Witness Name: Louise Williams

Statement No.: WITN4690005

Exhibits: WITN4690006 -008

Dated: 27 April 2021

INFECTED BLOOD INQUIRY

SECOND WRITTEN STATEMENT OF LOUISE WILLIAMS

I, Louise Williams (LHSA Archivist), on behalf of Lothian Health Board, will say as follows:

1. Searches, including search terms used

List of searches

1.1. The Inquiry's Rule 9(2) request of 15 August 2018 related to documents from the Edinburgh Haemophilia and Thrombosis Centre, excluding health records of individual patients. Documents produced for this request came from two main sources: files outside business use transferred to LHSA and files still in retention, kept inside NHSL long-term storage. A small number of paper files were later added to these. Born digital files from NHSL electronic storage were also listed.

Archive files: Acc15/022

1.2. Professor Christopher Ludlam transferred 19 boxes of files from the Centre no longer inside their retention periods to LHSA in 2015 (Acc15/022). These had been partially listed on a spreadsheet at the time of the August 2018 Rule 9(2) request [WITN46900006]. The existing spreadsheet listing was completed for the purposes of the Inquiry, with each folder being described in a line (folder title, box of origin and description). More relevant files were highlighted in red. These were determined through their subject matter (for example, those mentioning).

HIV, hepatitis, bleeding disorders, or relating to the day-to-day running of the Centre) and relevance to the Inquiry's Terms of Reference. The spreadsheet was compiled by LHSA Archivist, Louise Williams.

Files still in retention

- 1.3. The search for relevant material across NHSL sites was co-ordinated by Director of Public Health and Health Policy, Professor Alison McCallum. As a result, LHSA's existing spreadsheet was expanded to include material from the Edinburgh Haemophilia and Thrombosis Centre still inside its retention period in long-term NHSL storage. This material was transferred to LHSA secure storage for the purposes of listing and in order to provide appropriate conditions for Inquiry staff to access material if desired. These boxes were identified as being of relevance through searches of finding aids to files in NHSL long-term storage by current haematology clinical staff.
- 1.4. These boxes were moved to LHSA in two stages for easier access and listing. Seven boxes (B313455 B313461) were transferred in October 2018. One box contained papers and data relating to the Scottish Haemophilia Study, with the remaining six made up of copy patient records compiled for use in the Penrose Inquiry. In December 2018, a further 21 boxes of material were transported from NHSL long-term storage to LHSA archive stores (B215314 B215334). These comprised the remainder of Professor Ludlam's files from the Edinburgh Haemophilia and Thrombosis Centre (that is, those still in retention, with which Acc15/022 originally belonged). They were also added to the listing spreadsheet, with one folder described per line of the spreadsheet. Although all folders were described, material believed to be more relevant was highlighted in red, based upon subject matter (reference to HIV, hepatitis C or haemophilia, for example), the Inquiry's Terms of Reference, and the key timeframes of 1980s and 1990s.

Separate additions

1.5. A further three folders of material were added to the listing spreadsheet in January 2019, after they were donated by Professor Ludlam: statistical return sheets for the Edinburgh Haemophilia and Thrombosis Centre, correspondence with Dr D B L McClelland (Scottish National Blood Transfusion Service), and handwritten notes on individual patients. These files are stored with boxes B215314 - B215334, and were given a temporary accession number of Acc18/036

1.6. It was later identified that Acc18/008, donated by Professor Ludlam, also featured some Edinburgh Haemophilia and Thrombosis Centre material (two folders and loose documents). Acc18/008 was listed on an initial audit spreadsheet of material held across LHSA of possible relevance to the Inquiry compiled when the Inquiry was announced, and later supplied to GRO-D An updated spreadsheet for the Edinburgh Haemophilia and Thrombosis Centre is supplied with this statement for clarity, which includes more detailed descriptions of relevant Acc18/008 folders

NHSL digital files

1.7. In October 2018, digital files compiled by Sheena Walter (now NHSL Service Manager, Capacity Development and Commissioning) in response to the Penrose Inquiry were securely transferred from NHSL electronic storage to the UE Data Safe Haven (a protected digital repository holding confidential research resources). Ms Walter co-ordinated the supply of material created by the Edinburgh Haemophilia and Thrombosis Centre during the Penrose Inquiry. These files were listed in a separate spreadsheet. They included administrative files outlining NHSL's work around the Penrose Inquiry (including logistics for document preparation and identification of medical records), communication with Penrose Inquiry staff, statements prepared in response to the Penrose Inquiry, and some scanned archival documents (from originals now in Acc15/022 and B215314 – B215334).

