

# RELATIVE CONSENT FORM

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

- Please initial boxes
1. I have read this consent form and information sheet (Version 2, 07 March 2017) and have had the opportunity to ask questions about them.
  2. I understand that taking part is voluntary and that a decision not to take part will not alter treatment that I would normally receive, now or in the future.
  3. I understand that information collected about me will be kept confidential by the research team.
  4. 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 my family and understand that they also have to provide consent and a blood or saliva sample.
  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 give permission for the General Records Office for Scotland to give the research team any medical information they may hold about me should this be required.
  7. I agree that the sample I give and the information gathered about me can be stored by the research team at the University of Edinburgh for possible uses in future research. I understand some of these projects may be carried out by other medical research groups including researchers working for commercial or pharmaceutical companies, including other industry partners, in the development of treatments and for use in the prediction of cancer in order to prevent disease.
  8. I understand that new or previously unknown genetic conditions may be identified during the course of this research which may have implications for me and my family. I give permission for these findings to be reported to my healthcare provider who will notify me directly of the results.
  9. I understand that my General Practitioner will be notified about my participation in the study.
  10. I understand that I am free to withdraw from the study at any time without giving a reason.
  11. I understand that the results of this study are expected to have no direct medical benefit to me but rather will help in the overall understanding of the causes of bowel cancer.
  12. 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 some significant relevance to my health:**

- 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. YES NO

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NAME OF RELATIVE (please print)	SIGNATURE	DATE	DATE OF BIRTH
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NAME OF RESEARCHER	SIGNATURE	DATE
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Whole genome sequencing study of young  
colon cancer patients and their parents



## Chief Investigator

EDINBURGH

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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**

Senior Clinical Scientist

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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 family, and considered whether you might wish to take part, we would be grateful if you would complete this consent form.

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

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

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& MOLECULAR MEDICINE

