

**From:** [mailto: ]@infectedbloodinquiry.org.uk]  
**Sent:** 18 March 2019 10:01  
**To:** (NORTHERN LINCOLNSHIRE AND GOOLE NHS FOUNDATION TRUST)  
**Subject:** re: Request of the Infected Blood Inquiry for assistance

Dear

My apologies for the late response. Thank you for your email and for confirming Northern Lincolnshire and Goole's NHS Foundation Trusts' support and commitment to the Inquiry by incorporating the retention notice we have sent you into your retention policy.

Kind Regards,

## **NORTHERN LINCOLNSHIRE AND GOOLE NHS FOUNDATION TRUST)**

**From:** (NORTHERN LINCOLNSHIRE AND GOOLE NHS FOUNDATION TRUST)  
**Sent:** 15 March 2019 11:28  
**To:** i@infectedbloodinquiry.org.uk  
**Cc:** (NORTHERN LINCOLNSHIRE AND GOOLE NHS FOUNDATION TRUST); (NORTHERN LINCOLNSHIRE AND GOOLE NHS FOUNDATION TRUST); (NORTHERN LINCOLNSHIRE AND GOOLE NHS FOUNDATION TRUST); (NORTHERN LINCOLNSHIRE AND GOOLE NHS FOUNDATION TRUST)  
**Subject:** RE: Request of the Infected Blood Inquiry for assistance  
**Attachments:** Retention Appraisal and Disposal of Clinical Paper Health Records Policy and Procedure (DCP020).pdf

Dear

I have now had the opportunity to discuss your email with the Trust's Head of Health Records and provide a summary below.

The relevant staff within the Trust are fully aware of the requirements in respect of the Infected Blood Inquiry. I can also confirm that the Trust has not destroyed any Health Records since 2013 following the Goddard Inquiry. Further, the specific requirements relating to the Infected Blood Inquiry have been incorporated within the Trust's 'Retention, Appraisal and Disposal of Clinical Paper Health Records Policy & Procedure' (sections 4.10 – 4.10.2 refer) and a copy is attached for your reference and assurance.

As you will be aware, charges for SAR requests are no longer applicable following the introduction of the GDPR in May 2018 and the Trust is also compliant with these new arrangements.

Finally, in order to raise further awareness of this issue, your communication will be brought to the attention of the Trust's Health Records Committee on 19 April 2019.

I hope that my communication provides the information and assurance required but please do not hesitate to contact me if I can be of any further assistance.

Kind regards,

**Trust Secretary**

Northern Lincolnshire and Goole NHS Foundation Trust



*Working together we will deliver the highest quality, innovative, safe and compassionate healthcare services*



Pride in Ourselves, Respect for Others

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**From:** (NORTHERN LINCOLNSHIRE AND GOOLE NHS FOUNDATION TRUST)  
**Sent:** 12 March 2019 17:51  
**To:** @infectedbloodinquiry.org.uk  
**Subject:** Fw: Request of the Infected Blood Inquiry for assistance

Dear

Your email dated 25 February 2019 has been passed to me and has been shared with relevant Trust staff. My apologies for missing the initial deadline. I will come back to you more fully as soon as possible.

Thank you and regards,

**Trust Secretary**  
Northern Lincolnshire and Goole NHS Foundation Trust



*working together we will deliver the highest quality, innovative, safe and compassionate healthcare services*



Pride in Ourselves, Respect for Others

**From:** <@infectedbloodinquiry.org.uk>  
**Date:** February 25, 2019 at 11:38:32 AM GMT  
**To:** @nhs.net  
**Subject:** Request of the Infected Blood Inquiry for assistance

Dear

I am a Paralegal with the Infected Blood Inquiry and I am contacting you to request your assistance in preserving potentially relevant information to the Inquiry's Terms of Reference, and your assistance in the provision of medical records to Inquiry witnesses.

Please find attached a letter from the Solicitor to the Inquiry which sets out the Inquiry's requests in more detail, together with correspondence between the Inquiry Chair, [REDACTED], and NHS England, and a statement by the Inquiry Chair published on our website on 14 February 2019.

