

INFORMATION SHEET FOR PARENTS

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 lead to liver disease. HCV was discovered in 1989 and doctors are still learning about the kind of disease it can cause. If you would like more information about HCV itself you can contact:

Children's Liver Disease Foundation (Registered Charity No: 1067331)	36 Great Charles Street, Birmingham, B3 3JY Tel: 0121 212 3839 Email: info@childliverdisease.org Website: www.childliverdisease.org
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The British Liver Trust (Registered Charity No: 298858)	6 Dean Park Crescent, Bournemouth, BH1 1HL Tel: 01425 481320 Email: info@britishlivertrust.org.uk Information Line: 0800 652 7330 Website: www.britishlivertrust.org.uk
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The Hepatitis C Trust (Registered Charity No: 1104279)	27 Crosby Row, London, SE1 3YD Tel: 020 7089 6220 Email: admin@hepctrust.org.uk Helpline: 020 7089 6221 Email: helpline@hepctrust.org.uk Website: www.hepctrust.org.uk
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NHS Hepatitis C Website	Website: www.nhs.uk/HepC
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What is the HCV National Register and why do we need it?

The HCV National Register was set up to help us learn more about HCV. It collects information about children and young people who have HCV. Patients who have been diagnosed with HCV can be enrolled into the Register providing we can establish when they acquired their infections. Because HCV is relatively rare in children and young people we do not necessarily need to have a precise date of infection to include them. The Register also gathers information on other people who are not infected with HCV, but who may have been exposed to the virus in the past.

How am I helping?

We can learn more about HCV by looking at medical information of children and young people with HCV. The more patient information we can review, the more we can learn about HCV infection. Your child's medical information, along with information about other registered patients, will help us to understand how disease develops, including the effects and response to treatment. The Register will also enable us to find out who is at greatest risk of developing liver disease. We aim to help doctors provide better information to children and young people about the infections they have. Being included in the Register will help us to help other people.

What information will be included in the Register and why?

We will collect the following:

a) Medical information

Information from your child's medical notes, including details of any treatments, blood tests and investigations that they may have had for their HCV management.

b) Spare blood samples

Any samples of your child's blood that have already been taken by their doctor and are left over. These help to find out whether different strains of the virus (genotypes) cause different types of disease. We would not need to take any new blood samples.

c) Spare liver biopsy sections

Any spare sections from liver biopsies that your child may have already had. One of the best ways 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 is useful for us to look at all of the biopsies together in one laboratory.

Your doctor will be asked to pass all this information directly to the HCV National Register. You will not need to provide any of this information yourself.

What about Confidentiality?

Your child's name and address will **not** be recorded in the Register. Your child's NHS number will be recorded in the Register to help us keep in contact with their hospital doctor or G.P. Access to this information is restricted to key authorised staff. All medical information, blood specimens and liver biopsy slides are securely stored at Public Health England's (PHE) National Infection Service. 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. We will never pass information that could identify your child to other researchers or doctors. Every year or so we will contact your child's current doctor to collect any new information.

Is consent required for my child to be in the HCV National Register?

This study has been approved by the North Thames Multi-Centre Research Ethics Committee (MREC/98/2/47). Approval has also been given to process HCV National Register information **without consent** under Section 251 of the National Health Service Act 2006 and under Regulation 3 of the associated Health Service (Control of Patient Information) Regulations 2002. The law on protecting personal information, known as the General Data Protection Regulation (GDPR) and the Data Protection Act 2018, allows us to use the personal information collected and held in the HCV National Register. You can find out more about the personal information PHE collects, uses and sometimes shares to do its job, along with how this is protected, and your rights, via this link from the HCV National Register web page: <https://www.gov.uk/government/publications/hepatitis-c-national-register/hepatitis-c-national-register-privacy-information>

Who can I contact to learn more about the HCV National Register?

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.

Dr Helen Harris, Register Co-ordinator Tel: 020 8327 7676
Annastella Costella, Hepatitis Scientist Tel: 020 8327 7086

HCV National Register, Blood Safety, Hepatitis, Sexually Transmitted Infections (STI) and HIV Service,
National Infection Service, Public Health England, 61 Colindale Avenue, London. NW9 5EQ.

The HCV National Register is operated by Public Health England Further information is available here:
<https://www.gov.uk/government/publications/hepatitis-c-national-register>