

Familial Hypercholesterolaemia Project in Primary Care

Patient Information Sheet

What is the service?

This service is designed to help general practices ensure that patients with Familial Hypercholesterolaemia (FH) receive treatment that reflects best practice according to the National Institute for Health and Clinical Excellence (NICE) guidelines. FH may affect 1 in 250 of the population. FH is a genetic disorder. Genes are the instructions or recipes made of DNA that tell our bodies how to build and repair themselves. Genes come in pairs and we inherit one copy in each pair from our mother and the other from our father. Each of the two different copies of a gene can have tiny differences in their genetic code. It is these subtle differences in our genes that make us all different and unique. Sometimes a change in the genetic code of a gene can prevent the gene from working properly. An individual with a dominant genetic condition such as FH will have a change or genetic misprint (which scientists call a mutation) in one copy of a particular gene. While the other copy of the gene is a working copy this is not sufficient to prevent the condition. The effects of the changed gene override the working copy. FH causes high cholesterol in the blood.

This service will identify patients at high risk of FH and aim to reduce the risk of people having heart attacks and strokes.

Who is providing the service?

The service is provided by FH Specialist Nurses employed by the Northern Genetics Service at the Centre for Life based in Newcastle on behalf of xxxxxxxxxxxxxxxxxxxxxxxClinical Commissioning Group.

Who is this service for?

This service is for all patients who may be at high risk from FH either due to having high cholesterol levels in the past or because of having heart disease. Your GP has requested this service to help screen patients.

What will happen to me at this appointment?

The Specialist Nurse will:

- ❖ talk to you about FH and cholesterol levels
- ❖ ask you about relevant family history
- ❖ discuss your past cholesterol levels
- ❖ examine your eyes, ankles, hands and elbows for signs of cholesterol

You may be offered genetic testing at this appointment. This will be a blood sample (about 10 mls) which will be sent to the Centre for Life in Newcastle.

The appointment will last approximately 45 minutes.

Can you tell me about the Nurses who will be running the FH patient clinics?

The FH Specialist Nurses are registered nurses employed by the NHS within the Northern Genetics Service based at the Centre for Life and have been asked to provide this clinical service at your GP surgery.

Is this a research study?

No. It is an NHS service provided free of charge to GP practices in the North East of England who request it.

Am I going to benefit from attending this appointment?

You may learn more about your cholesterol levels. You and your family may benefit from having a genetic test which may establish a cause for high cholesterol levels, provide a treatment plan and help to reduce the risk of heart attacks and strokes in your family.

How has this service developed?

The Academic Health Science Network for the North East and North Cumbria (AHSN NENC), The Newcastle upon Tyne Hospitals NHS Foundation Trust, xxxxxxxxxxxxxxxxxxxxxxxxClinical Commissioning Group, Amgen and Sanofi working in partnership have developed this service.

Who is the Academic Health Science Network for North East and North Cumbria (AHSN NENC)?

The AHSN NENC is a publicly funded body which acts as the trusted intermediary between the NHS, academia and industry and is committed to:

- Supporting Economic Growth
- Improving Population Health
- Transforming Patient Safety and Quality Improvement

The AHSN NENC, is part of a national network of 15 AHSNs and receives funding from NHS England, NHS Improvement and The Office for Life Sciences to accelerate the spread and adoption of innovative devices, services and pathways through dissemination of best practice.

What will happen with my confidential information?

If you require genetic testing for FH during your clinic visit, your confidential information will be shared with the Northern Genetics Service. In addition we will be using your pseudonymised information (personal information that is anonymous to the people who hold or receive it) but contains codes that would allow others (e.g. those responsible for the individual's care) to identify you. To safeguard your rights, we will use the minimum personally-identifiable information possible. The Newcastle upon Tyne Hospitals NHS Foundation Trust will act as the data controller for this pseudonymised information and retain it for 7 years after the project has completed according to policies and procedures.

Where can I get more information about FH?

You could contact the FH Nurse Specialist (number below) or have a look at the Heart UK website: <https://www.heartuk.org.uk/>

If I am not happy about the FH service what should I do?

If you, a family member or a carer are not happy with the FH Nurse Specialist or the service provided please contact the Patient Advice & Liaison Service (PALS) for confidential advice on any aspect of care Tel: 0800 0320202. If you would like any further information please contact the FH Nurse Specialists: (0191) 241 8828.