Inquiry Presentation on the Destruction and Retention of Medical Records

Introduction

1. This presentation examines the difficulties infected individuals and their affected family members have had obtaining medical records. It does not seek to answer the individual circumstances of missing or destroyed records but addresses key themes in medical record retention and destruction. It first considers NHS retention and destruction policies, then addresses examples of environmental destruction of medical records, such as by fire and flood. This presentation also addresses the difficulties infected individuals and their affected family members have had in applying for records, including themes of delay and the impact of missing records. Lastly it considers examples of significant interference in medical records and evidence as to whether there has been intentional destruction or removal of medical records.

2. At the most fundamental level individuals who are not able to access a complete set of their own, or a family member's, medical records do not have a full picture about the medical treatment received. The absence of an official record has made it impossible for many individuals to ascertain how, where and when they were infected with blood-borne viruses. For adults who were infected as children there is a particular desire to understand what happened to them as children. For family members of deceased individuals there is also a desire to understand family members' treatment and what caused their death. This often is particularly the case for children of infected parents, who have attempted to reconstruct what happened to their parents.

3. Beyond this absence of information, the lack of access to a complete set of medical records has also meant that many individuals have been unable to access financial assistance from the Skipton Fund and successor Schemes or have had to go through lengthy appeal processes in order to attempt to prove the source of their infection. There are also examples of clinicians being unable to access a patient's earlier medical records to understand the source of an infection or what treatment a patient had previously received.

4. A key theme in the information received by the Inquiry is how challenging it has been for many patients to obtain medical records. There was, and remains, no central system where medical records are held and individuals have to apply to specific NHS Trusts, health boards or GP practices. This becomes more complex, particularly in the case of those with

haemophilia, where patients have received treatment over a number of years, from a number of hospitals and/or have moved throughout England, Wales, Scotland or Northern Ireland over the course of their lives. Individuals who received transfusions, particularly in the case of childbirth, have found that hospitals have long since closed down and medical records have been destroyed without any prior notification to patients. Some women have found that their medical records have not been updated or collated following a change from their maiden to married names, which has led to confusion and, for some, their records going missing.

5. Most individuals who have struggled to obtain a full set of medical records have stated that the process of obtaining historic medical records should be more straightforward than it is. One woman describes trying to obtain her late father's medical records as *'like a battle of wills'*.[1] She describes applying to a variety of organisations and seven different hospital trusts: '*chasing them up and asking them to look in specific departments and archives and sometimes having to complain.*'[2]

6. Another affected daughter describes attempting to obtain her mother's records in the following terms:

   '*we struggled to find someone who could assist us. At one point I called everyday but often no one would call me back.*

   Eventually, we received a letter saying that the records were no longer available and they could not help us. When we enquired further, we were given different reasons for this, including that the records had been destroyed in a fire and that they did not retain records for that long.'[3]

7. The Inquiry has also received many accounts of individual clinicians and GPs assisting patients and their families to apply for medical records, particularly in the context of applying for financial assistance. However, there are also examples of people with poor health or suffering a bereavement having to undertake a significant administrative burden in order to try and access a complete set of medical records.

[1] §5 of WITN3125001
[2] §5 of WITN3125001
[3] §§56-57 of WITN0709001

8. Many witnesses have commented that when they have received medical records they have been provided in a muddled and unchronological order.[4] Infected individuals and their family members have described difficulties reading through and understanding unsorted and unpaginated records. This is an especially difficult task for those who are suffering from health conditions. The records received are often partial and it is up to patients or their family members to try to identify what records are missing.

9. Some infected individuals and their affected family members, whose medical records have been destroyed, have queried whether there has been a cover up and/or a purposeful destruction of medical records in order to hide evidence and avoid a finding of fault against clinicians. The Inquiry has investigated a number of these concerns and approached individual trusts, health boards and social care trusts,[5] in order to obtain an explanation as to why medical records have been destroyed.[6] In the main, it has been difficult for the Inquiry to obtain sufficient evidence to enable these conflicts to be easily resolved due to the passage of time and the absence of clear evidence documenting why, when, and how medical records were destroyed.

Retention and destruction policies

10. This presentation first examines the legislative provisions about the retention and destruction of medical records. It then sets out the policies of a sample of individual NHS trusts / health boards, refers to the evidence of some clinicians about local practices and policies on record keeping and then provides some examples from infected individuals and their affected family members of medical records being destroyed under retention and destruction policies.

11. Before examining the legislative frameworks in the four countries that make up the UK, it is worth noting that the law concerned specifically with the retention and destruction of medical records, sits within a wider legal framework that addresses a range of important

[4] For example, see §3 of WITN1578001

[5] This presentation uses the phrase "NHS trusts / health boards" to encompass the various NHS organisations in England, Scotland, Wales and Northern Ireland.

[6] On the whole, the Inquiry has not investigated instances of missing GP records because of the high number of GP practices but has focused instead on NHS trusts / health boards.

issues such as the right to access health records,[7] the requirement to keep clear, accurate, and legible records,[8] the requirement to keep certain information confidential[9] and to abide by data protection laws,[10] and of course freedom of information.[11] These issues are beyond the scope of this presentation.

The legislative framework for retention of medical records in England

12. The Public Records Act 1958, as amended by the Public Records Act 1967, is the principal piece of legislation relating to public records.[12] Records of NHS organisations are public records: see Schedule 1 of the Act. The Secretary of State for Health and Social Care and all NHS organisations have a duty under the Act to make arrangements for the safekeeping and disposal of all types of records.

13. The Act provided authority for NHS staff to destroy records in accordance with an approved '*Retention and Disposal Schedule*' enshrined in circular HM(61)73 issued in 1961 entitled '*Preservation and destruction of hospital records.*'[13]. The minimum retention periods were set out as follows:

    (a) '*Medical records and allied documents in hospitals*' (including blood transfusion records) should be preserved until six years after the conclusion of the treatment or where the patient dies in hospital, three years after their death.

---

[7] See, for example, the Access to Health Records Act 1990 (as amended) which governs the rights of access to deceased patient health records by specified people.

[8] See for example the GMC guidance 'Protecting Children and Young People: The responsibilities of all doctors' https://www.gmc-uk.org/-/media/documents/protecting-children-and-young-people---english-20200114_pdf-48978248.pdf

[9] See for example the Caldicott Principles - https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/942217/Eight_Caldicott_Principles_08.12.20.pdf

[10] The current data protection law being set out in the Data Protection Act 2018, which governs how records, information and personal data are managed, and the UK General Data Protection Regulation 2016, which came into effect on 1 January 2021.

[11] The Freedom of Information Act 2000 which came into force in January 2005 governs access to non-personal public records.

[12] Under the Public Records Act records of bodies working wholly or mainly in Scotland or concerned with Scottish affairs, and Welsh public records as defined in the Government of Wales Act 2006, are not public records: https://www.nationalarchives.gov.uk/information-management/legislation/public-records-act/pra-faqs/ However the Government of Wales Act 2006 establishes at section 148 that records of health service hospitals in Wales are not 'Welsh public records' and so are not exempted from being public records under the Public Records Act.

[13] DHSC0050744

(b) Summaries of clinical notes taken (Front Sheets, Registrars' Books, etc.) should be preserved.

The article 'Wirral Hospital Records' by D.N. Thompson, passing comment on the guidance in HM(61)73, observed that the circular appeared to take a very narrow view of what was worth preserving.[14]

14. The Department of Health and Social Security issued guidance in 1980 entitled '*Health Services Management: Retention of Personal Health Records (for possible use in litigation) HM(80)7*'.[15] The minimum retention periods in the guidance are as follows:

(a) Obstetric records should be kept for twenty five years.
(b) For children and young people, their records should be kept until their 25th birthday or eight years after the last entry if longer.
(c) Other records should be kept for eight years after conclusion of the treatment and the same period after the death of a patient.

15. In 1981 the Lord Chancellor established a committee (the Wilson committee) to advise on the retention of public records.[16] The committee's report was entitled '*Modern Public Records: Selection and Access*' London HMSO, March 1982.[17] The Government responded with a white paper, rejecting the recommendations in relation to clinical records but accepting the advice that the guidance should be revised.[18]

16. According to the expert report by the Public Health and Administration Group[19] guidance was published in 1985 which stated that the minimum period for retention of records was extended to eight years after the conclusion of treatment or the death of the patient (with exceptions for mental health patients (twenty years) and obstetric records (twenty five years)). The Inquiry is attempting to locate this guidance.