You will see from the Chair's statement that we are in the process of contacting all NHS Trusts, Foundation Trusts and CCGs in England. I am responsible within the Inquiry for administering this process and I would be grateful if you could email your response to me by 11 March 2019.

Kind regards

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**Infected Blood Inquiry**

**Mobile:**

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

**Email:** [\[REDACTED\]@infectedbloodinquiry.org.uk](mailto:[REDACTED]@infectedbloodinquiry.org.uk)



Fleetbank House  
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EC4Y 8AE

Chief Executive Officer  
Northern Lincolnshire and Goole Hospitals NHS Foundation Trust  
Sent by email

25 February 2019

Dear

**Notice of retention/non-destruction of documents relating to the Independent Public Inquiry into Infected Blood and Blood Products (the Infected Blood Inquiry)**

I am the Solicitor to the Infected Blood Inquiry, which was formally set up on the 2 July 2018 by a statement made to Parliament by the Minister of the Cabinet Office and Chancellor of the Duchy of Lancaster,

I am writing to you in your capacity as Chief Executive of an [NHS Trust/NHS Foundation Trust/Clinical Commissioning Group] to request that you retain and refrain from destroying any documents and information that your organisation holds that may be of relevance to the Inquiry.

**1. Background**

The Inquiry Chair, [redacted] wrote to the Chief Executive of NHS England, [redacted] on 5 July 2018 to request that measures be put in place to secure the retention of all documents and information relevant to the Inquiry's Terms of Reference across the NHS in England. The Chair requested that his letter and the Inquiry's Terms of Reference be circulated to all parts of the organisation, intending to mean all organisations within the NHS in England.

National Medical Director of NHS England, [redacted] responded on 19 July 2018 and confirmed that robust safeguards would be put in place within NHS England to preserve all potentially relevant material. On receipt of this letter, the Inquiry understood that safeguards had been put in place across all NHS

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organisations in England in connection with this Inquiry. However, we now know that the steps taken by NHS England apply only to the documents and information for which NHS England, as a commissioning body, is responsible.

In these circumstances, the Inquiry is writing directly to each NHS Trust, NHS Foundation Trust and Clinical Commissioning Group in England, rather than seeking to implement safeguards through a single point of contact.

## **2. Documents and information to be retained**

To assist as a guide, the information that the Inquiry requests be retained includes, but is not limited to, the following types of material: individual patient medical records, reports, reviews, briefings, minutes; notes and correspondence however held (paper, electronic, microfiche, audio, video and any other means), which is potentially relevant to the Inquiry's Terms of Reference and List of Issues which can be found on our website (<https://www.infectedbloodinquiry.org.uk/terms-reference>). You will note from those documents the breadth of issues into which we are inquiring. If you are at all unsure as to whether information and documents in the possession or control of your [NHS Trust/NHS Foundation Trust/Clinical Commissioning Group] are of relevance, please ensure retention and contact the Inquiry for clarification.

## **3. Confirmation of documents and information destroyed since 5 July 2018**

It may be that you have taken independent steps to ensure the retention of potentially relevant documents and information. If this is the case, I would be grateful if you could confirm the position.

If not, please circulate this letter to all parts of your organisation to preserve all potentially relevant material and to ensure that no line of investigation is prejudiced by the destruction of files and records.

In the event that documents and information that may have relevance to the Inquiry have been destroyed since 5 July 2018, please provide to the Inquiry a copy of the record of destruction.

## **4. Access to medical records and waiver of fees**

Individual patient medical records will be highly relevant to the work of the Inquiry. It is critical that relevant records are retained and made available in full to those patients and/or their families who are seeking to engage with the Inquiry. The Chair has requested specifically that any fees that might be chargeable for accessing

medical records held by NHS organisations be waived and that requests for medical records be processed without delay. We would be very grateful for your assistance in this regard.

