

PATIENT INFORMATION SHEET

Patients 11-15 years old

Familial Hypercholesterolaemia Paediatric Register

Invitation

You are invited to take part in a project to learn more about children with FH. We hope to learn more about the long term usefulness of treatments on your overall health and your risk of heart disease when you are an adult, and to improve both the treatments and the care provided.

Before you make any decisions, it is important for you to understand why this is being done and what it will involve. Please read the following information carefully and discuss it with your parents, friends, relatives and your own doctor if you wish. Please ask your doctor or the clinic staff to explain any words or information that you do not clearly understand. Please take all the time you need to decide whether or not you wish to take part. Thank you for reading this.

What is the purpose of the project?

Familial Hypercholesterolaemia (FH) is a condition in which the gene which makes an important protein that removes cholesterol from the blood doesn't work properly. This faulty gene is passed down through families. Because of new tests, more children with the faulty gene are being found and offered treatments such as medicines and advice on diet and exercise. This project has set up a register to collect information to learn more about FH and how these treatments work.

Why have I been chosen?

You have been diagnosed with FH. We would like to collect information about all children and young people with FH who live in the United Kingdom.

Will it help me?

Taking part may not help you directly right now. The information collected will be used for research and to improve the care and treatment for all children and young people with FH and may therefore be of benefit to you sometime in the future.

Do I have to take part?

You do not have to take part. Even if you don't take part, your normal treatment will not be any different to those who are taking part.

You are being asked for your agreement to take part. Because you are under 18 years, your parents or guardians will also have to give their consent (permission) for you to take part. When you are 18 years old, you will be asked again for your permission. If you don't agree, we will stop collecting information about you. We will also delete the information already collected if you wish.



What will I have to do?

You don't have to do anything differently from before. Information about your treatment will be put on the Register by your medical team each time you visit the doctor.

Will other people know more about me?

Your information will get a special number to protect your identity and your name will not be given to people not working with this project. It will be stored on a secure server (computer) at the Royal College of Physicians. When the information is used by the people doing the research, it will not contain your name or anything that may identify you, so no one will know who you are.

What will happen to the information?

The results could be published in medical journals or presented at medical conferences but in a way which will not identify you. Your doctor will discuss the overall results with you in future.

Contact for more information

Thank you for considering taking part in this project. If you have any further questions about the project please talk to your doctor. If you want to know more about the project, contact the Project Manager (fh@rcplondon.ac.uk).

You may also contact HEART UK if you are concerned.
Helpline: 0845 450 5988 Email: ask@heartuk.org.uk

I agree to allow information about my condition and treatment to be put into the Register.

Yes

No

Patient's Name (printed) _____

Patient's Age _____

If you sign this form, you agree to allow us to put some information about you on our computer for research studies:

Signature of Patient

Date

Person obtaining consent

SIGNATURE _____

First Name _____ Last Name _____

Job title _____

Date _____