Information sheet for aged 13 - 16 years

Title of the project:

Name of PI:

**Introduction.**

You are being invited to take part in the following research study (***insert name here***) because: (***insert reason here***)

The research is supported by (***insert funder here***) and is taking place (***insert single NHS site or nationally or internationally***)

Before you decide whether to take part, it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with your parents. Please feel free to ask us any questions.

**What are we researching and why are we doing this?**

Give a lay summary of your research here – appropriate to the age group.

* What are you proposing
* Why are you doing this research
* what is already known

**Why have I been asked to take part?**

***Explanation why the young person approached meets the inclusion/exclusion criteria:*** You have been asked to take part because you have or don’t have the following conditions and meet the following criteria.

**What would taking part involve?**

Synopsis of the research protocol as it applies to the participant, procedures involved in participation/including data and sample collection, how many and how much samples, what will happen to them. ***Can do this in the form of bullet points, images, flow chart or short paragraphs.***

**Do I have to take part?**

It is up to you and your parents if you take part in this study. If you agree to take part, we will then ask you and your parents to sign a consent form. It is not a problem if you do not want to take part.

**What if I don’t want to take part?**

If you decide not to take part in this study or to withdraw at a later date it will not affect your treatment or hospital visits in any way, and you do not have to say why. You are free to withdraw at any time, without giving a reason.

**Benefits of taking part**

Being part of the study will help other children and young people with similar conditions as yourself. This research will help doctors to understand more about the condition (***insert here***), discover new treatments and help more children and young people with this condition in the future.

**Are there any risks of taking part?**

This project has been checked and given favourable opinion by an independent Research Ethics Committee who believes that it is of minimal risk to you. We will take any blood at the same time as the ones your doctor wants so there will be no extra tests.

**Who will have access to my samples and data?**

Only the researchers working on this study will have access to your data and samples. If you agree we may look at some sections of your medical notes when it will help the research.

All information that we collect will be kept strictly confidential and follow the law. All data and samples will be anonymised, this means they will be labelled with a code, not your name. All of the research – paper and electronic – records will be stored securely.

**Will my data be shared with others?**

Yes we might share your data with other scientists and doctors from around the world, if the work will benefit children and young people like yourself. All data will be shared in a way that means you are not able to be identified.

**What will be done with the results of this study?**

Results from this study will be written up in medical journals which you can read if you want. (***Will results be shared with participants through PPIE networks etc if applicable to your research***)

The data and samples from this study may be kept for other studies in the future if you agree.

**Will we be contacted again?**

If you agree to take part in the study when you are old enough – 16 years old – we will contact you again to see if you are still happy to take part.

We may contact you and your parents about other studies but it will be up to you and your parents if you take part in these.

**What if you have questions or worries?**

If you or your child have a concern about any aspect of this study please discuss them with your parents, doctor or the researcher collecting the information.

**Thank you for taking the time to read this information sheet and considering taking part in research.**