Inquiry research visits

1.8. Staff from the UK Infected Blood Inquiry paid three visits to LHSA in 2018 and 2019 in order to view material identified during this response to this Rule 9(2) request. GRO-D and GRO-D visited in October 2018 in order to view selected files from Acc15/022. GRO-D and GRO-D visited in May 2019, reviewing material from boxes B313455- B313461 and B215314 – B215334. GRO-D visited LHSA with a team of researchers in July 2019, and viewed all unseen material from boxes B313455 – B313461 and B215314 – B215334,

and selected additional folders from Acc15/022. Copies of relevant documents were requested during the three visits.

1.9. **GRO-D** and her team will view Acc18/008 on their next visit to the archive (postponed from April 2020 due to COVID-19 restrictions).

Future transfers / listing

1.10. Due to the continuing nature of transfers to LHSA from NHSL, LHSA listing spreadsheets will be updated should files be accessioned that are relevant to the discussed Rule 9 order and / or the Inquiry's Terms of Reference. Updated spreadsheets will be forwarded to Inquiry staff immediately following the listing of any unseen potentially relevant material. LHSA Archivist, Louise Williams, will view and list potentially archival documents found as part of the process of ongoing request and review of such material as soon as COVID-19 restrictions are lifted.

Search terms used

- 1.11. Collections directly related to Edinburgh Haemophilia and Thrombosis Centre were either uncatalogued (if accessioned to LHSA i.e. Acc15/002, Acc18/008) or from long-term NHSL storage (boxes with B numbers, temporary accession Acc18/036, NHSL digital files). LHSA did not hold detailed / complete digital finding aids in which to search before spreadsheet listings were compiled for the Inquiry.
- 1.12. Finding aids to catalogued LHSA collections are available online (https://bit.ly/390NCqT). LHSA keeps an internal database of accessions after 2000, and word-processed lists of accessions from 1996 to 2007. Relevant material from accessions and LHSA catalogued collections has been highlighted in an LHSA audit spreadsheet provided to the Inquiry, from which Inquiry research teams have selected documents to view.
- 1.13. In order to identify relevant documents / collections, the following search terms were used across all finding aids to collections identified in paragraphs 1 10: blood, hepatitis, HIV (and expanded), HTLV III (and expanded), AIDS (and expanded), transfusion, haemophilia, hemophila, haematology, hematology. A

subsequent search of electronic finding aids has been carried out under further terms suggested by the Inquiry in their letter of January 2020, and no further relevant documents have been identified beyond that which has already been requested by Inquiry research teams.

- 2. The Trust's information repositories (from 1950 to present day) such as local authorities, University archives and The National Archives
 - 2.1. LHSA is NHSL Lothian's archive based in the University of Edinburgh (UE). LHSA is owned and core funded by NHSL; it is project funded by a variety of institutions, including the Wellcome Trust. LHSA is the designated archive for NHSL under compulsory Element 7 of NHSL's model records management plan produced in compliance with the Public Records (Scotland) Act 2011 (PRSA). PRSA requires Scottish public authorities to have proper arrangements in place for the management of the records they produce.
 - 2.2. LHSA is the only archive (in its present and past forms) over which the Trust and Health Board has ever had and has control, responsibility, or oversight. No archive for the Trust or its predecessor bodies existed until an archive was founded in 1967, caring for the historical records of the Royal Infirmary of Edinburgh (see below). Before that time, all historic records for the region's hospitals were kept on clinical or Board sites. The archive expanded in 1974 to take records from all Lothian hospitals and Boards (see LHSA Background, below). In the event that another archive repository existed for other Lothian hospitals and local Boards either before 1967 or between 1967 and 1974, investigations were carried out (see below). No other repository over which the Trust had control was found.