---

[14] RLIT0001174
[15] DHSC0105700
[16] The National Archive has some information about this at https://discovery.nationalarchives.gov.uk/details/r/C10265
[17] DHSC0105702
[18] DHSC0105705
[19] P. 71 of EXPG0000047

17. In 1999 the Department of Health published '*For the record: Managing records in NHS Trusts and health authorities*'.[20] The Inquiry has also found the Welsh version (see paragraph 25 below) and these publications suggested minimum periods for the retention of NHS records as follows:

(a) For clinical records, eight years after conclusion of the treatment or death.
(b) For children and young people, the records should be retained until the patient's 25th birthday or 26th if the young person was 17 at the conclusion of the treatment, or eight years after the patient's death if death occurred before the patient was 18.
(c) Obstetric record, twenty five years.
(d) Oncology records, eight years after the conclusion of the treatment.

18. In 2006 the NHS published a new code of practice '*Records Management*' Part 1[21] and part 2.[22] This was updated in 2016. This provided that:

(a) GP records were to be kept for ten years after a patient died or after the patient had permanently left the country.
(b) Maternity records were to be retained for twenty five years.
(c) Hospital records were to be kept for eight years with some exceptions (such as clinical trials).
(d) In relation to children's records it stated: '*Retain until the patient's 25th birthday or 26th if young person was 17 at conclusion of treatment, or 8 years after death. If the illness or death could have potential relevance to adult conditions or have genetic implications for the family of the deceased, the advice of clinicians should be sought as to whether to retain the records for a longer period*'.
(e) For the records of those diagnosed with Creutzfeldt-Jakob disease, their records should be retained for thirty years from diagnosis (clinical and GP), including for deceased patients.
(f) Oncology records should be retained for thirty years.

[20] RLIT0001726
[21] RLIT0001712
[22] DHSC5001727

19. The current NHS Code of Practice is the Records Management Code of Practice for Health and Social Care 2021 ("the Code").[23] The Code governs retention periods under its retention schedule. Under the present iteration of the Code, adult health records should be retained for 8 years.[24] However, the Code notes:

> *'Records involving pioneering or innovative treatment may have archival value, and their long term preservation should be discussed with the local PoD[25] or the National Archives.'*

20. Paediatric records, including midwifery records, should be retained up to a person's 25th birthday, or 26th birthday if the patient was aged 17 when the treatment ended.

21. GP records for deceased patients should be retained for 10 years.[26] For living patients, if the patient has not been seen in 10 years or a request for transfer to a new GP has not been received, the GP practice should check the Personal Demographics Service for indication of death or other reason for no contact.[27] If there is no reason to suggest why there has been no contact, then the record must be kept by the GP practice.[28]

22. For further examples of retention periods in this schedule, see paragraph 27 below.

The legislative framework for retention of medical records in Wales

23. Prior to the coming into force of the Government of Wales Act 2006, the situation in Wales was much the same as is set out above for England. For example, at the same time as the DHSS issued its circular in 1980 HC(80)7, the Welsh Office issued a circular in the same terms, WBC(80)9.

24. Guidance in relation to GP records was set out in WHC(99)7 '*Preservation, Retention & Destruction of GP General Medical Services Records Relating to Patients*'[29] (replacing FHSL 42/94 or FHS forms). This provided that:

---

[23] RLIT0001284
[24] Unless limited exceptions apply: see Appendix II Retention Schedule of the Code.
[25] Places of Deposit
[26] Appendix II Retention Schedule of the Code.
[27] Appendix II Retention Schedule of the Code.
[28] Appendix II Retention Schedule of the Code.
[29] RLIT0001727

(a) Maternity records should be retained for twenty five years.

(b) Records relating to children and young people (including paediatric, vaccination and community child health service records) should be retained until the patient's 25th birthday or 26th if an entry was made when the young person was 17; or ten years after death of a patient if sooner.

(c) All other personal health records should be retained for ten years after conclusion of treatment, the patient's death or after the patient had permanently left the country.

25. In 2000 a circular was issued in Wales entitled '*FOR THE RECORD - Managing Records in NHS Trusts and Health Authorities*' and issued to the chief executives of Health Authorities and NHS Trusts.[30] It set out minimum periods for which certain categories of records should be held as follows:

(a) Children and young people – until the patient's 25th birthday, or 26th if the young person was 17 at the conclusion of treatment; or eight years after the patient's death if death occurred before the 18th birthday.

(b) General records – eight years.

(c) Maternity – twenty five years.

(d) Oncology - eight years after conclusion of treatment, especially when surgery only was involved.

26. Following the enactment of the Government of Wales Act 2006, the Public Records Act continues to apply to the records of health service hospitals in Wales pursuant to section 148(1)(e) of the Government of Wales Act 2006.

27. The current position in Wales is set out in the '*Records Management Code of Practice for Health and Social Care 2022: A Guide to the Management of Health and Social Care Records*'.[31] The circular accompanying the Code[32] makes it clear that it is based on the Code of Practice developed by the NHS in England '*Records Management Code of*

[30] RLIT0001725
[31] RLIT0001718
[32] RLIT0001724

Practice for Health and Social Care 2021' (see paragraphs 19 - 21 above). This Code of Practice replaces the 2000 circular '*For the record*'. As with the English version of the Code of Practice the minimum retention dates for medical records are as follows:

(a) For adult records – eight years.
(b) Children's records – up to the child's twenty fifth or twenty sixth birthday.
(c) GP records for deceased patients – ten years.
(d) Obstetrics, maternity, antenatal and postnatal records – twenty five years.
(e) Cancer/oncology records: any patient - thirty years, or eight years after death.
(f) Creutzfeldt-Jakob Disease: patient records – thirty years or ten years after death.
(g) Long-term illness, or illness that may reoccur: patient records - twenty years,or ten years after death.
(h) Blood bank register – thirty years minimum.

The legislative framework for retention of medical records in Scotland

28. In 1937 the Public Records (Scotland) Act was passed.[33] Section 12 of that Act provided that regulations could be made regarding the disposal by destruction of records '*which are of insufficient value to justify their preservation*'. Pursuant to section 12, Regulations were passed (SI 1940/2107) which appear to have required the Lord Justice General, the Lord President and the Secretary of State to produce schedules of those documents considered to be of insufficient value to be retained by the Keeper of the Records of Scotland. One such Schedule the Inquiry has located dated June 1958 entitled '*The Scottish Hospital Service Destruction of Records*',[34] provided that hospital records (including blood transfusion records) might only be destroyed in accordance with the legislative framework set out above. The schedule set out the minimum periods for which certain classes of document should be kept. This provided that medical records must be kept for six years after the patient's treatment at the hospital, or three years if the patient died at the hospital.

29. This guidance was not updated until 1 December 1993 when the Scottish Office circulated '*Guidance for the Retention and Destruction of Health Records*'[35] (1993 (MEL) 152). This

[33] RLIT0001720
[34] PRSE0000552
[35] SCGV0000038_042

Guidance defined health records as '*those records which relate to the physical or mental health of an identifiable individual which have been made by or on the advice of a health professional in connection with the care and treatment of that person or in connection with the organisation of that care*'. It set out the minimum period of retention for such records, as follows:

(a) For general hospital and community health service records, six years from the date of the last recorded entry or three years after the death of the patient.
(b) For children and young adult's records, when the patient reached the age of 25, or three years after death if this is earlier.
(c) For obstetric records, twenty five years after the birth of the child.
(d) For GP records held by Health Boards, there was to be no change to the requirement to hold these for three years after the death of the patient. Where a patient had left the country temporarily with an intention to return, the records were to be kept for six years or some other agreed period.
(e) Records of patients with cancer should be kept for three years after their death.
(f) For patients with genetic disorders, it was for the provider units (including NHS Trusts) to consider the retention periods for such patients beyond the six year minimum.
(g) Records from clinical trials were governed by the EC Directive on Good Clinical Practice for Investigators taking part in Clinical Trials, implemented in July 1991 and should be kept for a minimum of fifteen years.

30. In 2006 the 1958 guidance on administrative records was updated to take account of legislative changes including the Freedom of Information (Scotland) Act 2002 and the Data Protection Act 1988. The new guidance - NHS/HDL (2006) 28 '*Management: Retention and Disposal of Administrative Records*'[36] - made it clear that for personal health records, the 1993 guidance would continue to apply, albeit further guidance on this matter was to be forthcoming by the end of 2006.

