

Witness Name: Louise Williams

Statement No.: WITN4690001

Exhibits: WITN4690002 – 004

Dated: 22nd November 2022

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF LOUISE WILLIAMS

I, Louise Williams, will say as follows:

This document is a response from Lothian Health Services Archive to the above Rule 9 request. It covers arrangements, actions and procedures relating to Lothian Health Services Archive only.

1. A complete account of the Board's archiving system, (whether considered relevant to the Inquiry's Terms of Reference or not).

- 1.1. Records outside their retention period which are worthy of permanent preservation (those no longer in active business use with enduring value for evidential, research or legal reasons) are transferred to Lothian Health Services Archive (LHSA), NHS Lothian's (NHSL) 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.

LHSA Background and purpose

1.2. 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).

1.3. 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.

1.4. 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

1.5. Three members of staff are employed in LHSA: one Manager, one Archivist, and one Access Officer. The LHSA Manager is an Accredited Conservator, and the LHSA 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.

Collection policy and transfer systems

1.6. Records worthy of permanent preservation are transferred to LHSA at the end of their retention periods (that is, when they are no longer in active business use or are required to be retained for healthcare, on-site research or legislative reasons). Transfers are instigated when NHSL staff make contact with LHSA when records reach the end of their current business use. Retention periods of both NHSL administrative and personal health records are assigned in annexes of the Scottish Government Records Management: Health and Social Care Code of Practice (Scotland) 2020. These annexes also give guidance on whether particular record types are worthy of permanent preservation in the archive: <https://bit.ly/3fQSs3A>

1.7. LHSA collects NHSL administrative records which evidence key functions of hospitals and boards – these tend to be high level records reflecting key decisions (such as finance committee minutes) rather than ephemeral information (such as collections of receipts). LHSA also collects archival patient records (no longer in active use and outside their retention periods), although more recent records are often sampled (either randomly or due to potential historic significance). All administrative and patient records prior to 1948 offered to the archive are retained.

1.8. Prior to the Health and Social Care Code of Practice (Scotland) 2020, guidance on the retention and destruction of records was included in the following documents:

Scottish Government Records Management: NHS (Scotland) Code of Practice, Version 2.1 (2012)

Scottish Government Records Management: NHS Code of Practice (Scotland) Version 2.0 (August 2010)

CEL 28 (2008) - Records Management: NHS Code of Practice (Scotland)

HDL (2006) 28 - The Management; Retention and Disposal of Administrative Records

MEL (1993) 152 - Guidance for the Retention and Destruction of Health Records

ECS(A) 21/1969 - Disposal of Records That Have Lost Their Value;

SHM 58/60 - Scottish Hospital Service Destruction of Hospital Records.

- 1.9. Due to NHS service re-organisation in the early 1990s (from Boards to NHS Trust status), a gap in records management and retention guidance for hospitals and boards may have led to the inadvertent destruction of some records which would otherwise have been transferred to the archive.
- 1.10. In addition to records designated as archival in the Health and Social Care Code of Practice (Scotland) 2020 and predecessor guidance, criteria for placing records in the archive can also be based on existing collection strengths (for example, LHSA holds significant collections around the history of HIV and on local psychiatric institutions). Similarly, awareness of gaps in collections (both in terms of document types and in particular perspectives) can also govern decisions on acquisition. All decisions on material to be placed in the archive are taken by appropriately qualified and experienced LHSA staff, often in consultation with appropriate NHSL colleagues.
- 1.11. A formal, board-specific schedule for the transfer of records from NHSL will be developed following the establishment of a business classification scheme (a compulsory element of records management plans produced in compliance with PRSA, currently in development for most NHS boards across Scotland). At present, LHSA is alerted to records of potential relevance by individual staff members and departments, whilst taking a pro-active approach to ensuring transfers to the archive.
- 1.12. LHSA's close working relationship with NHSL ensures awareness of the archive function in fulfilment of the obligations of PRSA. Staff have a presence on a number of NHSL and NHS Scotland committees and forums related to information governance and records management, and on ad hoc committees connected to particular initiatives (such as hospital moves/ closures).

