

Supplemental material

Appendix 2: Parent Consent form

Parent Participation Consent Form (Parent providing consent for their own participation)

Declaration by the Participant

The study

I have read or had read to me in a language that I understand, the Participant Information Sheet. I understand its contents.

I understand the purposes, procedures and possible risks of my involvement in this study.

If my child has joined the research study, I understand that:

- I will also be asked to provide a blood sample from which my DNA will be collected.
- The genetic test may find a gene fault linked to a cancer predisposition syndrome (CPS) in me. The results of this test will be given to me by my child's treating doctor.
- If I am found to have a CPS it may mean I have an increased chance of cancer. This may have implications for my future.
- As we are looking at both my child's and my DNA, there is a small chance that the test could identify family relationships that are different from expected. These results will not be reported to my child's doctor or to me.
- There is a small chance that the test could unexpectedly identify other genetic information. This may be about a condition that I have now or may develop in the future (incidental findings). My DNA may be tested for genes which may be linked to cancer but at this stage we still don't know. These research results will not be reported to me.

I understand that:

- I am consenting to provide a blood sample from which my DNA will be collected, for the purposes of this study.
- I am free to withdraw my consent at any time by completing the Withdrawal Form during the study. I know this will not affect my child's current or future care.
- The genetic test results may have implications for the health/genetic risks of my blood relatives, now or in the future.
- My information will be available to health professionals involved in my child's care.
- Results are confidential and may be released to others only with my consent, or as required by law.
- My personal and health information may be held by the study for a period of up to 15 years from the publication of the study's final report. After this period of time, this information will be securely destroyed.

I understand I will receive a copy of the Participant Information Sheet and Consent Form.

Consent to take part

I do consent I do not consent

Optional consent

I do I do not consent to the disclosure of cancer-related gene faults and relevant incidental findings found in the study to my child's treating doctor and to me.

I do I do not consent to the storage and use of my sample and genetic data for future ethically and scientifically approved research, provided that I cannot be identified.

Name of Participant (please print)	_____	
Signature of Participant	_____	Date _____
Signature of Interpreter (if applicable)	_____	Date _____

Declaration by Study Doctor/Senior Researcher†

I have given a verbal explanation of the research project, its procedures and risks and I believe that the parent/guardian has understood that explanation.

Name of Study Doctor/ Senior Researcher† (please print)	_____	
Signature	_____	Date _____

† A senior member of the research team must provide the explanation of, and information concerning, the research project.

Note: All parties signing the consent section must date their own signature