For information, please find attached a copy of the Chair's correspondence with NHS England relating to the matters discussed in this letter, together with a copy of the Chair's statement published on the Inquiry website on 14 February 2019.

Please do not hesitate to contact me should you require any further clarification,

Yours sincerely

**Solicitor to the Inquiry**

**Email:** [info@infectedbloodinquiry.org.uk](mailto:info@infectedbloodinquiry.org.uk)  
**Telephone:**

On 5 July 2018 I wrote to the relevant heads of the NHS in the UK to request that no documents, files or paperwork that may be of interest to the Inquiry be destroyed. I wrote again on 12 December about the delays some people have been experiencing accessing medical records and asking for action.

In Scotland, Wales and Northern Ireland the Inquiry's request was circulated to all NHS Trusts, Foundation Trusts, Health Boards and other statutory bodies within those countries.

The Inquiry has learned, through the diligent work of [redacted] and Factor 8, that this did not occur within the NHS in England. I am grateful to [redacted] for bringing this matter to my attention.

NHS England apparently interpreted my request as applying only to itself as a stand-alone organisation. It is disappointing both that this narrow approach was taken when NHS England presents itself as leading the National Health Service in England, and that NHS England did not tell the Inquiry that it did not intend to pass my request on to Trusts, Foundation Trusts and Clinical Commissioning Groups.

Those people participating in the hearings – whether in London, Belfast, Leeds, Edinburgh, Cardiff or following at home – should not have to worry about accessing medical records, nor about current NHS record keeping, whatever criticisms there may be of its record keeping in the past.

In these circumstances, and to avoid any further delay, I have instructed the Solicitor to the Inquiry to contact each NHS Trust, NHS Foundation Trust and Clinical Commissioning Group in England direct, rather than now relying on NHS England to do so. We will request and require that each Trust and Group retains all relevant documents and waives fees for people seeking copies of their medical records. I will also seek to determine whether any relevant documents (and if so which) are likely to have been destroyed in the meantime. I look for the fullest co-operation from NHS England in this.

I am being told that the great majority of people at the heart of this Inquiry have for years felt that they have been ignored, and that when they ask for information or explanation, are met with a wall of silence. Many have complained about being kept in the dark. I am determined that the Inquiry itself should not be a body against whom such allegations can be made. Whoever the participant is, whether a person, organisation or official body, trust in the work of the Inquiry can only be achieved through transparency. Accordingly, I have set out what did not happen, why it did not happen, and what is being done to put the position right.

Chair of the Infected Blood Inquiry

*This statement was provided in advance to NHS England*



Chair  
Infected Blood Inquiry  
1<sup>st</sup> Floor, Fleetwood House  
2-6 Salisbury Square  
London  
EC4Y 8AE

National Medical Director  
6<sup>th</sup> Floor, Skipton House  
80 London Road  
SE1 6LH

15 January 2019

**By Email**

Dear

**Infected Blood Inquiry**

Thank you for your recent letter in which you highlight delays in accessing medical records held by NHS England. I have responsibility for leading NHS England's response to the Inquiry.

May I firstly reiterate NHS England's commitment to supporting the Infected Blood Inquiry (IBI) and ensuring those who may have been affected are swiftly responded to.

We now expect that, where NHS England holds patient records, they will be released within the next three weeks, following appropriate redaction and identity verification. Unfortunately, there are some medical records which NHS England does not hold and further information will be provided to all applicants in the very near future.

It has taken some time to respond due to the need to obtain the relevant information governance advice and approval but I want to reassure you that, now the process has been put in place, the path will be smoothed for future applications.

To ensure we continue to be responsive to the Inquiry I would be happy to meet with you or your team. I would also like to take this opportunity to invite a representative of the Inquiry to join NHS England's IBI Response Steering Group. The next meeting will be held on 4<sup>th</sup> February 2019.

We will send further details to the Inquiry's solicitor, with whom I know the team here at NHS England has been in regular contact.

