



Newsletter

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Message from Catherine Nalty, Deputy Secretary to the Inquiry

At the end of October two issues were raised frequently in our “local” meetings with Inquiry participants. The first was the different reactions of GPs and other clinicians to requests for liver scans or other measures to monitor the impact of cirrhosis. The second was the timing for publishing participants’ witness statements on the Inquiry website. So we’ve provided some information on both subjects below. We have also been told that the combination of the compensation study and the Inquiry is causing some additional anxiety so please remember the Inquiry’s British Red Cross team, who can provide confidential support on the phone and are available every week of the year. For longer term psychological support, the infected blood support schemes all now offer some psychological support.

Follow-up care for people infected with hepatitis C

If you are having difficulty getting a referral, we hope this evidence given to the Inquiry might help. Please get in touch with us if you think we could assist with further information.

In early 2020 the Inquiry’s expert group on hepatitis gave evidence that while follow-up care for hepatitis C infected patients after a sustained virological response (SVR) will be tailored to an individual patient’s clinical condition and personal circumstances, the key factors to consider include:

- whether a patient has evidence of liver fibrosis/cirrhosis
- whether a patient is considered at risk of liver cancer (HCC)
- whether a patient is at risk of reinfection
- personal preferences of the patient and ability to attend clinics.

They also said that people with significant fibrosis or cirrhosis are likely to need monitoring every six months, through ultrasound scans and blood tests, for the risk of HCC.

Following this, the Inquiry requested information from NHS organisations across the UK on the level of support offered. When asked what scans, blood tests and/or other checks are, or should be, offered to a person who has been diagnosed with hepatitis C, they responded as follows:

Claire Forman on behalf of **NHS England** confirmed that *“for a patient with cirrhosis, standard follow up would include a review every 6 months with an assessment of liver function by blood tests, including a full blood count, liver function tests and, usually, clotting assessment. A liver cancer screen would be performed with an ultrasound scan and an alfa-feto protein assessment.”*

[\(Second written statement of Claire Forman on Behalf of the NHS Commissioning Board \(known as NHS England\), p.10\)](#)

Professor John Dillon on behalf of the **Scottish Government**, confirmed that *“those with evidence of cirrhosis should be treated and remain under 6 monthly review to screen for compli-*

cations of cirrhosis, in particular Hepatocellular carcinoma (with 6 monthly hepatic ultrasounds and estimations of alpha-feto protein) and gastrointestinal varices (3 yearly upper gastrointestinal endoscopy)."

[\(Written statement of John F Dillon, p.3\)](#)

Professor Chris Jones on behalf of the **Welsh Government**, confirmed "*if the patient has advanced liver disease then they would be followed up appropriately by that service (i.e regular liver scan for hepatocellular carcinoma (HCC) and regular monitoring with hepatology).*"

[\(Written statement of Professor Chris Jones, p.3\)](#)

Caroline Leonard for **Belfast Health and Social Care Trust** confirmed "*patients who have a Fibroscan suggestive of advanced fibrosis or cirrhosis are kept under long-term review at the liver clinic. These patients require an ultrasound and blood tests for alpha-feto protein (AFP) every six months to screen for hepatocellular cancer. In addition, such patients have a six monthly clinical review.*"

[\(Fourth written statement of Caroline Leonard for Belfast Health and Social Care Trust, p.6\)](#)

Timing for witness statements on the Inquiry website

With the publication of around 500 statements this month, the Inquiry has now published approximately 1600 statements by people infected and affected on our website. We know that some of you have been waiting for a while to see your statement on the website, and as a general rule we aim to publish the statements which were completed first. We also try to publish together any statement made by family members.

Preparing statements for publication takes time as every statement is reviewed thoroughly to check that no personal information is included which should be redacted. Sir Brian continues to read every statement submitted and all the statements will be placed on the website before Sir Brian publishes his final report.

We expect the next set of statements to be published in spring next year and you will be informed shortly before your statement is published.



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Tel: 0800 458 9473 or 0203 417 0280 at these times:

Monday between 11am - 1pm;
Wednesday between 7pm - 9pm; and
Friday between 2pm - 4pm.

Or leave a message any time and you will receive a call back as soon as possible