

January 2020

To: Primary and Secondary Care NHS Organisations including:
GP Practices, Clinical Commissioning Groups, Commissioning Support Units;
Medical Directors of Secondary Care, Mental Health and Community Trusts; and
Clinical Leads of Integrated Care systems and Sustainability & Transformation
Partnerships

Dear Colleague

NHS organisations were contacted in April 2019 regarding the **Infected Blood Inquiry** – details of which are included below as Annex A – reminding about the retention of relevant records and explaining how the NHS can support the Inquiry and patients/families who may have been affected.

Over this last year, the Inquiry themselves have also contacted all NHS organisations to make them aware of the Inquiry and again to remind about the retention notice of medical and corporate records, with organisations confirming back to the Inquiry that this was being implemented.

The Inquiry have informed us that a core participant to the Infected Blood Inquiry has since reported there are a number of cases where the Retention Notice from the Inquiry had apparently not been received.

The Inquiry appreciates that with such large organisations within the NHS, discrepancies such as this can arise within an individual organisation. However, the need to preserve relevant evidence and to assure core participants that this has been done, is vital to the success of the Inquiry, particularly in the context of this Inquiry, which specifically identifies cover up and document destruction within the Terms of Reference.

I would therefore appreciate your help in ensuring that the messages contained within the letter in Annex A are shared with and implemented by all relevant colleagues and teams across your organisation to help facilitate the Inquiry and support the patients and families affected.

In the meantime, we are continuing to work with the Inquiry to refine the records retention parameters for NHS organisations.

Many thanks for your assistance.

Yours sincerely

Prof Stephen Powis
National Medical Director
NHS England & NHS Improvement



ANNEX A

[sent in April 2019]

To GP practices, CCGs, CSUs and Medical Directors of Secondary Care, Mental Health and Community Trusts

Infected Blood Inquiry

Dear Colleague

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, in the late 1970s, 1980s and early 1990s, men, women and children in the UK 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](#) 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. The Inquiry seeks to establish, not only what was done, but also what should have been done in relation to making blood and blood products safe.

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, National Medical Director, NHS England and NHS Improvement, 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 NHS organisations 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

**Regional Medical Director
NHS England & 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 September 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 September 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 September 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 September 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 September 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 for further support details).

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 Inquiry, 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. The Inquiry has been notified recently that family members continue to experience difficulty and delays in accessing hospital or GP records of their deceased loved ones. It would very much assist the Inquiry, and those witnesses who are engaging with it, if NHS organisations could be encouraged to respond promptly to requests for records connected to the Inquiry, and to exercise discretion in providing access to records on the basis that the Inquiry provides a clear justification, in the public interest (see paragraph 8.6 of the BMA's guidance on access to health records).

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 below.

Further support/contact details

Infected Blood Inquiry

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

Infected Blood Inquiry 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 British Liver Trust:

Confidential helpline: 0800 652 7330

General enquiries: 01425 481320

Website: www.britishlivertrust.org.uk.