31. This new guidance did not in fact materialise until 2008 when the Scottish Government published the Scottish Government Records Management: Health and Social Care Code of

[36] RLIT0001171

Practice.[37] Annex D sets out the minimum retention periods for a wide range of personal health records including:

(a) Adult records – to be retained for six years after the date of the last entry, or three years from the date of death if earlier.
(b) Children and young people – to be retained until the person's 25th birthday, or 26th if they were 17 at the conclusion of the treatment, or three years after death. '*If the illness or death could have potential relevance to adult conditions or have genetic implications, the advice of clinicians should be sought as to whether to retain for a longer period.*'
(c) Donor records (blood and transplantation) – to be retained for thirty years after the donation.
(d) GP records – to be retained for the lifetime of the patient and until three years after their death. This includes both paper and electronic records.
(e) Oncology records – to be retained for thirty years.

The schedule also refers to records arising from clinical trials.

32. This Code of Practice was updated in March 2010[38] and January 2012.[39] The relevant current code of practice for managing medical records in Scotland is the 2020 version of this Code of Practice.[40] This has been updated to reflect legislative changes in data protection law (arising from the General Data Protection Regulation 2016 and Data Protection Act 2018) and the Public Records (Scotland) Act 2011. Retention periods for different classes of health record are set out at section 6. The retention periods for the classes of documents referred to in paragraph 31 above remain the same.

The legislative framework for retention of medical records in Northern Ireland

33. A summary of the chronology of the relevant legislation in place in Northern Ireland on record retention and destruction from 1923 onwards is set out below (parts of this chronology can be found in WITN3449018).

[37] RLIT0001146
[38] RLIT0001151
[39] RLIT0001152
[40] §1.4 of WITN4690014; RLIT0001150

34. In 1962, the Northern Ireland Hospital Authority Circular HMC 75/62[41] came into force. This provided that blood transfusion service laboratory records relating to the donor were to be kept for a minimum of one year after the death of the donor. Hospital medical records and other blood transfusion records should be kept for six years after the conclusion of treatment and three years after the date of the patient's death where the patient died in hospital.

35. This circular was amended in 1983 by the DHSSPS Circular HSS (OS)1/83.[42] This laid out new minimum periods for the retention of records as a minimum of twenty five years for obstetric records, eight years after the death of a patient or the conclusion of treatment, and for records relating to children and young people they were to be kept until the person's 25th birthday or eight years after the last entry, if longer. This did not apply to records held by the Central Services Authority.

36. In 1996 the HSSE (SE) 3/96 Retention of Personal Health Records (for possible use in litigation)[43] came into force. This set out new guidance on destruction of confidential health records, not held by the Central Services Authority. Records of children and young people should be retained until they turned 25, or for eight years after the last entry or their death, whichever was longer. Maternity records should be kept for twenty five years. All other records (save for the special periods which were set out for mentally disordered patients) should be kept for eight years after the last entry.

37. In 2004 '*Good Management Good Records*'[44] was published. This set out the minimum periods for the retention of Health and Personal Social Services records of all types, except for GP medical records. It also indicated which records were likely to be appropriate for permanent preservation. The recommended minimum retention periods for patient/clinical/medical records were eight years after the conclusion of treatment, for children and young people until their 25th birthday (unless they were 17 at the conclusion of treatment, in which case until their 26th birthday or eight years after the last entry, whichever is longer), or eight years after death if death occurred before the age of 18.

---

[41] WITN3449019
[42] WITN3449020
[43] WITN3449021
[44] WITN3449009

38. GP records were addressed by Circular HSS (PCCD) 1/2000 entitled '*Preservation, Retention and Destruction of GP Records*'.[45]

39. In 2011, Good Management Good Records[46] was reviewed and updated, and the 2011 standard now applies to all health and social care records. This sets out minimum retention categories for records as follows:

    (a) For adults this is eight years after the conclusion of their treatment or death.
    (b) For children and young people until their 25th birthday (unless they were 17 at the conclusion of treatment, in which case until their 26th birthday or eight years after the last entry, whichever is longer), or eight years after death if death occurred before the age of 18.
    (c) GP records should be retained by the GP until the patient either dies or is no longer a patient of the GP, at which point the records should be sent to the Health and Social Care Board[47], which should hold most of the GP records (there are some exceptions) for 10 years after the person's death or they have left the country permanently.

40. In 2015 there was a moratorium on destruction of Belfast Health and Social Care Trust records following an instruction from the Historical Institutional Abuse Inquiry and there has been no destruction of records since 2015.[48] On 24 August 2018, following receipt of a letter from the Inquiry[49] about retention and destruction of documents, the Permanent Secretary and HSC Chief Executive wrote to (amongst others) the HSC Trusts and the Northern Ireland Blood Transfusion Service[50] asking them to take '*all necessary steps to preserve and catalogue any such material*' that may be relevant to the Inquiry.

NHS Trusts'/ health boards' destruction and retention policies

41. The Inquiry has sought information from a range of NHS trusts and health boards in Scotland, England, Wales and Northern Ireland in relation to their policies for destruction

[45] The Inquiry has not yet found a copy of this document.
[46] WITN3449011
[47] Albeit this closed in March 2022, but the guidance has not been updated to take account of this.
[48] WITN3449018
[49] INQY0000375
[50] DHNI0001504

and retention of medical records. These trusts / health boards have provided copies of their policies and the frequency of review of such policies. This presentation does not reproduce the various policies but sets out the relevant references below. On the whole, the trusts and health boards approached by the Inquiry can demonstrate that they presently have retention and destruction policies in place, which are regularly reviewed. However, most of those approached by the Inquiry are unable to evidence detailed policies and procedures on retention and destruction for the pre-2000 period.

42. Iain Paterson, Corporate Services Manager of the Greater Glasgow Health Board, has provided two statements to the Inquiry about the policies in place for destruction or retention of medical records for Greater Glasgow and Clyde ("NHSGGC").[51] He states that NHSGGC '*followed national guidance on retention and destruction of health/hospital records… throughout the period of interest for this Inquiry and has only produced local guidance for administrative/business records.*'[52] He states that, following the creation of NHS Trusts in 1993/1994 there was '*widespread destruction of non-current clinical records, particularly those dating to the 1950s, 1960s and 1970s.*'[53] In 2002:

> '*the shelving for the archives of Glasgow Royal Infirmary and Gartnavel Royal Hospital collapsed within the Archives repository. The affected records were safely recovered from the collapsed shelving with no lasting damage…. To the best of my knowledge, there have been no further unforeseen events or incidents that impacted upon records held by NHSGGC.*'[54]

43. Louise Williams, archivist at the Lothian Health Services Archives ("LHSA"), has provided three statements to the Inquiry.[55] She sets out the records stored at the Archives and highlights the records which were reviewed by the Inquiry on visits.[56]

44. Caroline Leonard, Director of Cancer and Specialist Services at Belfast Health and Social Care Trust ("BHSCT"), has provided statements to the Inquiry as to BHSCT's retention policies.[57] She states that there are '*several archives of microfilm and microfiche records*

---

[51] WITN6911007
[52] §8 of WITN6911007
[53] §3 of WITN6911007
[54] §7 of WITN6911007
[55] WITN4690014
[56] See e.g. §3.3.2 of WITN4690014.
[57] WITN3449095.

from Trust legacy organisations relating to Belvoir Park Hospital, Musgrave Park Hospital and Purdysburn Hospital mental health facility (now known as Knockbracken).'[58] In 2018-2019 an exercise was undertaken to '*locate and compile the medical records for all patients that received infected blood and/or blood products and consequently contract HIV and/or HCV.*'[59]

45. Keith Leakey, Head of Information Governance and Management at Guy's and St Thomas' NHS Foundation Trust, has provided a statement to the Inquiry.[60] He states that to his knowledge '*no records have been intentionally destroyed. Documents which have been backed up on microfiche are retained and stored offsite.*'[61] He states that some of the older haemophilia records, approximately 200, are stored in the basement at Guy's Hospital.[62] He has provided copies of the Trust's Health Records Policies from 2008 to the present day as well as various retention and destruction policies.[63]

46. Claire Alexander, Director of Quality Governance at Liverpool University Hospitals NHS Foundation Trust, has described the process of converting existing medical records onto microfilm when the Royal Liverpool Hospital opened in 1978.[64] She has provided the Trust's retention and destruction policies from 2004 onwards[65] but the Trust '*is not aware of documents*[66] *that were in place prior to 2004.*'[67]

