

A large graphic element on the left side of the page. It features a solid green horizontal bar at the top. Below it is a light blue rectangular area containing the title text. The bottom of this light blue area is a wavy line that separates it from a dark blue area below. The wavy line is composed of a green top curve and a blue bottom curve.

Information for patients on Hepatitis C Clinical Registry System

What is Hepatitis C?

Hepatitis means swelling or inflammation of the liver. Hepatitis C, also known as HCV or Hep C is a virus that is carried in the blood and infects and damages the liver. The Hepatitis C Virus (HCV) is a major cause of liver disease. A person can be infected with Hepatitis C for many years without having any symptoms. Left untreated, Hepatitis C can eventually progress to cause more serious liver damage.

What is the Hepatitis C Clinical Registry System and why do we need it?

Your information is recorded in the Hepatitis C clinical registry system for the purpose of your care, to ensure that the care you receive from us is safe, effective and of the highest possible quality.

The information held in the system includes:

- Basic information about you
- Contact we have had with you, such as clinic visits and referrals
- Details and records about the Hep C treatment and care you have received
- Outcomes of treatments and medications provided
- Hep C test and investigation results

We will make every effort to ensure your information will always be kept confidential, secure and accurate.

The clinical team looking after you may share this information with each other including:

- Healthcare professionals such as doctors, nurses, pharmacists, physiotherapists and occupational therapists.
- Administrative support staff
- Healthcare students in training

- Pathology and radiology staff involved in the analysis and reporting of diagnostic tests
- Staff conducting local clinical audits to evaluate the care provided to you.

Your information may be used both by the Trust and NHS England to:

- Assess the number of cases and the need for Hepatitis C treatment nationally
- Ensure that Hepatitis C needs in the future can be met
- Ensure the treatment provided is of the highest standard
- Conduct health research and development
- Prepare statistics on performance, audit services, investigate complaints, legal claims or untoward incidents.

Confidentiality

Everyone working for the NHS has a legal duty to keep information about you confidential. Anyone who receives information from us is also under a legal duty to keep it confidential.

Public Health England play an important role in monitoring infections throughout the country and they will have access to your information and maintain a national clinical registry to allow us to monitor the progress of hepatitis C in England. This data will only be accessed by named doctors working at Public Health England and the data will not be shared with any other group.

I would like to know more

If you have concerns about this please discuss them with your doctor or nurse.

You can get access to your own records by following the Trust Subject Access Request process.

This is available at <http://bit.ly/SubjectAccessRequest>

or you can call **01273 696955 Ext: 4186**
(lines are open from 10am to 3pm)

or email: SAR@bsuh.nhs.uk

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Disclaimer

The information in this leaflet is for guidance purposes only and is in no way intended to replace professional clinical advice by a qualified practitioner.

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