

17 July 2018

Dear Colleague

UK INFECTED BLOOD INQUIRY – RETENTION OF RECORDS

Summary

This Director's letter asks you to ensure any patient or other records you hold which may be relevant to the UK Infected Blood Inquiry are not destroyed. It also asks you to ensure that patients or, in the case of patients who have died, their relatives are not charged for copies of their medical records.

Background

The Infected Blood Inquiry will consider the events which led to NHS patients across the UK becoming infected with hepatitis c and/or HIV (and in some cases also hepatitis b) as result of treatment with blood products or via blood transfusions or tissue transplants up to 1991. It will also consider more broadly how those patients were diagnosed and advised of their diagnoses and the treatment and support they have received since diagnosis.

I have attached a copy of a letter from the chair of the UK Infected Blood Inquiry to Paul Gray, which includes a copy of the Inquiry's terms of reference. I should be grateful if you would review the letter and terms of reference to consider what records you have which may be relevant to the inquiry.

Whilst it has provisionally been agreed that the inquiry will not duplicate areas already considered by the Penrose Inquiry in relation to Scotland, it is still possible that the inquiry team will want to access copies of records which Lord Penrose previously considered. In addition, the UK Inquiry's scope is broader than that of the Penrose Inquiry, both in terms of subject matter and the time periods considered, so you may still have records which were not relevant to the Penrose Inquiry terms of

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Addresses

For action

Chief Executives, NHS Boards
Medical Directors, NHS Boards

For information

Chairs, NHS Boards
Directors of Public Health

Enquiries to:

Samantha Baker
3E, St Andrew's House
Regent Road
Edinburgh EH1 3DG

Tel: 0131 244 7011

E-mail sam.baker@gov.scot

reference, but which will be relevant to the UK Inquiry. Therefore, if there is any possibility that records may be relevant I would ask that they are retained, at least for the next two years. As well as the records held by the Scottish National Blood Transfusion Service and the Scottish haemophilia centres, records which could be relevant may also include anything related to: policies and decision making regarding provision of blood transfusions or tissue transplants, records regarding diagnosis and treatment of patients with hepatitis c, HIV, hepatitis b and patients suspected to be at risk of variant CJD.

I understand that there is already a hold on destroying GP patient records due to the Scottish Child Abuse Inquiry. I would ask that you also ensure hospital patient records are not destroyed for the time being – at least for the coming year – where they might be requested by the Inquiry or patients or their families. That will particularly apply to any records about whether or not a patient had a blood transfusion up to September 1991, any records relating to patients with inherited bleeding disorders and any other records relating to patients diagnosed with either hepatitis C or HIV, or both, who may have acquired their infection via NHS blood, tissue or blood products.

Sir Brian Langstaff's letter also asks that any fees for patients and their families to access patient records are waived. I would hope that this is not problematic. Under the General Data Protection Regulation (GDPR), it is no longer permissible to charge patients for access to their own medical records, although there are a few exceptions, such as for second or further copies which are requested within a short period of time. Whilst GDPR does not apply in the case of patients who have died, I would also ask that you do not charge fees in the case of family members seeking medical records of a deceased relative.

Action

I would therefore ask that you review the attached letter from Sir Brian Langstaff and arrange for staff in relevant areas to:

- Seek to identify records which may be relevant to the Inquiry and ensure that those records are not destroyed;
- Ensure that fees are not charged for access to patient medical records, including in the case of patients who have died.

Yours sincerely,



Gareth Brown
Deputy Director and Head of Health Protection Division