

PATIENT INFORMATION SHEET

What is Hepatitis C?

Hepatitis means swelling or inflammation of the liver. One of the most common causes of hepatitis is viral infection. Hepatitis C infection (also known as Hep C or HCV) is one such virus that can cause long-lasting infection and can lead to liver disease. If you would like more information about hepatitis C itself you can contact:

The British Liver Trust
(Registered Charity No: 298858)

2 Southampton Road, Ringwood, BH24 1HY
Tel: 01425 481320; **Fax:** 01425 481335
Email: info@britishlivertrust.org.uk
Information Line: 0800 652 7330
Website: www.britishlivertrust.org.uk

The Hepatitis C Trust
(Registered Charity No: 1104279)

27 Crosby Row, London, SE1 3YD
Tel: 020 7089 6220; **Fax:** 020 7089 6201
Email: admin@hepctrust.org.uk
Helpline: 0845 223 4424
Email: helpline@hepctrust.org.uk
Website: www.hepctrust.org.uk

NHS Hepatitis C Website

Website: www.nhs.uk/HepC

What is the HCV National Register and why do we need it?

The HCV National Register collects anonymous information about patients who have hepatitis C. Any patients who have been diagnosed with hepatitis C can be enrolled into the register providing we can establish when they acquired their infections. Because hepatitis C infection is relatively rare in childhood, children do not necessarily need to have a precise date of infection to be included. The Register also gathers information on other people who are not infected with hepatitis C, but who may have been exposed to the virus in the past.

As hepatitis C is one of the more recently discovered viruses, doctors are still learning about the kind of disease it can cause. The HCV National Register was set up to help us learn more about hepatitis C.

How can I help?

We can learn more about hepatitis C by looking at medical information about patients. Because hepatitis C is relatively rare, the more patients we can include, the better. By participating in this study your medical information, along with information about other registered patients, would help us to understand how disease develops and how it can be treated. The Register will enable us to find out who is at greatest risk of infection or of developing liver disease. Every new patient entered into the register will assist us. We aim to help doctors provide better information to patients about the infections they have, and how best to treat them.

What information would be included in the Register and why?

We would like to collect the following:

a) Medical information

Information from your medical notes, including details of any treatments or tests that you may have had for hepatitis C.

b) Spare blood samples

Any samples of your blood that have already been taken by your doctor. We would use these to find out whether different strains of the virus (genotypes) cause different types of disease. We can do this by looking at spare samples; we would not need to take any new blood.

c) Spare liver biopsy sections

Any spare sections from liver biopsies that you may have already had. The best way to assess damage to the liver is by looking at a piece of the liver itself – this is called a liver biopsy. During a biopsy 2 or 3 pieces of liver, each about the size of a rice grain, are taken. These pieces are specially treated, cut, spread onto glass slides, and then examined under a microscope. Because different hospitals record what they find on liver biopsies in different ways, it would be useful to look at all of the biopsies together in one laboratory.

If you participate in this study, your doctor will be asked to pass all this information directly to the registry. You will not need to provide any of this information yourself. Every year or so we will contact your current doctor to collect any new information.

Confidentiality

Your name will **not** be recorded in the register. All medical information, blood specimens and liver biopsy slides are securely stored at Public Health England, Health Protection Services. All blood samples and liver biopsy slides are labelled with a unique study number that links them to the anonymous information held in the register. Your NHS number will be recorded in the register to help us keep in contact with your current hospital doctor or G.P. Access to this information is restricted to key authorised staff. We will never pass information that could identify you to other researchers or doctors.

This study has been approved by the North Thames Multi-Centre Research Ethics Committee.

It is important to understand that participation in this study would not affect the care that you receive from your doctor in any way. You are completely free to withdraw from the study if you change your mind at a later date – this will in no way affect the care that you receive from your doctor.

I need to know more....

If you require any further information about the HCV National Register, please feel free to contact us – we will be happy to answer any questions that you may have. Our contact details are given below. If you would like us to keep you updated with the results of this research, just let us know and we will be happy to send these to you.

Dr Helen Harris, Register Co-ordinator
Tel: 020 8327 7676; Fax: 020 8327 7404

HCV National Register
Immunisation, Hepatitis and Blood Safety
Department,
CIDSC, Health Protection Services
Public Health England
61 Colindale Avenue
London NW9 5EQ

What do I do now?

If you are willing to participate, please sign the consent form and return the top two copies to your doctor, using the stamped addressed envelope we have provided. Please retain the bottom copy for your information. We will then contact the doctor to obtain your medical information. Thank you.

The HCV National Register is operated by Public Health England