Yours sincerely,

**National Medical Director  
NHS England**



Fleetbank House  
1<sup>st</sup> Floor, 2-6 Salisbury Square  
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EC4Y 8AE

Chief Executive of NHS England  
By email

12 December 2018

Dear

**Infected Blood Inquiry**

Thank you for the support for the Inquiry of NHS England. The Inquiry is receiving large volumes of material and appreciates the work across NHS England that has contributed to that.

Letter of 19 July confirmed that fees would be waived for people infected and affected accessing and obtaining copies of their medical records. However, some people are experiencing delays accessing medical records and this is understandably causing distress and delay for those who would otherwise be ready to give witness statements.

Your actions in reducing these delays would assist the Inquiry in hearing first from people infected and affected. It is vital that those who wish to review contemporaneous records are able to do so without any further delays and I would ask that you take the necessary measures to ensure this is the case.

A copy of this letter will be published on the Inquiry's website.

Yours sincerely,

**Infected Blood Inquiry**

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[contact@infectedbloodinquiry.org.uk](mailto:contact@infectedbloodinquiry.org.uk)

19 July 2018

Dear :

Thank you for your letter dated and received 5 July 2018, concerning the Infected Blood Inquiry.

NHS England is fully committed to this inquiry. I understand your team has already met with representatives from NHS England's medical and corporate records teams. This has established a co-operative and productive relationship which will no doubt get stronger as the inquiry progresses.

We will ensure robust safeguards are put in place within NHS England to preserve all potentially relevant material held by or on behalf of NHS England, and ensure that the investigation is not compromised by the destruction of relevant files or records over which NHS England has control. We are considering what arrangements are necessary in NHS England to ensure we meet our commitments to the Inquiry in a timely and effective way.

The new Data Protection Act 2018, which came into force on 25 May 2018, introduced a new condition on fees that stipulates that, in most cases, organisations cannot charge a fee to comply with a request for personal data. This therefore supports one of the requests in your letter. Our Information Governance colleagues will ensure this is the case, and that requests for such data are handled sensitively with any potential fees waived.

One potential implication of us ensuring we are fully compliant and responsive to the needs of the enquiry is the substantial costs of retaining the large volume of records implied by the scope of the enquiry. This is particularly the requirement to retain GP medical records for deceased patients as well as those for patients who are not currently registered with a GP where records are now outside their standard retention period but could be within scope of the Inquiry. Due to the volumes involved these costs could rise above £2m per annum. I trust that the Inquiry will be sympathetic to practical suggestions for how to identify the required records in an expedient way and then allow for the appropriate

*High quality care for all, now and for future generations*

destruction of the records that are not required to limit the costs to the public purse.

I hope my reply reassures you and I look forward to working with you on this inquiry.

Yours sincerely,

**National Medical Director  
NHS England**



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Chief Executive of NHS England  
By email

05 July 2018

Dear

**Notice of retention/non-destruction of documents relating to the Independent Public Inquiry into Infected Blood and Blood Products (the Infected Blood Inquiry)**

On 2 July the Minister of the Cabinet Office and Chancellor of the Duchy of Lancaster, announced the formal set up of an independent public inquiry, the Infected Blood Inquiry, of which I was appointed Chair on 8 February.

I write in my position as Chair of the Inquiry with regard to the large amount of information and records with potential relevance to the work of the Inquiry held by your organisation and by those for whom you are responsible.

The Terms of Reference for the Inquiry (attached) are broad and cover a lengthy period and there is potential for material from around the time of the inception of the NHS to be considered in evidence.

Specific requests for information will be made by my team following some initial scoping work, and in order to preserve all potentially relevant material and to ensure that no line of investigation is prejudiced by the destruction of files or records I would be grateful if you would please circulate this letter and the attached Terms of Reference to all parts of your organisation. My team and representatives of the NHS are already in contact and I anticipate a co-operative and productive relationship over the course of the Inquiry.

To assist as a guide, the information that I request is retained includes, but is not limited to, the following types of material: reports, reviews, briefings, minutes; notes and correspondence however held (paper, electronic, microfiche, audio, video and any other means), which is potentially relevant to the issues set out in the attached

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## Terms of Reference.