Archiving systems inside LHSA

1.13. Transfer and storage of records

- 1.13.1. Transfers / donations to the archive are known as 'accessions'. NHSL records are securely transferred to LHSA on NHSL transport or couriered by LHSA staff. Paperwork relating to each transfer is signed by both NHSL and LHSA staff and kept permanently in the archive. Transfers of paper and digital records to LHSA from NHSL are recorded inside LHSA's accession database, and assigned a unique identifier. Material is physically checked (e.g. for pests / mould) before being moved to secure archive storerooms.
- 1.13.2. Paper and analogue multi-media records are housed on mobile shelving. The shelves are strong enough to support heavy records, with good ventilation between rows spaced to allow easy and safe access. The collections are not exposed to natural light, with artificial lighting used only when access is required. Direct access is restricted to LHSA staff trained in proper handling of archival material. All LHSA holdings are covered by an intruder alarm, CCTV and smoke detectors connected to the building's fire alarm system. The collections are covered by the UE Disaster Response and Recovery Plan. There is an air conditioning system for the storage areas and climatic conditions are monitored by the UE Preventive Conservator. Temperature and relative humidity are stable and within the recommendations of BS EN 16893:2018. An Integrated Pest Management Plan is also overseen by the Preventive Conservator. The long-term preservation of the collections is managed in accordance with the LHSA Preservation and Conservation Policy to ensure that continued storage, display and handling conditions meet the highest standard attainable.
- 1.13.3. Transfers of born-digital records are stored in dedicated, permissions-protected storage on UE servers.

- 1.13.4. New accessions (including transfers from NHS Lothian) are listed on the LHSA website:

<http://www.lhsa.lib.ed.ac.uk/collections/Accessions.htm>

- 1.13.5. Each year, lists of accessions are also sent to The National Archives to add to its Accessions to Repositories survey:

<https://www.nationalarchives.gov.uk/accessions/>

1.14. *Archiving systems inside LHSA: Appraisal*

- 1.14.1. On being taken into the archive, records are examined for their permanent archival value: a process known as appraisal. This is discussed in more detail in the context of disposal and destruction of records in Question 6.

1.15. *Cataloguing*

- 1.15.1. LHSA catalogues (i.e. describes and orders) NHSL's archival records after they have been taken in as accessions. Catalogues meet international best-practice standards of archival description (International Standard Archival Description (General) ISAD(G)) and are completed in compliance with established LHSA internal guidelines. LHSA adds new accessions to a cataloguing spreadsheet in order to determine priorities for future cataloguing (all archives have a cataloguing back-log due to the resource-intensive nature of the task). Once completed, catalogues are published on the LHSA website: <http://www.lhsa.lib.ed.ac.uk/collections/index.html>

- 1.15.2. Whereas legacy catalogues were produced as Word documents / PDFs, more recent catalogues are entered into the collections management system used by UE: ArchivesSpace. For example: <https://archives.collections.ed.ac.uk/repositories/4/resources/85769>

- 2. A list of all the Board's repositories, including those storing documents and information in hard copy, electronic format, and any other form (whether the documents and information stored within the repositories are considered relevant to the Inquiry's Terms of Reference or not), together with an**

indication of the quantity of documents and information stored at each facility.

2.1.1. LHSA is NHSL's archive under Element 7 of their records management plan in compliance with PRSA. LHSA holds 3100 linear metres of paper material, photographic material and objects held in the UE Main Library (30 George Square, Edinburgh, EH8 9LJ) and in the UE University Collections Facility (20 – 22 South Gyle Crescent, Edinburgh, EH12 9EB). LHSA also holds c. 9.175 GB of born-digital archive material on dedicated UE permissions-protected servers.

3. An account of the process for archiving the Board's documents and information at Lothian Health Services Archive and all other places of deposit. To include, but not limited to, the following information: the criteria for the transfer of Board documents and information to an archive or place of deposit; whether original documents are transferred and if so whether the Health Board retains copies; whether as part of the archiving process hard copy material is transferred to electronic format and if so whether the hard copy material is retained.

