

26 April 2019

To: Medical Directors of Secondary Care, Mental Health and Community Trusts

Dear Colleague

Infected Blood Inquiry (IBI)

In July 2017 the Government announced an inquiry to examine the circumstances in which patients treated by the NHS had been given infected blood and infected blood products. The Inquiry will examine why men, women and children in the UK, primarily in the late 1970s and early 1980s, were given infected blood and/or infected blood products; the impact on their families; how the authorities (including government) responded; the nature of any support provided following infection; questions of consent; and whether there was a cover-up.

Chaired by Sir Brian Langstaff, the [Infected Blood Inquiry \(IBI\)](#) was established in July 2018. Public hearings start on 30 April this year and will hear directly from people who were infected by blood or blood products, and from the people close to them who were affected by this.

Sir Brian Langstaff has requested access to information pertinent to his inquiry, including records, documents and data held by organisations across the NHS. Individual NHS organisations are responsible for ensuring that appropriate records are kept and supplied as requested by the Inquiry.

Professor Stephen Powis confirmed to the Inquiry in July 2018 that NHS England does not have access to the majority of files that will be required; and that it is for individual trusts to ensure that the appropriate records are kept and supplied as requested by the Inquiry.

This letter is to help healthcare providers support the Inquiry and patients who have, or who believe they may have, been exposed to risks associated with infected blood or blood products.

I hope this is helpful in how we can support and facilitate the work of the Inquiry team and those patients and families affected.

Yours sincerely

David Levy
Regional Medical Director North West
NHS England and NHS Improvement



Appendix

Engagement

NHS organisations are obliged to participate with the Inquiry and should have been contacted directly by the Inquiry team, requesting their help in searching, retaining and disclosing any relevant information, records and data. I would like to encourage NHS organisations to participate fully with the Inquiry in the interests of those affected by the incident.

Infection

Prior to 1991, blood and blood products were not tested for blood-borne viruses. As a consequence, there is a risk that patients who received blood or blood products prior to 1991 could have become infected with a blood-borne virus. The greatest risk is in relation to Hepatitis C. It is estimated that during the mid-1980s, between 0.6-1% of the population was infected by Hepatitis C.¹

Approximately 1% of transfusions given prior to 1991 could have contained an infected agent such as Hepatitis C.

Action

Hepatitis C often does not have any noticeable symptoms until the liver has been significantly damaged. This means some people have the infection without realising it.

When symptoms do occur, they can be mistaken for another condition. This can include:

- flu-like symptoms, such as muscle aches and a high temperature
- feeling tired all the time
- loss of appetite
- abdominal pain
- feeling and being sick

The only way to know for certain if these symptoms are caused by Hepatitis C is to get tested. Clinical staff should therefore consider asking patients who present with nonspecific symptoms whether they have had blood or blood products prior to 1991 and offering them a screen for blood-borne viruses. There may also be some patients who are not fully aware that they have received blood or blood products, for example, if they were involved in a road traffic accident (RTA) or childbirth etc. prior to 1991.

Those patients who test positive for Hepatitis C should be referred to the local hepatology service for treatment. New hepatitis C treatments are oral tablets for 8 - 12 weeks and have minimal side effects and over 95% cure rates."

Guidance has been sent to support GPs in this matter.

¹ The Penrose Inquiry <http://www.penroseinquiry.org.uk/finalreport/>



Support for patients

Untreated Hepatitis C infection causes cirrhosis and liver cancer but now very effective, well tolerated oral therapies are available on the NHS and most people diagnosed with Hepatitis C can be cured.

Support for patients is available from the Hepatitis C Trust and the British Liver Trust. In addition, for those patients engaging with the inquiry, the Inquiry recognises participating can be difficult and has therefore organised a confidential support line staffed by the British Red Cross (see appendix).

Access to records

Sir Brian Langstaff has written to request that no documents, files or paperwork that may be of interest to the inquiry be destroyed – this includes both medical and corporate records.

The Inquiry Team is requesting relevant corporate records/documents/data and searching millions of pages from the Department of Health and NHS organisations including arms-length bodies, primary and secondary care organisations and other health related organisations.

It is contacting all NHS organisations to make them aware of this and its work. In some instances, where relevant and appropriate to the IBI, this may include a set of relevant search words to help guide the identification process across both paper and electronic repositories. Each NHS organisation is responsible for their own disclosure of records.

Medical records have been handled differently with specific records being requested predominantly from family members of those infected.

Although patients seeking a Subject Access Request (SAR) can do so without charge, it is important to note that organisations should also waive fees for people seeking copies of their medical records.

If you have records that are not within the scope of the Inquiry which have exceeded their retention period and you would like to dispose of them, please discuss this with the appropriate Records Management official in your organisation. Please do not destroy any records without seeking prior advice.

Along with the Infected Blood Inquiry, there are other ongoing legal Inquiries which have issued legal holds on records and information within the scope of their investigations. These are: the [Independent Inquiry into Child Sexual Abuse \(IICSA\)](#) and the [Grenfell Tower Inquiry](#).

Support to the Inquiry

NHS staff may have personal reflections from previous roles where they were working closely with transfusion or related services that they may feel has a bearing on the work of the inquiry. If you would be interested in making a statement to the Inquiry, contact details can be found in the appendix.



Further support/contact details

Infected Blood Inquiry (IBI)

Tel: 0808 169 1377

Email: contact@infectedbloodinquiry.org.uk

Address: Fleetbank House, 1st Floor, 2-6 Salisbury Square, London EC4Y 8AE

Website: www.infectedbloodinquiry.org.uk

Confidential support

IBI confidential support line staffed by the British Red Cross:

Tel: 0800 458 9473 or 0203 417 0280

Monday between 11am - 1 pm

Wednesday between 7pm - 9pm

Friday between 2pm - 4pm

Hepatitis C Trust

Support for patients is available from the Hepatitis C Trust:

Confidential helpline: 020 7089 6221

Website: www.hepctrust.org.uk.

British Liver Trust

Support for patients is available from the the British Liver Trust:

Confidential helpline: 0800 652 7330

General enquiries: 01425 481320

Website: www.britishlivertrust.org.uk.