47. Christine Morris, Associate Director of Safety and Learning at the Lancashire Teaching Hospital NHS Foundation Trust ("LTHTR"), has provided a statement to the Inquiry.[68] She states that since 2012 all medical records have been scanned to the Electronic Paper Records system referred to as Evolve: '*these records are added to by clinicians and are stored on the Lancashire Teaching Hospital NHS Foundation Trust Server. There is a*

---

[58] §2.5 of WITN3449095
[59] §3.1 of WITN3449095.
[60] WITN7124001
[61] §6 of WITN7124001. See also §12 of WITN7124001
[62] §6 of WITN7124001
[63] See WITN7124002 - WITN7124014
[64] P. 2 of WITN7166001. See also below for issues of environmental destruction of records.
[65] See WITN7166003- WITN7166016
[66] I.e. Trust policies on retention.
[67] P. 1 of WITN7166001.
[68] WITN7209001

robust process to back up data stored on the server.'[69] Her evidence to the Inquiry is that the Trust's procedural documents – not medical records – were themselves subject to a retention period of 10 years '*after which time the items were destroyed both electronically and in paper format.*'[70] This means that any retention policies that were in place at the time of a fire in 2005 were purposefully destroyed under the Trust's retention policy in 2015. This was the case for both the paper and electronic documents. This position changed in 2018 and all procedural documents are now held electronically.[71]

48. David Burbridge, Chief Legal Officer of the University Hospitals Birmingham NHS Foundation Trust, has provided a statement to the Inquiry, which sets out the retention policies from 1999 onwards.[72]

49. Ben Pearson, Executive Medical Director and Caldicott Guardian of the Derbyshire Community Health Services NHS Foundation Trust, has provided a statement to the Inquiry about the Trust's Information Lifecycle and Records Management Policy.[73]

50. Eric Sanders of the University Hospitals Bristol and Weston NHS Trust has provided a statement to the Inquiry about the Trust's retention policies from January 2003 onwards.[74] The Trust is not aware of any incident when medical records were disturbed, misplaced or destroyed as a result of environmental factors.

Clinicians' views on retention and destruction

51. In addition to the written responses from NHS trusts / health boards about their policies on retention and destruction of medical records, the Inquiry has received a range of evidence from clinicians about individual practices for storage of medical records. This evidence is not repeated within this presentation, but some key examples are set out below. Some of these local policies, such as at Cardiff, showed a variance with the national position.

---

[69] §17 of WITN7209001; WITN7209006
[70] §12 of WITN7209001
[71] §17 of WITN7209001; WITN7209007
[72] WITN7143001
[73] WITN7228001
[74] WITN7125001

52. Dr Dolan, Consultant Haematologist at the Queen's Square Medical Centre, Nottingham, from 1991 until 2015, has told the Inquiry that when he arrived at Nottingham '*there had been a significant issue with case records*' and '*some consultations were recorded on discrete hospital out patient paper and some of these did not get filed.*'[75]

53. Professor Gordon Lowe of Glasgow Royal Infirmary[76] told the Inquiry:

> '*every patient had case records, obviously. For a severe haemophiliac, these could become several volumes, several feet high, over the years from the number of submissions that they had. And we always wanted to keep all the records available in the haemophilia unit. Now, as you know, records can be destroyed at intervals by managers and records departments just wanting to keep their shelves clear, but there was a general recommendation by the UK Genetic Disorder Society, or whatever it was called -- I can't remember -- that it was preferable that these records not be destroyed. And there was a very good reason for that in patients with haemophilia because, as you will know, it's transmitted by female carriers, and it skips generations. So if a patient, say, dies and the records department say, "Well, that's that", and destroy the records, the problem is that 40 years later some granddaughter becomes pregnant and wants to know if she is a carrier and what kind of haemophilia was it. So in general we tried to keep all the records in the haemophilia centre, and the number of filing cabinets increased from about I think one, when I arrived in 1975 -- at last count I think it's about 20 filing cabinets.*
>
> *If a patient died, we would put them in a locked cupboard within the haemophilia centre, because we occasionally had the problem that the records department said seven years, or whatever is the current policy, and would destroy them. So we tried to retain them as much as we could. But, in practical terms, we had a small folder in the unit, as I think many other centres did, which listed the basic details of the patient and what treatment they were on and information like the family tree and the UKHCDO registration number, so that if a patient turned up in the middle of the night and for some reason the case sheets had gone missing, they had attended another clinic, they had gone to a surgical ward for operation, we had the essential information that was needed to know what kind of haemophilia it was and what the treatment would be.*'[77]

54. When asked about whether records were destroyed as part of any moves or computerisation, his evidence was: '*I think we were pretty good. So we had on the front of every case record a big stamp routinely saying: "Please return notes to haemophilia centre - Do not destroy*".'[78]

---

[75] §10 of WITN4031001

[76] For a full list of his various positions and responsibilities see §2 of WITN3496013.

[77] P. 26-28 of INQY1000083

[78] P. 28 of INQY1000083

55. Professor Peter Collins, who was Consultant Haematologist at the Cardiff Haemophilia Centre from September 1996 to August 2001, was asked about missing records reported by patients under the care of Professor Bloom and whether he had direct experience of missing records:

'*I think the only key documents that were missing which came up in the audit by Dr Hill was that the people's HIV results were filed -- they were all filed together, separate from the notes. As far as I'm aware, those are the only key documents that were not in the notes that one would have expected to be in the notes. When I arrived in Cardiff, all of the notes of the people who had died of HIV were in a cupboard in the office that I inherited and we have kept those notes ever since.*

I am not aware that those notes have -- we just kept them. We haven't -- I haven't been through them to look to see if there are key documents missing or elements that I think should have been there. I haven't been through the notes to make that assessment. So the only thing I'm aware of is this issue of filing HIV notes separately.'[79]

56. He further stated:

'*I think if there had been any systematic issue, I would have noticed, yes. I think -- I can't remember a case where I have been unable to find the information that I was expecting to find. It was all to me clear what was there. So, yes, I can't think of any issues.*'

57. In his written statement to the Inquiry, Professor Collins stated that there was a policy at Cardiff to keep the records of those infected with HIV after they have died and to keep records generally for the life of his patients.[80] His evidence was that this policy '*appears to have been in place since the 1980s*' and that '*over the years, this policy has been complied with.*'[81] Professor Collins was asked whether this policy was formal hospital policy or simply the policy of his centre:

'*It's the policy of the haemophilia centre to keep those. I think the policy in general in the NHS would be not to keep records of people who have died, you know, only for a period and I think that if someone doesn't attend the hospital for maybe ten years or so the policy might be not to retain the records. Of course, someone with a bleeding disorder might not attend for 20 years and then come with a problem, and so we needed to retain the notes.*'

[79] P. 84-87 INQY1000089
[80] §§231-232 of WITN4029001
[81] §232 of WITN4029001

58. He stated that he did not receive '*any push-back [from the hospital]... apart from to say "Well, you find the space then", which is what we've done.*'[82]

59. The Inquiry has also received written and oral evidence from Dr Saad Al-Ismail, Consultant Haematologist at Swansea from June 1982 to February 2018.[83] He told the Inquiry that prior to the proper establishment of the Swansea Haemophilia Centre medical records '*would have been in the general records [and] would not be in the haematology department. It's only when we moved to Singleton that we kept the haemophiliac notes in the Haematology Department.*'[84] He stated that upon the death of a patient '*very often*' the notes would be taken to prepare the death certificate. He described that one had to '*insist*' on the notes being returned.[85] In his oral evidence to the Inquiry he described a situation where he was unable to access a patient's records, despite reviewing them only two to three years previously, because he was told they had been destroyed.[86]

60. In relation to medical records of blood transfusions at Swansea his evidence was that:

> '*…up to 1980, all the blood transfusion documents, that is blood and blood products on part of haemophiliacs, were actually paper documents, and they were since, being many years, been lost. Then between 1980 and 1984 we acquired the computer system called TelePath, and -- oh, maybe before that we acquired a computer system. Anyway, so at 1985 that was changed. It may be changed to TelePath, and we were told that the previous computer system we -- would be microfiched and stored. And -- but that actually -- it was microfiched but it was unrecoverable, I was told by the head of blood transfusion, when the first request from the Infected Blood Inquiry came to the Chief Executive. In 1985 to [1991] was TelePath, and this is the one which was microfiched. And then after 1991 until 2003 we changed to another system, called ACT, and when that laboratory system moved to another system called MasterLab, in 2003, all the documents were transferring to MasterLab. So anything really which was in TelePath – if you like, you would not be able to get any documentation after 1991 from our computer system, unfortunately… the haemophilia records were separate, really, because, you know, sort of all the time we gave a unit of cryoprecipitate or a unit of -- or a bottle of concentrate, that was documented in the patient notes and then transferred to UKHCDO. So that's different.*'[87]

---

[82] P. 87 INQY1000089
[83] WITN3761001
[84] P. 138-9 of INQY1000074
[85] P. 153-154 of INQY1000074
[86] P. 154 of INQY1000074
[87] P. 149-150 of INQY1000074

Patients' perspectives of destruction of records under policies

61. The Inquiry has received many statements from infected individuals and their affected family members who were told that medical records have been destroyed in line with NHS trusts' / boards' policies on retention and destruction. Some examples are set out below.