LHSA Background

2.3. In 1967, an archive was created for Edinburgh's main general hospital (and Scotland's first voluntary hospital), the Royal Infirmary of Edinburgh (RIE). The archive was founded on account of an accumulation of historic material from the institution's long history across the RIE site needing specialist management. When the National Health Service was re-organised in 1974, the archive widened its collecting policy beyond the RIE to take in archival records from other hospitals and services administered by Lothian Health Board. In 1980, Lothian

Health Board and UE entered into an agreement to found the Medical Archive Centre (now LHSA), supported by the Scottish Records Office (now National Records of Scotland). The Medical Archive Centre was located in High School Yards, on the UE estate. In 1988, LHSA moved to the UE Main Library, where it is still based. LHSA now collects all records worthy of permanent preservation from Lothian NHS hospitals and their governing and predecessor bodies (LHB collections), along with more general records relating to health and healthcare in the Lothian region donated by private individuals and organisations outside the NHS (GD collections).

2.4. LHSA is part of the UE Centre for Research Collections (CRC). The CRC is part of the Library & University Collections (L&UC) division of Information Services (IS), UE.

For organisational charts see:

https://www.ed.ac.uk/files/atoms/files/isorganisationchartsections may2019.pdf

https://www.ed.ac.uk/files/atoms/files/library and university collections november 2019.pdf

Three members of staff are employed in LHSA: one Manager, one Archivist, and one Access Officer. All staff hold professional archive / conservation vocational qualifications. The LHSA Manager is an Accredited Conservator, and the L HSA Archivist is a Registered Member of the Archives and Records Association.

For further information about LHSA services, please see the LHSA website: www.lhsa.lib.ed.ac.uk.

- 2.5. The following local archives with medically-related material were checked to ensure that only LHSA has, and had, a direct relationship with NHSL and its predecessor local Boards:
- 2.6. Archives held in CRC, UE
 - 2.6.1. The catalogue for UE's organisational archive was consulted:

https://archives.collections.ed.ac.uk/repositories/2/archival objects/17 084

2.6.2. No obvious records relevant to the Inquiry's terms of reference were found in the organisational collection, despite the historic close relationship between UE and NHSL in clinical activity (clinical research / teaching). UE holds copies of governance agreements with the Board as part of their joint business:

https://archives.collections.ed.ac.uk/repositories/2/archival objects/7150

- 2.6.3. However, these would have been kept from the UE side of this activity, and do not signal that UE acted as a repository or NHSL or its predecessors.
- 2.6.4. CRC, UE, also holds personal papers beyond UE's organisational archive some of these may be of interest to the Inquiry. Sir Ken Murray's papers reflect his work in hepatitis B and HIV, including files on AIDS research and blood transfusion:

https://archives.collections.ed.ac.uk/repositories/2/resources/86282

- 2.6.5. Since these papers are not owned by NHSL (therefore not held by LHSA), and LHSA staff have no physical access to them, they were not included in listings of NHSL material produced for the Inquiry. The <u>Centre for Research Collections</u>, University of Edinburgh, should be contacted for access. The Murray papers have not so far been seen by or copies provided to the Inquiry.
- 2.6.6. Papers from NHS Education for Scotland South East Deanery, found on UE premises, are also listed in the 'personal papers' section of the archive. They look to be less immediately relevant to the Inquiry's Terms of Reference:

https://archives.collections.ed.ac.uk/repositories/2/resources/85097

- 2.7. Royal College of Physicians of Edinburgh and Royal College of Surgeons of Edinburgh
 - 2.7.1. To the best of their knowledge, the Colleges' archivists are not aware that their respective archives ever acted as a repository for Lothian boards. The Colleges' archives have never been controlled by Lothian boards, and online catalogues have been searched with no evidence of collections donated by Lothian boards. Some individual documents collected by individual donors working for NHSL and predecessors may exist inside privately donated collections.