3.1. Please see Question 1 for a history of LHSA and an account of archiving processes. Original documents are transferred to LHSA: NHSL does not intentionally retain copies. However, there may be cases when a number of copies of documents have been produced (such as bound volumes of Board minutes, for example). In these circumstances, LHSA may hold one set, and (unknown to LHSA) other copies may exist across NHSL departments. LHSA does not retain exact duplicates of documents other than in exceptional circumstances (where duplicate copies of items in LHSA's UNESCO inscribed HIV/AIDS collections exist, three copies are retained on account of the significance of the collections, for example, and some microfilm copies have been produced for reasons of preservation). Hard copy documents are not transferred to digital format as part of the archiving process itself. However, some items in LHSA have been digitised to a high quality standard (for use in exhibitions, for example, or to reduce handling of the original). When items are digitised, originals are always retained (i.e. digitised materials are surrogates for, rather than replacements of, original documents).

4. A list and summary of all organisations and agencies that processed information (together with current contact details which may be provided separately) for which the Health Board had or has any control, responsibility, or oversight and material potentially relevant to the Inquiry's Terms of Reference and/or List of Issues, including NHS Lothian Laboratories.

4.1. Lothian Health Services Archive, University of Edinburgh Main Library, 30 George Square, Edinburgh, EH8 9LJ. 0131 650 3392. llsa@ed.ac.uk. Lothian Health Services Archive is an Accredited Archive Service, and NHS Lothian's designated archive under compulsory Element 7 of the organisation's records management plan under the Public Records (Scotland) Act 2011.

5. An account of the searches undertaken in response to the Inquiry's Rule 9(2) request dated 15 August 2018, including the search terms used, repositories checked and documents uncovered (whether considered relevant to the Inquiry's Terms of Reference or not).

5.1. 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 LLSA 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

5.2. Professor Christopher Ludlam transferred 19 boxes of files from the Centre no longer inside their retention periods to LLSA in 2015 (Acc15/022). These had been partially listed on a spreadsheet at the time of the August 2018 Rule 9(2) request. 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 LLSA Archivist, Louise Williams.

Files still in retention

5.3. The search for relevant material across NHSL sites was co-ordinated by Director of Public Health and Health Policy at that time, 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.

5.4. 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. These files were formally transferred to LHSA custody in December 2020.

Separate additions

5.5. 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.

- 5.6. 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** **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.

- 5.7. Since the Inquiry's Rule 9(2) request dated 15 August 2018, two further groups of files have been transferred to LHSA from the Edinburgh Haemophilia and Thrombosis Centre through the NHS Central Legal Office (NHS CLO). Four boxes of material relating to vCJD and haemophilia were transferred in December 2020 (Acc20/013). A further 23 boxes of material (mostly relating to issues of blood products to individual patients and compilation of statistics around this) was transferred in January 2022 (Acc22/001). The Inquiry is aware of these records, and requested and took receipt of digital copies from NHS CLO prior to transfer of all originals to the archive.

NHSL digital files

- 5.8. 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

5.9. Staff from the UK Infected Blood Inquiry paid five visits to LHSA from 2018 to 2021 in order to view material identified in the 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. Visits in January 2020 (a team led by [GRO-D]) and July 2021 ([GRO-D] [GRO-D] and [GRO-D]) concentrated on more general documents held by LHSA (such as material from collections about HIV, and administrative health board documents) and any remaining material relevant to the Edinburgh Haemophilia and Thrombosis Centre (Acc18/008). Copies of documents were requested by Inquiry teams during the five visits.

Future transfers

5.10. 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 Section 9 request 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.

6. An account of all the Board's retention and destruction policies, both past and present, together with an account of any material known to have been destroyed with potential relevance to the Inquiry's Terms of Reference and/or List of Issues. Please also provide copies of all destruction policies, past and present, as exhibits to the written statement.

6.1. LHSA carries out destruction of some records donated to the archive if they do not fulfil collection aims (see Collections Development Policy (WITN4690002 and Collections Management Policy (WITN4690003, attached) and are not considered worthy of permanent preservation. However, LHSA collects all personal health and administrative records generated by NHSL's predecessor bodies created prior to 1948. If possible, donations and

transfers to the archive are appraised for evidential value before material is officially taken into the archive (accessioned). If this is not possible, appraisal may be carried out when cataloguing material. Reasons for destruction of material include:

- Exact duplication of a document in LHSA's existing collections;
- Material designated as ephemeral;
- Material that should have been destroyed according to the retention schedules in the latest version of the Health and Social Care Code of Practice (Scotland) 2020;
- Material outside the scope LHSA's collection policy (e.g. general medical textbooks, medical instruments of unknown provenance, documents about health services outside Edinburgh and the Lothians, general practice records).