62. The Inquiry received a statement from a woman who has been unsuccessful in obtaining medical records relating to two procedures, one in 1957 and one in 1976.[88] She has been a patient of the same GP practice for 60 years.[89] She believes she contracted HCV after receiving a blood transfusion following surgery to remove a polyp at the Manchester Northern Hospital in 1957.[90] She was kept in hospital for 13 days.[91] She also thinks that she might have had a blood transfusion during a hysterectomy in 1976 at the Wythenshawe hospital, Manchester.[92] She states that she made '*extensive inquiries [sic] of the Manchester Northern Hospital Crumpsall Hospital, Withington Hospital, Wythenshawe Hospital and Darlington Hospital*' but has been informed that her hospital records no longer exist.[93] The Manchester Northern Hospital closed '*many years*' earlier.[94] She was assisted by her GP in a process that '*took many months and proved to be fruitless.*'[95] She has only been able to locate limited records kept by her GP:[96] her notes from the 1950s to 1970s were '*extremely brief and in some cases illegible.*'[97] She was told that there is no requirement to keep hospital records for more than 10 years.[98] Her application for financial assistance and subsequent appeal with EIBSS were rejected.[99]

63. The Inquiry received a statement from a woman whose husband was diagnosed with Hodgkin's Lymphoma and died in July 1984 aged 41.[100] Her husband was treated at the Queen Elizabeth Hospital, Gateshead and the Newcastle General Hospital from the 1960s

[88] WITN0384001
[89] §2 of WITN0384001
[90] §10 of WITN0384001
[91] WITN0384003
[92] §21 of WITN0384001
[93] §80(d) of WITN0384001
[94] §87 of WITN0384001
[95] §84 of WITN0384001
[96] §86 of WITN0384001
[97] §91 of WITN0384001
[98] §89 of WITN0384001
[99] §99; §112 of WITN0384001
[100] §2 of WITN0339001

until his death. He received blood transfusions and factor VIII.[101] When she attempted to obtain copies of her husband's medical records in order to support an application to the Skipton Fund she was told that the records had been destroyed. She states: '*I tried to take the matter further, even using the ombudsman, but got no further and cannot access his records*.'[102] She provided to the Inquiry a letter from the Newcastle upon Tyne Hospitals NHS Trust, dated 14 April 2016, which confirmed that '*all records held at the Newcastle General Hospital were transferred to the Royal Victoria Infirmary*'.[103] However, the author of the letter stated that she was '*unable to trace [the witness'] husband as being registered with the Newcastle Hospitals.*' It was further stated that it is likely that the records have been destroyed:

'*Under the Public Records guidelines adult case notes are required to be retained until 8 years after death and then destroyed and therefore it is likely that [the witness'] husband's case notes are no longer available and have been destroyed.'*

64. Her application and subsequent appeal to the Skipton Fund were unsuccessful.

65. An affected son, whose mother died in 1981 of chronic active hepatitis, applied for his mother's medical records in order to ascertain the circumstances of her death and what information was known to the doctors at the time she became ill:

'*I received a response from Bart's Trust Archives in which they confirmed that in 2012 Whipps Cross, Newham, Bart's and the London Hospitals merged in 2012 to form Barts Health NHS Trust. They further confirmed that as far as patient records were concerned they did not hold admission/discharge registers, detailed case notes or operations registers. They stated that they only received transfers of archival records of Whipps Cross Hospital since 2012 and did not hold any information on the hospital's records retention practices prior to 2012. As such they advised me that they would not assist me with my application.*'[104]

66. It appears that the witness was not given an explanation about why there was no information as to retention prior to 2012. The Inquiry has contacted Barts NHS Trust for a witness statement on retention and destruction and a response is awaited.

---

[101] §12 of WITN0339001
[102] §28 of WITN0339001
[103] WITN0339010
[104] §41 of WITN0656001

67. A person with haemophilia, who was infected with HIV and HCV, was treated at the Coventry and Warwickshire Hospital from 1974 to 1994.[105] He was then treated at the Queen Elizabeth Hospital, Birmingham from 1994 and then at the Royal Free Hospital from 2001.[106] In late 2018 he applied for his medical records from these hospitals, his GP and the UKHCDO. He was informed that his medical records from the Coventry and Warwickshire Hospital and Queen Elizabeth Hospital, Birmingham have been '*largely destroyed*'[107] due to an 8 year retention period.[108] He has received some records from after 1987 from Coventry and Warwickshire Hospital, some limited GP records and some UKHCDO records but these do not mention the fact he received US Armour product, which his mother had recorded at the time.[109] He has received detailed records from the Royal Free Hospital.[110] He is of the view that hospitals and UKHCDO have '*destroyed crucial evidence… or have placed it in locations difficult to locate.*'[111]

68. A man, who was stabbed during a mugging in 1981, received a blood transfusion at the Walton Hospital, Liverpool.[112] He applied for medical records but his records from 1981 were incomplete.[113] He is aware that the hospital had a destruction policy but notes that parts of his records have been supplied to him. He has provided the Inquiry with a letter, dated 10 November 2005, from a Sister in the gastroenterology unit of the Royal Liverpool University Hospital which states that she had contacted the Blood Blank Manager at the Aintree Hospital but:

> '*unfortunately they only keep records of the last 11 years as this was the requirement at the time. They were not computerised in 1981, so unfortunately they cannot provide the information that we were looking for. My advice to you is to write this on your Skipton Fund form or contact your GP to discuss it further.*'[114]

---

[105] §8 of WITN1389001
[106] §25; §27 of WITN1389001
[107] §28 of WITN1389001
[108] WITN1389002
[109] §28 of WITN1389001
[110] §28 of WITN1389001
[111] §60 of WITN1389001
[112] §§6-8 of WITN0691001
[113] §48 of WITN0691001
[114] WITN0691003

69. He was successful in obtaining a Skipton payment after an appeal.[115]

70. The Inquiry received a statement from a former district nurse who was diagnosed with HCV in 1995. She received a blood transfusion during a planned caesarean section in 1973 at the Royal Berkshire hospital.[116] She recalls being told that there had been complications during the procedure and she had lost a lot of blood. She recalls seeing the blood and the drip was a blood transfusion.[117] This was the first time she received blood and she has not been given blood since.[118] She has been unable to gain access to her medical records, which has prevented her from receiving financial help.[119] She has been told that the records have been destroyed:

'*I first tried in 1995 when I found out about being infected. I asked my treating consultant if I could see my medical records from my caesarean section. She asked me why I wanted to do so, which gave me the impression that she did not want to let me access the information. Two days later I received a letter from her telling me my notes had been destroyed.*'[120]

71. In 2012 she applied to the Health Records Department of the Royal Berkshire NHS Foundation Trust to access her maternity records. On 24 April 2013 she received a letter, which stated:

'*As we discussed maternity records are now kept for 25 years but until the law changed in 1990 the maternity records were kept for 21 years so the consultant was right to say that they had been destroyed...*

Pathology notes were kept for 20 years at that time and therefore they had nothing, but interestingly in the reply letter from the pathology lab they stated that 'blood bank ledgers will not be destroyed in the hope that another patient may be helped.' ...

