

## Genetic Factors Affecting the Timing of Puberty

### Information sheet for patients aged 12-16 yr

#### **What is this study?**

This study aims to find out why you are going through puberty (developing into an adult) either earlier or later than other people. We are doing a study to look at genes that might cause problems with the timing of puberty (when children develop into adults). We would like you to agree to allow us to take a blood sample from you.

#### **Why have I been invited?**

You have been invited because you have a problem with the timing of your puberty. Investigating your genes may help us to understand more about how problems with the timing of puberty happen, and hopefully it will lead to new and better treatments to help other patients in the future. Your blood sample will help us to see if there is something in your genes (DNA) that is causing the problem.

#### **Do I have to take part?**

It is up to you to decide whether or not to take part. You will be asked on another form if you would like to be part of these studies. You don't have to do this and you can change your mind at any time. If you decide not to take part, this will not affect the care you receive. **If you don't want to take part, no one will be upset with you**

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

We will need to take one small sample of blood (this means having a needle prick to get the blood), and we will carefully look at your genes.

#### **What are the possible benefits of taking part?**

We cannot promise the study will help you but the information we get might help treat young people with problems with the timing of puberty with better medicines in the future.

#### **Will my taking part in this study be kept confidential?**

Only your parents, the doctor and nurses looking after you and the people doing the research studies will know that you are taking part. We will also let your family doctor (GP) know.

#### **What will be done with the information and blood used in the research?**

All information and samples that are collected during this research study will be used to learn more about puberty problems. The samples will be kept for future ethically approved research projects. The information about you will be stored securely and will be destroyed at the end of the research studies.

#### **Did anyone else check the study is alright to do?**

A group of people called the Ethics Committee have checked that the study is OK to do. The London-Chelsea Research Ethics Committee has approved the research study. We are also asking your parents permission. The study is being conducted as part of an educational project (PhD).

#### **Who can I contact to find out more about this study?**

If you have any questions please contact the following:

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Thank you for thinking about taking part in our research. We would very much appreciate it if you were able to help us.