

# PATIENT CONSENT FORM



Whole genome sequencing study of young  
colon cancer patients and their parents

Please initial  
boxes

1. I confirm that I have read and understand the information sheet (version 3.0, 7 March 2017) for the study. I have had the opportunity to consider the information and ask questions.
2. I understand that taking part is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
3. I give the University of Edinburgh research team permission for relevant study specific medical information to be gathered from my medical records and any NHS electronic medical records for the duration of the study. I understand that a limited amount of personal identifiable data will be transferred to the coordinating centre in Edinburgh.
4. I give permission for the General Register Office to give the research team any medically relevant information they may hold about me.
5. I understand that relevant sections of my medical notes and data collected during the study will be looked at by the study researchers and individuals from the Sponsor (The University of Edinburgh), regulatory authorities or from the NHS organisation or other authorities where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
6. I understand that the blood or saliva sample and archived tissue sample that I provide will be used to obtain my genetic material (DNA) and that these will be used for genetic studies including next generation sequencing (NGS) of the whole genome and blood biomarkers. I agree to discuss the risks and benefits of participation with each of my parents and understand that they also have to provide consent and a blood or saliva sample.
7. I understand that we do not expect these to give individually useful clinical information. However, if new or previously unknown genetic conditions be identified during the course of this research which may have implications for me or my family, I give permission for these findings to be reported to my healthcare provider who will notify me directly of the results.
8. I understand that my research samples will be stored and will be used in research studies now and in the future. These studies will be carried out by Researchers in the University of Edinburgh, but also potentially with collaborators within, and outwith, the UK. However, all my personal, medical and genetic information will be used in an anonymised form and access will be strictly controlled. This work may be undertaken by commercial or pharmaceutical companies or other industry partners in the development of treatments and for use in in prediction of cancer in order to prevent the disease.
9. I understand that I will not benefit financially if this research leads to the development of a new treatment or medical test.

**If the research reveals results in the future that may have significant relevance to my medical condition, or that of my family:**

- a). I would like the research team to attempt to contact me. (Please circle, which applies) YES NO
- b). If yes, I agree to give details of my next of kin and a blood relative to be contacted if I cannot be reached at the address I have given. (If you agree, the researcher will ask you for their details) YES NO

.....  
NAME OF PATIENT (please print)

SIGNATURE

DATE

.....  
NAME OF PERSON TAKING CONSENT

SIGNATURE

DATE

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## Chief Investigator

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Professor of Coloproctology, University of Edinburgh.

## Contact details for research team

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Or, if you wish to speak to someone not involved in the study, or have a complaint to make, you could contact:

**Dr David FitzPatrick**

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## Explanation of consent procedure

After you have had time to read the information sheet (version 2.0, 8 June 2016) and discussed the study with a member of our research team and your parents, and considered whether you might wish to take, we would be grateful if you would complete this consent form.

All individual data and biological samples will be anonymised and confidential.

## Thank you for agreeing to take part in this research.

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& MOLECULAR MEDICINE