I appreciate that this doesn't get you any closer to finding out how you contracted your illness but I hope that it helps knowing that there was no way that you could have found out when you asked in 1994.'[121]

---

[115] §§41-43 of WITN0691001
[116] WITN0880001
[117] §8 of WITN0880001
[118] §9 of WITN0880001
[119] §3 of WITN0880001; WITN0880002
[120] §14 of WITN0880001
[121] WITN0880004

72. Despite efforts from her MP and assistance from a friend who worked as a magistrate, she has not been able to access the records from the caesarean section in 1973.[122]

73. The Inquiry received a statement from a retired nurse, who received a blood transfusion following a termination in around 1976.[123] She states that after she received her diagnosis of HCV, she was sent to Leeds for a fibroscan and she asked to look through her notes to see if there was any information about receiving blood: '*I was given a couple of minutes to scan through them as the nurse effectively turned her back. I found nothing but didn't really have time.*'[124]

74. She states that in 2007 she was admitted to the Airedale Hospital due to a cardiac episode: '*I also took the opportunity to ask again if there was any evidence of a blood transfusion in my records. The Sister wouldn't let me look but she did [look] and there was nothing about a blood transfusion, according to her.*'[125]

75. On 10 December 2015 she wrote to the NHS Access to Health Records department at the St James Teaching Hospital in Leeds requesting information about the assimilation of her GP records from before her marriage under her maiden name. She received correspondence stating that the record retention and destruction period was 8 years and she was given a new address to write to.[126] She was then told that the medical records under her maiden name were destroyed in October 2011 and the records under her married name were scanned in February 2013.[127] She queries why the notes for her maiden and married names were not joined up and why her medical records were destroyed without her permission.[128]

Environmental destruction

76. Infected individuals and their affected family members have been told that records have been destroyed due to environmental incidents. This section of the presentation addresses

[122] §17 of WITN0880001
[123] §§9-11 of WITN4311001
[124] §44 of WITN4311001
[125] §45 of WITN4311001
[126] §94-§97 of WITN4311001
[127] WITN4311002
[128] §91 of WITN4311001

the evidence obtained by the Inquiry about fires, floods and sewage leaks. Broadly, the available evidence demonstrates – with some limited exceptions – that some patients have been told their records have been destroyed in environmental incidents but that trusts / health boards are unable to confirm to the Inquiry that this is the case. The main reason for this appears to be that some trusts / health boards do not presently hold records about historic instances where medical records were destroyed. There appears to have been no historic requirement, either nationally or as part of individual trusts' / health boards' policies, to record and evidence environmental destruction of medical records. Further, in many instances, where records of environmental destruction did exist, these documents themselves have now been destroyed under retention policies.

77. Another hurdle to obtaining evidence about environmental destruction is that it is apparent from the Inquiry's investigations that many patients and their family members were told orally about records being destroyed; either in person at hospitals or over the telephone. It has therefore been challenging for the Inquiry to investigate these aspects because there are no written records of such conversations, most of which happened many years ago.

Flood

78. The Inquiry received a statement from a woman who was given a blood transfusion in 1984 when she gave birth to her first daughter at the Jessops Hospital for Women in Sheffield.[129] She recalls having two drips attached to her '*one was blood and the other contained clear liquid.*' She states that her mother-in-law told her that she had had a blood transfusion and that her mother-in-law had '*had to sign something*' so she could undergo surgery.[130] She was diagnosed with HCV in 1999 and believes that she was intentionally infected.[131] She has requested her medical records:

'*The GP records I have received tell me that only some of my medical records have gone missing; very oddly there is a period of time from August 1983 where there is only one piece of information saying that I am pregnant ... then there is nothing. There is nothing more about me being pregnant, nothing about me giving birth, nothing about the operation, nothing about any of it. Nothing about my eldest baby. This gap goes on until September 1985, which is one month after I had my second child.*'

[129] §3 of WITN1925001
[130] §3 of WITN1925001
[131] §7 of WITN1925001

79. She contacted the hospital to obtain her medical records: '*there are records missing from their records too during the exact same period of time; August 1983 to September 1985, they have said this is because they experienced a flood.*'[132]

80. The Inquiry has obtained a statement from Sandra Carman of the Sheffield Teaching Hospitals NHS Foundation Trust who has told the Inquiry that the Jessop Hospital closed in 2001 and a new Jessop Wing was built on a different site: '*Despite the thorough searches conducted and the engagement with colleagues across the Trust, we have not been able to identify any incident that has caused any irretrievable destruction to medical records by way of fire or flood.*'[133] Sandra Carman has confirmed to the Inquiry that these searches for medical records covered the Jessop Hospital.[134] The Inquiry has therefore not been able to resolve the issue of whether a flood destroyed medical records in 1983 to 1985.

81. The Inquiry has been told that there was a flood at Guy's and St Thomas' Hospital in the late 1990s:

> '*I am aware of a flood in 1998/1999 – I have seen reference to 'destroyed in flood' in comments in the previous PAS (Patient Administration System) although I do not have any further information in relation to this.*
>
> *I further understand that there was a leak / flood in 2008 in an old portacabin where some inpatient observation charts were kept. I understand that there were in the region of 150 boxes of records which were affected by the leak / flood and which were then consequently destroyed. This incident was investigated as part of a Serious Untoward Incident investigation. I have not yet been able to find the resulting report.*
>
> *To my knowledge, neither of these incidents relate to haemophilia records* '[135]

82. The statement does not address whether any other potentially relevant records, such as hepatology records, were affected.

83. A man with mild haemophilia A, who was treated at the Manchester Royal Infirmary during the 1960s to 1980s, was diagnosed with HCV in 2005.[136] He applied for his medical records

---

[132] §14 of WITN1925001
[133] WITN3425007
[134] WITN3425007
[135] §§8 -9 of WITN7124001
[136] §7 of WITN1929001

shortly after his diagnosis.[137] He was told that most of his records: '*had been destroyed and that they had experienced a flood in the past. I also applied to Lancashire and South Cumbria Agency for my medical records and was informed they had also been destroyed.*'[138]

84. He states that his application to the Skipton Fund was not accepted due to missing records.[139] The Inquiry has obtained a statement from Professor J Eddleston of the Manchester University NHS Foundation Trust. The Trust has been unable to confirm the existence of a flood:

'*despite enquiries made with Manchester Royal Infirmary's senior management team, Clinical Governance Team, Estates & Facilities Team, Subject Access Request Team and Medical Records Team, we have been unable to verify whether such an event occurred. This is due to the passage of time since the alleged event and the present day.*'[140]

85. One long-standing staff member could recall a '*series of floods at the MRI that affected the medical records library, which used to be in the basement.*' However, '*due to the passage of time, this member of staff cannot recall exactly when the floods occurred but does believe they were around the time in question (mid-1980s)'*.[141] Professor Eddleston has confirmed that no records – either patient case notes or other records that would reference a flood – exist because of Trust policy on retention, which means that these policy records have been destroyed.[142]

86. The Inquiry has received a statement from Caroline Leonard, Director of Cancer and Specialist Services at Belfast Health and Social Care Trust ("BHSCT"), which states that in June 2012 there was a flood at one of the Musgrave Park Hospital libraries, which was located in the basement of the Withers Orthopaedic Centre.[143] She states that a small number of records were damaged due to the flooding and they were subsequently sent to Harwell Restoration in Oxford and successfully restored. In October 2014 there was more

[137] §17 of WITN1929001
[138] §17 of WITN1929001
[139] §19 of WITN1929001
[140] §7 of WITN7041098
[141] §9 of WITN7041098
[142] §8 of WITN7041098
[143] §2.17 of WITN3449095

extensive flooding at the Musgrave Park Hospital site but no records were damaged.[144] Due to these flooding risks, the libraries have now been moved to another area.[145]

87. The Inquiry has also received evidence that in 2016 a contractor hit a plumbing pipe at the Royal Belfast Hospital for Sick Children. This leak caused '*substantial damage to offices and medical records were water damaged. The records were sent to a specialist restoration company in England who were able to successfully restore the records.*'[146]

88. In September 2020 BHSCT was told that there had been a flood at an offsite records storage site, Oasis. One of the records in a box was water damaged but was successfully professionally restored.[147]

89. The Inquiry has received evidence from an infected individual about the destruction by flood of medical records St Mary's Hospital, Portsmouth. The Inquiry has obtained a statement from Portsmouth Hospitals NHS Trust, which states that the Trust were '*unable to confirm or deny*' the existence of a flood. Incidents prior to 2002 '*were completed on paper and have been destroyed in line with retention policies.*'[148] Staff members who worked in the hospital from 1987 to 1997 do not recall a flood.[149]

Fire

90. The Inquiry has obtained a statement from Christine Morris, Associate Director of Safety and Learning at the Lancashire Teaching Hospital NHS Foundation Trust ("LTHTR"), which confirms that there was a fire at the site of Sharoe Green Hospital on 24 July 2005.[150] During this fire, health records were destroyed.[151] The hospital building was scheduled for demolition and had closed as a functioning hospital in December 2004 but medical records were being housed in this site.[152] The fire was in the former outpatient block and was caused

