Consent form for parents/guardians participating in research studies.

Title of the project:

Name of PI:

**Please initial**

**YES NO**

I confirm I have read and understood the information sheet dated XXX XXXX Version X. I have had the opportunity to consider the information and all my questions have been answered satisfactorily.

I understand that my participation is voluntary and we can withdraw at anytime without giving a reason, and without mine or my child’s medical treatment and legal rights being affected. If I was to withdraw I understand some research may have already taken place with my samples and data and this can’t be undone.

I agree to provide the following samples (***Add or remove as needed***):

Blood Synovial fluid Urine Stool Saliva

I understand that the collected samples, will be used for (Insert type of testing here) and this may occur at multiple sites.

I agree to my anonymised data and samples being shared with researcher at other universities and hospitals where appropriate. This may be within the UK or international.

I agree to my anonymised data and sample being shared with commercial collaborators where appropriate.

I agree at the end of this study for my samples to be stored in xxxx biobank for future analysis in ethically approved research.

I agree to be contacted in follow up to this study or about other studies.

I agree to take part in this study

Name of Participant

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SIGNED (Participant) PRINT NAME DATE

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*One copy for participant; one copy for R&D section in the Medical Notes; original to be kept in the PI’s site file*

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***Other items to consider including if relevant to your research study:***

I authorize the collection of information (data) from my medical notes for the purpose of the research study. I understand that this may involve personal data and sections of my medical notes being looked at by responsible people from the research team, or from regulatory authorities, where relevant to my participation in this research. I give permission for these individuals access to my records.

I agree to my GP to be informed of my participation in the study

I agree that the genetic information produced may be placed in a **permanent** electronic data archive indefinitely with no connection to my name or other personal identifier. **Once published** **this data cannot be erased.** My identity cannot be directly connected to the genetic information produced by these studies by anyone apart from the doctors and nurses in the study.

***In regards to return of findings:***

***If results are not going to be returned:***

I understand that the genetic techniques used are NOT suitable for diagnostic testing for known genetic defects, and that I will NOT be told about any genetic alterations in my samples which are identified as a by-product of this research. This will not affect my access to clinically approved genetic advice and genetic testing through other doctors caring for me in any way.

***If results can be returned:***

I would like to be informed of the results of any positive research findings.

If yes, I would like to receive any results in an aggregate format (for example, 3 out of 20 people assessed were found to have interesting results) If yes, I would like to receive results specific to me.

***If there is the option for additional findings:***

I agree to having additional findings that are not connected to this research looked for from the samples I give and would like them given to my clinical team. I understand I can change my mind at any time about receiving additional findings for myself.