Mother | ☐ Crohn's | ☐ Ulcerative colitis | ☐ IBDU | At age: ☐☐ yrs |
| Father | ☐ Crohn's | ☐ Ulcerative colitis | ☐ IBDU | At age: ☐☐ yrs |
| Brother 1 | ☐ Crohn's | ☐ Ulcerative colitis | ☐ IBDU | At age: ☐☐ yrs |
| Brother 2 | ☐ Crohn's | ☐ Ulcerative colitis | ☐ IBDU | At age: ☐☐ yrs |
| Sister 1 | ☐ Crohn's | ☐ Ulcerative colitis | ☐ IBDU | At age: ☐☐ yrs |
| Sister 2 | ☐ Crohn's | ☐ Ulcerative colitis | ☐ IBDU | At age: ☐☐ yrs |
| Child 1 | ☐ Crohn's | ☐ Ulcerative colitis | ☐ IBDU | At age: ☐☐ yrs |
| Child 2 | ☐ Crohn's | ☐ Ulcerative colitis | ☐ IBDU | At age: ☐☐ yrs |
| Cousin | ☐ Crohn's | ☐ Ulcerative colitis | ☐ IBDU | At age: ☐☐ yrs |
| Grandparent | ☐ Crohn's | ☐ Ulcerative colitis | ☐ IBDU | At age: ☐☐ yrs |
| Uncle | ☐ Crohn's | ☐ Ulcerative colitis | ☐ IBDU | At age: ☐☐ yrs |
| Aunt | ☐ Crohn's | ☐ Ulcerative colitis | ☐ IBDU | At age: ☐☐ yrs |

**Thank you very much for taking the time to complete this questionnaire.**

If you have any queries please contact the IBD/NIHR BioResource team:

Email: ibd@bioresource.nihr.ac.uk

Freephone: 0800 090 22 77 (office hours only Monday – Friday)

Address: IBD BioResource Box 299, University of Cambridge and Cambridge University Hospitals NHS Foundation Trust, Cambridge Biomedical Campus, Hills Road, Cambridge CB2 0QQ - UK