[144] §2.17 of WITN3449095
[145] §2.17 of WITN3449095
[146] §2.18 of WITN3449095
[147] §2.20 of WITN3449095. See also §2.19 regarding the destruction of a box of patient records in error.
[148] §1 of WITN7140001
[149] §1 of WITN7140001
[150] §3 of WITN7209001
[151] §5 WITN7209001
[152] §4 of WITN7209001

by an act of arson, for which there was a criminal prosecution.[153] Photographs of the damage have been provided to the Inquiry.[154] These demonstrate substantial damage. Approximately 87% of medical records held at the Sharoe Green Hospital were lost in the fire.[155] Paper medical records were not backed up in 2005 and '*as such records destroyed during the fire in 2005 are not available, although a list of the record numbers is available.*'[156] The medical records are now held electronically '*with server backup*' so '*any fire on Trust premises should not result in the permanent loss of those records.*'[157]

91. A man who was infected with HBV and HCV has told the Inquiry that he first attempted to obtain his records from the Birmingham Children's Hospital ("BCH") in approximately 1995.[158] He states that he was told by his solicitor that there had been a fire at BCH and his medical records were lost or destroyed.[159] He tried again in 1997 and was given the same response. The Inquiry requested a statement from BCH which falls under the University Hospitals of Birmingham NHS Foundation Trust. David Burbridge's evidence to the Inquiry is that there is '*no knowledge or awareness of any instances where records were disturbed, misplaced or destroyed because of an incident.*'[160] The Inquiry has therefore not been able to resolve the issue of whether a fire destroyed the witness' medical records.

92. A woman who was infected with HCV, after receiving a blood transfusion on the day she was born in 1974 due to a petechial haemorrhage at King's College Hospital, has been unable to access a complete set out records.[161] When she was 18 she was referred to the adult liver clinic at King's College Hospital and she received her HCV diagnosis in the early 1990s. She states that the new doctors:

---

[153] §6 of WITN7209001
[154] WITN7209004
[155] §9 of WITN7209001. Albeit '*this does not reflect the amount of records held relating to each patient (some patient records are much more extensive than others, so numbers only provide a partial picture*'.
[156] §11 of WITN7209001
[157] §21 of WITN7209001
[158] §4 of WITN0458001
[159] §4 of WITN0458001
[160] §8 of WITN7143001
[161] §4 of WITN0231001

'*wanted to refer back to my childhood notes but they could not find my records and then told me that they may have been destroyed in a fire at the hospital some years earlier. This seems rather convenient looking back?*'[162]

93. She has obtained her GP records but has not been able to find records from 1974 to the late 1980s.

94. An affected brother-in-law attempted to obtain the medical records of a man who died in 1996 at the age of 27 after being co-infected with HIV, HCV and HBV.[163] The man was treated at the Derbyshire Children's Hospital, the Derbyshire Royal Infirmary and Leicester Royal Infirmary. He has been unable to access any records, other than blood tests, from the Derbyshire Royal Infirmary:

'*I have received several versions of events for example, I was informed that they were destroyed in 1995; however, I do not believe that this is true as this would be a year before Simon died.*

I have asked for proof of destruction which I have never received. I have asked where they were sent to, and then I was told that there was a fire which destroyed them. They have now ceased to communicate with me.

In contrast the Leicester Royal Infirmary proved to be very helpful. I only had to send one email requesting [his] records and they provided me with full disclosure of the documents available, including the meals he had been given.'[164]

95. The Inquiry has obtained a statement from Paul Brooks, of the University of Derby and Burton NHS Foundation Trust, who states that the Trust has been unable to locate the nature or causes of a fire or '*any other event at UHDB which caused the destruction of records in 1995… The Trust has not been able to locate any information in relation to damaged medical records in relation to an incident around 1995.*'[165]

96. The Inquiry has therefore not been able to resolve the issue of whether a fire damaged or destroyed medical records in 1995.

---

[162] §7 of WITN0231001
[163] §2 of WITN1555001
[164] §§67-69 of WITN1555001
[165] WITN7164001. See p.1-2 of WITN7164001 for a list of the enquiries made.

97. The Inquiry obtained a statement from Claire Alexander, Director of Quality Governance at Liverpool University Hospitals NHS Foundation Trust.[166] She was asked about whether any records were disturbed, misplaced or destroyed due to environmental factors. Her response states that records were damaged from water and fire:

'*Prior to the opening of the Royal Liverpool Hospital (RLH), I understand that the closing hospitals in Liverpool were allocated a new RLH number to each convert their records to the same numbering system. This resulted in some patients having more than one number in the RHL. During this time, it is understood that there was some damage to roofs [sic] of some of the old building including water and fire damage, which resulted in paper records being 'officially' written off because they were unreadable/unusable. There is a potential for some of those (then) current records, which began before 1980 having been destroyed. The RLH opened in 1978.*

The non-current records at the opening of the RLB which needed to be retained were microfilmed, and if a patient presented to the (new) RLH their microfilmed records were copied under their old case-note number and another volume of records was commenced. Once discharged, the record was then microfilmed and then filed behind the first volume of microfilm, then second volume etc. The Royal and Broadgreen Hospitals amalgamated in 1995 and it is understood that the same process was followed. A number of paper records held in an attic in Broadgreen that were over 25 years old were sent for destruction.'[167]

98. The Inquiry has received evidence from an affected witness about the possibility of destruction of medical records due to a fire at the Leicester Royal Infirmary. The Inquiry obtained a statement from the General Manager of the Medical Records Service at the University Hospitals of Leicester NHS Trust, which states that the Trust have been unable to find any record of a fire.[168] The Inquiry has therefore not been able to resolve the issue of whether a fire destroyed the witness' medical records.

99. The Inquiry has received evidence from an infected witness about the possibility of destruction of medical records due to a fire at the Royal Victoria Infirmary. The Inquiry has obtained a statement from the Newcastle Hospitals NHS Foundation Trust.[169] Deborah Banks, the Head of Outpatients Health Records and Patient Administration, has confirmed that the Trust is '*unaware of any fire at the Royal Victoria Infirmary, which caused the destruction of records in the 1990s and early 2000s.*'[170] There is no record of any historical

[166] WITN7166001
[167] P. 2 of WITN7166001
[168] WITN7139001
[169] WITN7141001
[170] §1 of WITN7141001

fires either.[171] The Inquiry has therefore not been able to resolve the issue of whether a fire destroyed the witness' mother's medical records.

Sewage

100. The Inquiry has received a statement from a widower, whose wife contracted HIV and was diagnosed in 2003. She received blood transfusions at the St Mary's Hospital in Paddington in 1984 and 1985 during treatment for ulcerative colitis and septicaemia.[172] He states that his wife's records from St Mary's have '*disappeared*' although he has her medical records from treatment in Scotland.[173] He states that in 2003 a clinician found '*some scarce document on microfiche*'.[174] This contained information about her treatment in 1984 and 1985, including that five units of red cells and one unit of FFP were given in 1984 and four units of red cells in 1985.[175] In a 2003 letter from the National Blood Service to the woman's Consultant Physician described the attempts to obtain missing records:

'*There is no indication how many of the recorded units were administered…but we have proceeded to attempt to trace all those recorded in her file. Unfortunately, there are often problems in dealing with information obtained from microfilmed records. I am assuming that the entries were made by hand, and the opportunity for transcription or reading errors is quite high.*'

101. The National Blood Service concluded that the donation numbers were transcription errors (i.e. donations linked to different hospitals and/or at different times) and therefore no further investigation could be undertaken.

102. In 2007 the man tried to access his late wife's records from St Mary's Hospital:

'*I wrote to ask for them. After I hadn't heard anything in a long time. I phoned up to ask about them and I was told her records had been destroyed in a sewage leak. They said the sewage leak happened before 2003.*

I then phoned them up again and said that I thought they were mistaken, because our doctor accessed my wife's medical records in 2003 on microfiche. They then told me that the

[171] §1 of WITN7141001
[172] §2 of WITN0252001
[173] §8.2 of WITN0252001
[174] §8.3 of WITN0252001
[175] WITN0252002

records no longer existed because they routinely destroyed the medical records after 15 years so there was no chance of getting medical records.'[176]

103. The man's MP also attempted to access the records but could not obtain them.[177] The man questions why his wife's records were not kept because the 1984 surgery was a '*unique case*' as she was '*the first person to have a caesarean section and total colectomy at the same time. Her consultant had even asked her to speak to his students in an auditorium because she was such an important case. Why would you destroy those records?*'[178] He further states:

'*It's easy to go down the route of conspiracy theories but the whole situation leads to it. As much as I would like to think there isn't a cover up, I think one actually happened.*'[179]

104. The Inquiry has obtained a statement from Breda Kavanagh of the Imperial College Healthcare NHS Trust, who was asked whether there was a sewage leak, or any other event, at St Mary's Hospital which caused the destruction of records at some stage before 2003.[180] The response received is:

'*Attempts have been made to locate information regarding this and whilst it appears that a flood may have occurred, corporate records are only retained for 7-10 years and unfortunately therefore no information is available.*

A colleague who has worked in the health records department for some considerable years recollects a flood occurring, and that the papers records which were damaged were sent to a document recovery company, repaired and returned. Unfortunately no documents exist relating to this.'

