Information sheet for aged 9 – 12 years

Title of the project:

Name of PI:

Hello,

You are being asked to be part of our study because (***insert reason here***). We want to understand (insert disease here) and be able to treat the disease faster. Please read on to find out more and ask us any questions.

**Why is the study being done?**

This research is being done to (***insert aim of research here***).

**What will happen if I take part?**

(Explain the time line of what happens if they take part) Consider doing this in bullet point or a flow chart style to make it easier to understand.

* We ask you and your parents to sign a consent form, so we know you are happy to take part.
* We will ask you to provide the following samples (insert more information about when and where – such as during when the doctor wants them so not having more tests than usual.)
* We will collect some information from your notes from your doctor.
* Expand here on any other aspects of your study protocol.

**What will happen to my samples?**

We will use the samples you give us to look at xxxx, xxxx, xxxx. Each sample will be labelled with your special code, so no one will know it belongs to you. We will analyse it for xxxxxx xxxxx related to xxxxxxx disease.

**Is the study risky to me?**

No, there are no risks to you and your doctors will still continue to see and treat you in the same way.

**Will I benefit from the study?**

The main benefit will be knowing that by participating in the study you have helped improve the knowledge of (***this disease***). This research will help other children who also have similar problems in future.

**What if I want to stop being in the study?**

You can change your mind at any time and stop being in the study. You will continue to see the doctors as usual if you want to stop being in the study.

**Will my information be kept private?**

We will replace your name with a special code, so no one will know the information and samples belong to you. We might share your information with other groups also researching this but in a way that no one will know it is you. We follow the law, to keep your information private.

**Will I get information from the study?**

***No personal results from the study:***

Yes, the results will be published in scientific journals which you can read and the researcher will provide the participants with summaries in a newsletter once a year.

***If yes,***

We may find out things about your disease from this research. If we do we will tell your doctor and they will speak to you and your parents about what this means.

**What happens when I am an adult?**

When you turn 16 you are old enough to decide if you want to take part for yourself or still want to take part. We will contact you then to see if you still happy to be in the study.

We may also contact you to see if you want to take part in other studies like this one. Each time you and your family can discuss it and decide if you want to take part or not.

**Do I have to take part?**

No, if you and your parents don’t want you to take part that is fine; it won’t affect your treatment in any way.

**If you have any questions please ask your parents, the researcher or your doctor.**

**Thank you!**