6.2. If material is privately donated (as are most of LHSA's collections about the general history of health in Edinburgh and the Lothians) and material is not kept by LHSA, donors have the option to authorise the transfer of any unwanted material to another appropriate repository or to have the material returned to them.

6.3. LHSA logs each case of destruction after accession, the reason for the action, and the method of disposal used. LHSA uses NHS secure methods of destruction for (potential and actual) personal identifying information. All destruction decisions must be 'signed off' and reviewed by the LHSA archivist before physical destruction can be carried out.

6.4. It is rare that material is destroyed from LHSA's catalogued collections ('de-accessioned'). Where de-accessions occur, this has historically usually been to mark the movement of a collection item to another catalogued collection, or to assign an item a different status within LHSA holdings (for example, in the movement of a published text to the LHSA reference collection).

6.5. LHSA follows internal destruction and de-accession procedures (see attached WITN4690004).

6.6. LHSA keeps electronic destruction schedules from 2000. Nothing of potential relevance to the Inquiry is listed on these schedules.

6.7. In the case of hospital and NHS Board administrative records dated after 1948, the following guidance is followed to determine archival value of transfers, although the final decision on accession to LHSA rests with the archivist: Section 7, Scottish Government Records Management: Health and Social Care Code of Practice (Scotland) 2020. The retention of personal health records is also guided by Section 6 of the Scottish Government Records Management: Health and Social Care Code of Practice (Scotland) 2020. Since it is impossible to retain a historic health record (i.e. a health record outside its retention period) for every individual (for reasons including space, finance and management), personal health records after 1948 are only retained by LHSA under legislative imperatives, in order to aid research in areas of collection strengths (e.g. history of psychiatry), or to fill notable gaps in holdings. Often these records are sampled (either randomly or subjectively) by the donor institution or by LHSA on accession. High level records (for example, volumes of admission registers) are usually prioritised over case notes.

6.8. LHSA does not review all records created by NHSL at the end of their period of retention, and most destruction of records at the end of their retention periods will take place within individual hospitals and at board level. LHSA enjoys good relationships with records management and information governance professionals inside NHSL. Moreover, LHSA staff are always happy to be contacted about records of potential relevance to the archive, and provide online guidance to NHSL staff on records suitable for archival preservation. LHSA staff have also advised NHS colleagues from other Scottish boards on records management and archival practices, and is an established presence on the NHS Scotland Records Management Forum.

6.9. The latest guidance on the retention and destruction of health and administrative records dates from 2020 and is currently under consultation (a process in which LHSA is involved). Historically, guidance on the retention and destruction of records was included in the following documents:

- Scottish Government Records Management: NHS Code of Practice (Scotland) Version 2.1 (January 2012)

- Scottish Government Records Management: NHS Code of Practice (Scotland) Version 2.0 (August 2010)
- CEL 28 (2008) - Records Management: NHS Code of Practice (Scotland)
- HDL (2006) 28 - The Management; Retention and Disposal of Administrative Records
- MEL (1993) 152 - Guidance for the Retention and Destruction of Health Records
- ECS(A) 21/1969 - Disposal of Records That Have Lost Their Value;
- SHM 58/60 - Scottish Hospital Service Destruction of Hospital Records.

6.10. Due to NHS service re-organisation in the early 1990s (from Boards to NHS Trust status), a gap in records management and retention guidance may have led to the inadvertent destruction of records now covered by more recent guidance inside hospitals and boards. Different guidance documents on the retention and destruction of records have evolving levels of detail: therefore, retention periods used now may not have been used throughout the period investigated by the Inquiry, and destruction decisions should be placed in the context of legislation and guidance in place at the time.

Statement of Truth

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

Signed

GRO-C

Dated 22 November 2022

Table of exhibits

Description	Document ID
LHSA Collections Development Policy	WITN4690002
LHSA Collections Management Policy	WITN4690003
LHSA De-accessioning and Disposal Procedure	WITN4690004

