



IBD BioResource, part of the NIHR BioResource

Version 4, 03/10/17

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
 - 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.

2. SAMPLES

I agree to:

- give blood samples for research
- 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.	
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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 any genetic or biochemical results, as your samples are taken for research purposes
- The IBD team gives you the option for feed back 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 (option below)

Initial here to show that you understand	
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GENETIC 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 **do want** this information fed back to my doctor by the IBD team

OR

- I would like my sample only to be used for research and **do not want** information about rare genetic diseases to be fed back to me or my doctor.

Name of Participant (BLOCK CAPITALS)

Date

Signature

Name of Person taking consent (CAPITALS)

Date

Signature