

ADDITIONAL INFORMATION FOR NEW PATIENTS AT THE LIPID CLINIC, ROYAL INFIRMARY OF EDINBURGH AND ST JOHN'S HOSPITAL, LIVINGSTON

For your **first new patient appointment and any subsequent appointments at the Lipid Clinic we would like you to come fasted**. That is, you should not take any food after 11 pm the previous night and until you have had the blood sample taken at the Lipid clinic. It is fine to drink water overnight or at your usual breakfast time. The clinic itself provides some light refreshment once your blood sample has been taken. **If you are a diabetic on insulin do not attempt to come fasted but have your usual breakfast.**

It would be very helpful to have details about your family's health if you know this information, and in particular, if there is any history of heart disease. Please fill in the enclosed form as best you can and **bring it with you to the clinic.**

On arrival at the clinic you should report to the reception staff. One of the nursing staff will then meet you and measure your height and weight. The same nurse will also take a blood sample at this and any subsequent visits to the Lipid clinic. Once you have had a blood sample taken, the nurse will provide you with a drink and light snack.

The blood sample will be used to measure your cholesterol. Additionally, we would also like to test your kidney, liver and thyroid function and look for diabetes on the blood sample. This is because abnormal lipids can sometimes arise from kidney, liver or thyroid problems or diabetes. If you have any concerns over this testing, please speak initially to the clinic nurse.

Occasionally, we may use a blood sample to look for an inherited basis for your high cholesterol (called Familial Hypercholesterolaemia or FH, for short) but the doctor at the clinic will separately speak to you and seek your permission for this test.

Enclosed with this letter is a request for consent for recording some information about you in a secure Lipid Clinic database should you be tested for the condition FH. Please read the enclosed consent form and, provided you are happy with the contents, sign the consent form. If you feel that you want more information about the Lipid clinic database, do not hesitate to speak to one of the medical staff at the Lipid Clinic when you are seen.

Yours sincerely

Dr Sara Jenks, Dr Jonathan Malo and Dr Nicola Shand
Lipid Clinic Medical Team
RIE/SJH

To be completed by clinic staff
Addressograph label, or:



Name:

DOB:

UHPI/CHI:

Family History Sheet

Please complete as far as is possible:

Father's family	Age if living	Age at death	Any heart disease /cause of death
Father			
Father's father			
Father's mother			
Father's brothers			
Father's sisters			

Mother's family	Age if living	Age at death	Any heart disease /cause of death
Mother			
Mother's father			
Mother's mother			
Mother's brothers			
Mother's sisters			

Your family	Age if living	Age at death	Any heart disease /cause of death
Your brothers			
Your sisters			
Your sons			
Your daughters			

PLEASE REMEMBER TO BRING TO THE CLINIC

CONSENT FOR THE FH LIPID CLINIC DATABASE

To be completed by clinic staff
Addressograph label, or:



Name:

DOB:

UHPI/CHI:

With your consent, we would like to record some information about you should you be tested for a condition called Familial Hypercholesterolaemia (FH). Only some patients who attend the Lipid Clinic are tested for FH and the database entry would only apply if you happen to be tested for FH.

The FH Lipid Clinic database may contain information about health problems which you have had, medication which has been prescribed and the results of any blood tests or examinations that are performed on you in the clinic. The database is helpful for a number of reasons:

- To ensure that the best possible care is delivered. For example, the database will allow us to determine to what extent we are reaching nationally agreed targets for cholesterol levels in patients on treatment for FH.
- In the event of new developments in treatment, it will allow us to identify specific groups who might particularly benefit from such advances.
- The database will allow identification of patients with FH for the purpose of ethically approved clinical research into this disorder with a view to better clinical management.
- To share details of your lipid problem amongst the healthcare professionals who look after you. This may include your family doctor, the hospital doctors who participate in the Lipid Clinic and the nursing and dietetic staff who contribute to your care at the Lipid Clinic.

It is important for you to know that the database is secure and only those healthcare professionals who are involved with your care will have access to named information about you. Where the database is used to provide more general information about achievement of cholesterol targets, numbers on treatment, etc it is also important to stress that only anonymised data will be used for this purpose. If the register is used to identify people who may be suitable to participate in our research studies into various aspects of lipid disorders, your further consent would be required before you could be enrolled into such a study.

Your records are kept in accordance with the General Data Protection Regulation 2016 and you are free at any time to see what details are held about you on the register and to ask for them to be removed. If you would like more information, please speak to your doctor or one of the other members of the care staff at the Lipid Clinic. Otherwise, we will be grateful if you would indicate below that you agree to have your details on the FH Lipid Clinic database.

I consent to my clinical details being recorded on the Royal Infirmary FH Lipid Clinic Database.

Signature of patient

Name in block capitals

Date

For further information regarding Data Protection in NHS Lothian, please see:
<https://www.nhsllothian.scot.nhs.uk/YourRights/DataProtection/Pages/default.aspx>