2.8. National Records of Scotland

- 2.8.1. The archivist in charge of NHS records deposited in NRS has been contacted (NRS hold records from Scotland's special boards, but not territorial boards). She is not aware that any records from NHSL or predecessor boards have ever been deposited with NRS, or that NRS ever acted as an archive for Lothian boards.
- 2.9. Edinburgh City Archives (Edinburgh's local authority archive)
 - 2.9.1. Online catalogues confirm that Edinburgh City Archives hold records from the Public Health Department of the City of Edinburgh (since local authorities took a leading role in the provision of public health services):

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https://bit.ly/2InfRFu (SL26) [WITN4690007]
https://bit.ly/39vQQ6S (SL27)
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2.9.2. City Archives also hold a few annual reports from the Edinburgh Health Council, which involved Lothian Health Board:

https://bit.ly/2TswXrl (SL38)

2.9.3. The archivist at Edinburgh City Archives has been contacted about these holdings. Some of what became collection SL26 (Public Health Committee) was donated in 1987 from Community Health Services, Lothian Health Board (please see letter from then Edinburgh City

Archivist, Arnott Wilson, attached). City Archives hold a paper hand list of all records originally offered in this donation of duplicate minutes and published material (referred to in attached letter), which will indicate what had been considered worthy of permanent preservation. A copy of this list can be obtained following removal of the current COVID-19 restrictions, if needed. The current Edinburgh City Archivist states that this is the only collection deposited directly by the Board, and is not evidence of a deposit arrangement between City Archives and the Board (which had been in partnership with UE in the Medical Archive Centre – LHSA's immediate predecessor – since 1980).

2.10. Other Lothian council archives

2.10.1. East Lothian Council Archives, John Gray Centre

The archives hold images, plans and ephemera around the sites of East Lothian hospitals:

https://www.johngraycentre.org/connect/blog/a-history-of-health/

However, there is no evidence that East Lothian Council Archives was a repository over which the Trust ever had authority or control.

2.10.2. West Lothian Council Archives

West Lothian Council Archives hold records of the development of hospitals (in which the Development Corporation had an interest), and some records relating to education provision in hospitals for young people. This is not evidence that West Lothian Council Archives was a repository over which the Trust ever had authority or control.

2.10.3. Midlothian Council Archives

A fuzzy search of the online catalogues of Midlothian Council Archives for 'NHS', 'hospital', 'Board' and 'Lothian Health Board' returned no results.

- 3. Repositories and archives searched
 - 3.1. Please see response to question 1.
- 4. This section should only be used if documents have been destroyed. Please explain briefly and exhibit copies of the relevant document destruction record or policy to the statement.
 - 4.1. In line with the notice of April 2018 issued by Sir Brian Langstaff, no records requested in the Rule 9 request of 15 August 2018 held by LHSA have been destroyed. For information on LHSA's disposal procedures, please see attached document [WITN4690008].
 - 4.2. LHSA's internal record of deaccession (that is, removal of materials previously taken into the archive) and disposal was checked in order to ascertain whether any documents of potential relevance to the Inquiry held by LHSA have ever been destroyed. This information goes back to 2002 in electronic form. LHSA holds no previous paper record of disposals to the knowledge of the LHSA Archivist, following a search of departmental file inventories. From this search, the following items of possible interest once held in LHSA but now destroyed or deaccessioned were identified:
 - 4.2.1. One Lothian Health Board folder relating to the Scottish National Blood Transfusion Service (SNBTS) was securely destroyed during cataloguing in 2010, since it was considered ephemeral, only giving details of a site visit and having no historical value. No date was for this file was recorded before its destruction.
 - 4.2.2. Blood Transfusion Service Tissue Service records (no covering dates or further description recorded) were deaccessioned and transferred back to SNBTS in 2004.

Statement of Truth

I believe that the facts stated in this witness statement are true.

Signed:	GRO-C	

Dated: _27 April 2021_____

Table of exhibits

Date	Notes/Description	Exhibit Number
Created:	Catalogue of	WITN4690006
10.09.2018	Haemophilia/Thrombosis Centre	
Last modified:		
22.09.2020		
Created:	Collection SL26: List of Minutes of	WITN4690007
14.11.2000	Edinburgh City Archives Public	
Last modified:	Health Committee	
15.11.2000		
Created:	De-accessioning & Disposal	WITN4690008
25.03.2020	procedure	
Last modified:		
25.03.20		