

[Trust Logo]

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**IBD BioResource, part of the NIHR BioResource**

Version 5, 22/01/19

**PATIENT CONSENT FORM**

If you agree to take part in the IBD BioResource please:

- initial boxes 1, 2, 3 & 4
- initial your choices for reporting of genetic results feedback
- print, date and sign your name at the end of this form

**1. TAKING PART**

I confirm that I have read and understood the information sheet version \_ dated \_\_\_/\_\_\_/\_\_\_ for the IBD BioResource, and have had the opportunity to ask questions.

**I understand the following:**

- **The IBD BioResource is part of the NIHR BioResource**  
Specifically that by joining the IBD BioResource I am also joining the NIHR BioResource
- **I can decide to join the IBD BioResource or not.**  
My routine healthcare will not be affected in any way if I don't take part.
- **If I join, I can withdraw at any time**  
If I withdraw, I understand that some research may have already taken place using my data, and this can't be undone

**I agree to the following:**

- I agree to join the IBD BioResource
- I can be contacted by the BioResource to ask me to:
  - complete a health & lifestyle questionnaire and provide more information in the future (for .e.g. medication)
  - invite me to participate in other studies (which may be IBD or non-IBD related), including donating further samples
  - send me newsletters

Initial here to show you agree.	
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## 2. SAMPLES

I agree to:

- give blood samples for research
- use of samples already collected as part of my medical care
- my samples being tested as outlined in the patient information sheet, and this may include the reading of my entire genetic code.
- long-term anonymised storage of my samples (including cells and DNA) for research, with storage to continue in the event of my incapacity or death
- that these samples are a gift to the IBD BioResource and NIHR BioResource
- that anonymised samples may be used in future research without my further permission

Initial here to show you agree.

## 3. DATA

I agree that:

- the BioResource may access my medical and health related records, analyse and store this information long-term, even in the event of my incapacity or death
- data produced by studying my samples may be included in publications and/or placed in electronic archives (with no connection to my name or other personal identifiers).
- my personal details (name, date of birth and NHS number) and contact details (address, email, phone number etc.) can be stored on a secure database so that I can be contacted by the BioResource

I understand that:

- I may be invited to participate in other studies based on data held or accessed about me, and/or analysis (including of DNA markers) of samples I have donated
- this research may include work conducted by commercial companies, and that I will not benefit financially if this research leads to new medical tests, treatments or inventions.

Initial here to show you agree.

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**4. RESULTS**

- IBD BioResource will not routinely feedback my personal genetic or biochemical results to me
- I realise that clinicians will be surveyed to find out whether genetic information might prove useful to inform decisions regarding choice of treatment.
- In addition, the IBD team gives you the option for feedback in the rare event that you were found to have an increased risk of a genetic disease, which might be relevant for your future health (see results feedback options below). This is outlined at <https://www.genomicsengland.co.uk/information-for-participants/findings/> in the section “Additional or Secondary findings”

Initial here to show that you understand	
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**INCREASED RISK OF GENETIC DISEASE RESULTS FEEDBACK OPTION**

**Please put your INITIALS in ONE box only.**

I would like to be informed if I am at increased risk of rare genetic disease and <b>do want</b> this information fed back to my doctor by the IBD team	
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**OR**

I <b>do not</b> want information on genetic disease risk to be fed back to me or my doctor and I only want my sample to be used for research.	
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Name of Participant (BLOCK CAPITALS)      Date      Signature

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Name of Person taking consent (CAPITALS)      Date      Signature