May I separately raise with you two issues concerning the medical records of people who were infected and affected (which includes the families of people who sadly died as a result of infection from infected blood and blood products). First, to stress that such medical records are likely to be highly relevant to the work of the Inquiry and to request that all necessary steps are taken to ensure that they are preserved. Second, to request that any fees normally charged to access and obtain copies of medical records, including the records of a deceased family member, are waived in the case of infected and affected people who request access and copies for the purpose of providing evidence to the Inquiry. The Inquiry anticipates that many hundreds and possibly thousands of infected and affected people will seek to provide witness evidence to the Inquiry and will need to access and make reference to their or their family member's medical records for this purpose. The Minister for the Cabinet Office has already announced through a Notice of Determination pursuant to section 40 of the Inquiries Act 2005 (a copy of which can be found on the Inquiry's website [www.infectedbloodinquiry.org.uk](http://www.infectedbloodinquiry.org.uk)) that, because of the exceptional nature and gravity of the infected blood tragedy, means testing for publicly funded legal expenses will be waived. I would be grateful if you could indicate that similar arrangements, by way of a waiver of fees normally charged to access and obtain copies of medical records, might be put in place for witnesses to the Inquiry.

In line with the approach I set out to the Minister and the people infected and affected, for an open and transparent Inquiry, a copy of this letter will be published on the Inquiry's website.

Thank you in anticipation of your assistance.

Yours sincerely



## **INFECTED BLOOD INQUIRY**

### **TERMS OF REFERENCE**

#### **What happened and why?**

1. To examine the circumstances in which men, women and children<sup>1</sup> treated by national Health Services in the United Kingdom (collectively, the “NHS”)<sup>2</sup> were given infected blood and infected blood products, in particular since 1970, including:
  - a. the treatment of men, women and children who were given infected blood or infected blood products through transfusion or other means;
  - b. the treatment of men, women and children with haemophilia or other bleeding disorders who were given infected blood products (recognising that the position of those with mild, moderate and severe bleeding disorders may require separate consideration during the Inquiry);
  - c. what was, or ought to have been, known at any relevant time about the risks of infection associated with blood donations and blood products, by Government (in particular the Department of Health<sup>3</sup>), pharmaceutical companies, any relevant licensing authorities, NHS bodies, the medical profession, and other organisations or individuals involved in decision-making in relation to the use of blood and blood products;
  - d. to what extent people given infected blood or infected blood products were warned beforehand of the risk that they might thereby be exposed to infection, and if so whether such warnings as were given were sufficient and appropriate;

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<sup>1</sup> Including all gender identities.

<sup>2</sup> References to NHS used throughout is intended to encompass the National Health Service in England, Health and Social Care in Northern Ireland, NHS Scotland, NHS Wales and their predecessors.

<sup>3</sup> References to Department of Health used throughout is intended to encompass the Department of Health and Social Care, the Department of Health in Northern Ireland, Health and Social Care Directorates of the Scottish Government, the Department for Health and Social Services in Wales and their predecessors.



- e. the adequacy of the systems adopted for the screening of donors, and the collection, testing, licensing and supply of blood and blood products for use by the NHS;
  - f. the United Kingdom's failure to become self-sufficient in the production of blood products (and consideration of any relevant differences in terms of self-sufficiency between England, Wales, Scotland and Northern Ireland);
  - g. the actions of Government (in particular the Department of Health), pharmaceutical companies, licensing authorities, NHS bodies, the medical profession, and other organisations or individuals involved in decision-making in relation to the use of blood and blood products;
  - h. why people were given infected blood or infected blood products, including the nature and extent of any commercial or other interests which may have affected decision-making;
  - i. the extent to which the supply of infected blood or infected blood products could, and if so, should, have been avoided or been stopped earlier; and if so how best this might have been achieved.
2. To ascertain, as far as practicable, the likely numbers of people who have been infected (directly or indirectly) in consequence of:
- a. the use of infected blood; and
  - b. the use of infected blood products.
3. To examine whether, in addition to the HIV, Hepatitis C and Hepatitis B ("HCV" and "HBV") viruses with which it is known that people were infected, people may have been exposed to the risk of other diseases (such as vCJD) in consequence of the use of infected blood or infected blood products.

