NIHR | BioResource

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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*

IBD Health and Lifestyle Questionnaire

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 is your **gender** identity? ☐ Male ☐ Female ☐ Non-binary ☐ Prefer not to say

What was your **sex** assigned at birth? ☐ Male ☐ Female ☐ 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 Penicillin ☐ Yes ☐ No Other drug allergy ☐ Yes ☐ No Wheat ☐ Yes ☐ No Nuts ☐ Yes ☐ No Seeds ☐ Yes ☐ No Other food stuffs ☐ Yes ☐ No Other allergy ☐ Yes ☐ No	☐ Yes ☐ No
ANKYLOSING SPONDYLITIS ☐ Yes ☐ No	☐☐☐☐		☐ Yes ☐ No
ARTHRITIS ☐ Yes ☐ No	☐☐☐☐	Rheumatoid ☐ Yes ☐ No Osteo ☐ Yes ☐ No Other ☐ Yes ☐ No	☐ Yes ☐ No
ASTHMA ☐ Yes ☐ No	☐☐☐☐		☐ Yes ☐ No
BRAIN TUMOUR ☐ Yes ☐ No	☐☐☐☐	Non-cancerous ☐ Cancerous ☐	☐ Yes ☐ No

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

Steroids ☐ Yes ☐ No

Immunosuppressants ☐ Yes ☐ No

Hormone replacement therapy ☐ Yes ☐ No

Thyroid hormones ☐ 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? ☐ Yes ☐ No

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

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:

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