

PARENTAL CONSENT FORM CHILDREN/ ADOLESCENTS



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

- Please initial
boxes
1. We confirm that we have read and fully understand the information sheet (version 3.0, 7 March 2017) for the above study. We have had the opportunity to consider the information and ask questions.
 2. We understand that our child's participation is voluntary and that we are free to withdraw them from the study at any time without giving any reason and without their medical care or legal rights being affected.
 3. We give the University of Edinburgh research team permission for relevant medical information to be gathered from their medical records and any NHS electronic medical records during the course of the study.
 4. We give permission for the General Register Office to give the research team any medically relevant information they may hold about them.
 5. We understand that relevant sections of their medical notes and data collected during the study may be looked at by individuals from the Sponsor (The University of Edinburgh), from the NHS organisation or other authorities, where it is relevant to them taking part in this research. We give permission for these individuals to have access to their records.
 6. We understand that the blood or saliva sample and any archived tissue sample will be used to obtain genetic material (DNA) and that these will be used for genetic studies including next generation sequencing (NGS) of the whole genome and blood biomarkers.
 7. We understand that a blood or saliva sample will also be required from us as parents.
 8. We understand 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 the research which may have implications for our family, we give permission for these findings to be reported to the healthcare team who will notify us of the results.
 9. We understand that their 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 their 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, pharmaceutical or other industry partners in the development of treatments and for use in in prediction of cancer in order to prevent the disease.
 10. We understand that our child will not benefit financially if this research leads to the development of a new treatment or medical test.
 11. We agree that our child understands the study outlined in the Patient Information Sheet (v3, 7 March 2017) and give both our consents on their behalf for their participation.

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

- a). We would like the research team to attempt to contact us. (Please circle, which applies) YES NO

.....
NAME OF PARENT (please print)

SIGNATURE

DATE

.....
NAME OF PARENT (please print)

SIGNATURE

DATE

.....
NAME OF PERSON TAKING CONSENT (please print)

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

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MRC Institute of Genetics & Molecular Medicine
The University of Edinburgh
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Explanation of consent procedure

After you have had time to read the information sheet (Version 2.0, 8 June 2016), discuss the study with the member of our research team and consider whether you might wish to take part in the study, we would be grateful if you would complete this consent form.

All individual results will be confidential and will only be made available to the research team. All samples will be coded to remove any identifying information.

Thank you for agreeing to take part in this research.

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