## **Impact**

4. To consider the impact of infection from blood or blood products on people who were infected ("those infected") and on partners, children, parents, families, carers and others close to them ("those affected"), including:
  - a. the mental, physical, social, work-related and financial effects of:
    - i. being infected with HIV and/or HCV and/or HBV in consequence of infected blood or infected blood products;
    - ii. the treatments received for these infections;
  - b. the extent to which treatment, medical and dental care for other conditions was compromised by perceived infective status;
  - c. the impact of these infections on partners, children, parents, families, carers and others close to those infected, including the impact on those who suffered bereavement; children who were taken into care; those who were advised to, or did, terminate pregnancies; and those who had to take difficult decisions about whether or not to have children;
  - d. the wider social impact on those infected and affected, including the stigma associated with a diagnosis of HIV and/or HCV and/or HBV.

## **The response of Government and others**

5. To examine:
  - a. the nature, adequacy and timeliness of the response of Government (in particular the Department of Health), NHS bodies, other public bodies and officials, the medical profession, the UK Haemophilia Centre Doctors Organisation, the pharmaceutical industry and other organisations (including the Haemophilia Society), to the use of infected blood or infected blood products to treat NHS patients;

- b. the nature and extent of any attempt to identify those who may have been infected and might benefit from treatment, to include the adequacy of any “look back” exercise;
- c. whether Government or the NHS could or should have done more to counter any stigma associated with these infections.

#### **Consent**

- 6. To examine:
  - a. whether and to what extent people were treated or tested or their infection status was recorded without knowledge or consent;
  - b. the testing or treatment of a category of patients referred to as Previously Untreated Patients (“PUPS”).

#### **Communication and information-sharing**

- 7. To examine the adequacy of the information provided to people who were infected or affected, including:
  - a. the nature, adequacy and timeliness of the information provided to those infected about their condition(s);
  - b. how the results of tests or information about their condition(s) were communicated to those infected;
  - c. whether, and if so what, information should have been provided to those most closely affected by the infection of a patient about that infection and any consequent risk to them.

### **Treatment, care and support**

8. To consider the nature and the adequacy of the treatment, care and support (including financial assistance) provided to people who were infected and affected (including the bereaved), including:
  - a. whether and to what extent they faced difficulties or obstacles in obtaining adequate treatment, care and support;
  - b. the availability and adequacy of any counselling or psychological support for those infected or affected;
  - c. the actions of the various Trusts and Funds set up to distribute payments;
  - d. the differing criteria for eligibility for financial assistance applied by the various Trusts and Funds, the justification (if any) for such differences and whether such differences were or are equitable;
  - e. the appropriateness of preconditions (including the waiver in the HIV Haemophilia Litigation) imposed on the grant of support from the Trusts and Funds;
  - f. the extent of any differences in the arrangements made for financial assistance between England, Wales, Scotland and Northern Ireland;
  - g. a broad consideration of the extent to which support is and has been comparable with support for those similarly infected and affected in other countries, for example, Canada and EU nations, such as France and Ireland.

### **Candour, openness and cover-up?**

9. To examine whether:
  - a. there have been attempts to conceal details of what happened (whether by destroying documents or withholding information or failing to include

accurate information in medical records or otherwise), and if so the extent to which those attempts were deliberate;

- b. there has been a lack of openness or candour in the response of Government, NHS bodies and/or other bodies and officials to those infected or affected.

### **Responsibilities**

- 10. To identify, in relation to the matters set out above, any individual responsibilities as well as organisational and systemic failures.

### **Recommendations**

- 11. If the Inquiry considers it appropriate, to make interim recommendations.
- 12. To report its findings to the Minister for the Cabinet Office, and to make recommendations, as soon as practicable.