105. It therefore appears that no records exist of an event where records may have been destroyed. The Trust states that if such an incident occurred now, '*this would be reported in line with our risk management reporting processes (Datix) and investigated.*'[181] No explanation is given as to why there was not a similar system in place previously.

---

[176] §§8.3-8.4 of WITN0252001
[177] §8.6 of WITN0252001
[178] §8.7 of WITN0252001
[179] §8.8 of WITN0252001
[180] WITN7113001
[181] WITN7113001

Difficulty obtaining medical records

Closed hospitals

106. The Inquiry has received many examples of individuals who are unable to access their medical records due to the closure of hospitals. This most commonly arises for women who received transfusions as part of labour at specialist maternity hospitals or units, which have since closed down. Many of these witnesses question why there was no national or local policy or procedure in place that prevented destruction of their records in such circumstances. Others ask why their medical records were destroyed without their consent or prior notification.

107. One such example is of a woman who had her first child in 1980. Six weeks after the delivery in 1980 she went for a post-natal check-up and was rushed to Roose Hospital, Barrow-in-Furness, for an emergency dilation and curettage procedure. She was given a blood transfusion.[182] In 1982 during the birth of her second child at the Sharoe Green Hospital, Preston, she was given a blood transfusion.[183] She has been unable to access her medical records for either of these deliveries. In 2018 the witness' solicitors received a response from the University Hospitals of Morecambe Bay NHS Foundation Trust to a request for her medical records:

> '*Our Medical Records Team have been unable to find any records for the above client. If the records were not destroyed in the fire then they will have been culled after 25 years in line with the policy of the Trust/NHS.*'[184]

108. Her GP has been able to find a single reference in a GP record to a blood transfusion.[185] The Inquiry has obtained a statement from Christine Morris, Associate Director of Safety and Learning at the Lancashire Teaching Hospital NHS Foundation Trust ("LTHTR"), which confirms that there was a fire at the hospital site of Sharoe Green Hospital on 24 July 2005.[186] The hospital closed in December 2004.[187] As set out above in the environmental

[182] WITN1954001
[183] §4 of WITN1954001
[184] WITN1954002. See also WITN1954003.
[185] WITN1954004
[186] §3 of WITN7209001
[187] §4 of WITN7209001

destruction section of this presentation, approximately 87% of medical records held at the Sharoe Green Hospital site were lost in the fire.[188]

Request for medical records were ignored

109. The Inquiry has received a small number of accounts where infected individuals or affected family members state that their requests for medical records have been ignored. For example, an affected son, whose late mother was infected with HCV following a transfusion at the Selly Oak Hospital in Birmingham in June 1987,[189] has told the Inquiry that he '*hit a brick wall*' in relation to accessing his mother's medical records. He states that he contacted the University Hospital Birmingham NHS Family Trust on 23 August 2017 and did not receive a response.[190] He then sent another letter on 23 October 2017 and received a response on 8 November 2017.[191] The response from the Trust[192] is described by the witness as '*vague and did not confirm whether the records had been destroyed.*' The letter acknowledges receipt and states:

'*Primary Care Support England holds the GP records for deceased patients for a period of 10 years after death. Our records show the above named passed away over 10 years ago. Therefore, in accordance with NHS Policy, these medical records are no longer available. A refund will be issued to you for your payment in due course.*'

110. The witness then sent another letter on 29 January 2018 asking to confirm whether there were *any* records.[193] His mother's GP has stated that they are unable to locate her records either.[194] He has received confirmation from the hospital that his mother's records had been destroyed under the hospital's retention policy.

111. The Inquiry has received a statement from David Burbridge on behalf of University Hospitals Birmingham NHS Foundation Trust.[195] His evidence to the Inquiry is that the Director of Patient Service is not aware of any records being held in archives, on microfiche

---

[188] §9 of WITN7209001. Albeit '*this does not reflect the amount of records held relating to each patient (some patient records are much more extensive than others, so numbers only provide a partial picture*'.
[189] §6 of WITN0714001
[190] §41 of WITN0714001
[191] §41 of WITN0714001
[192] WITN0714004
[193] WITN0714005
[194] §42 of WITN0714001
[195] WITN7143001

or otherwise, and that records were destroyed. He states that a longstanding member of staff within the medical records team has a recollection that there was '*a microfiche machine in place when she joined the medical records team in 1988*' but the Trust has been '*unable to substantiate this or located any such microfiche archives.*'[196] The Trust Director of Patient Services, Deputy Director of Estates and Information Government lead have '*confirmed that they have no knowledge or awareness of any instances where records were disturbed, misplaced or destroyed because of an incident.*'[197] This includes there being no knowledge or record of a fire destroying records at the Birmingham General Hospital in the 1980s.[198]

Delay in obtaining records

112. Some individuals have been able to obtain their own or their family members' records but this has only occurred after a period of delay. For these cohorts of individuals, they have often had to make formal written complaints or approach their MPs in order to obtain some or all of the missing records. Some examples are set out below.

113. The Inquiry has received a witness statement from a haemophiliac who was infected with HCV.[199] He describes the process of obtaining his records from one hospital[200] as '*extremely difficult*'.[201] He states that he was initially told that no records were held for him. However:

'*after various letters and emails, including one to the Chief Executive, and using Public Inquiry Powers some notes miraculously turned up now! I now have a CD containing my notes; although I am still not convinced they are complete.*'[202]

114. In contrast, he described receiving his records from 1988 onwards from the Royal Hallamshire Hospital in Sheffield '*without too much difficulty.*'[203]

---

[196] §6 of WITN7143001
[197] §8 of WITN7143001
[198] §10 of WITN7143001
[199] WITN1319001
[200] Not named in this presentation due to the witness' anonymity.
[201] §6 of WITN1319001
[202] §6 of WITN1319001
[203] §7 of WITN1319001

115. Another example of delay in obtaining medical records is that provided by a man who was '*misdiagnosed*' with mild haemophilia A when he was around 6 weeks' old.[204] He has provided three statements to the Inquiry.[205] He was treated at the Birmingham Children's Hospital until he was 18 and was then transferred to Queen Elizabeth Hospital, Birmingham.[206] He was infected with HCV.[207] He was told in around 1993 that the Birmingham Children's Hospital had '*lost my medical records and made a big deal stating that they have been looked for over some weeks and then came back saying they were lost.*'[208] In his third statement to the Inquiry, he states that he received medical records from the Birmingham Children's Hospital in October 2020.[209] There were 734 pages, albeit with some empty pages and duplicate pages. [210]

116. One affected daughter approached a total of seven hospitals, plus the UKHCDO and GP, in order to access her late father's records.[211] It has been a laborious process to obtain some records that relate to her father.[212]

117. One woman, who received a blood transfusion following the birth of her daughter in 1980,[213] attempted to access her hospital records but was told that they had been destroyed.[214] She then managed to obtain two pages of records from her GP which prove that she had a transfusion:

> '*The administrators of my current general practice told me that there was no record of me ever having had hospital treatment. After asking specific information relating to my childbirth, they eventually found some doctor's notes. They claimed the pages were stuck together and that is why they could not find them. I received only two little notes, which prove that I received the blood transfusion.*'[215]

---

[204] §3 of WITN1103001
[205] WITN1103001; WITN1103002 and WITN1103007
[206] §4 of WITN1103001
[207] §7 of WITN1103001
[208] §39 of WITN1103001
[209] §4 of WITN1103007
[210] §4 of WITN1103007
[211] §5 of WITN3125001
[212] §5 of WITN3125001
[213] §5 of WITN0511001
[214] §§23-24 of WITN0511001
[215] §25 of WITN0511001

118. One man has been unable to obtain the medical records pertaining to his father's HIV infection.[216] He states that his father received blood transfusions as part of surgeries between 1986 and 1989 at a London hospital after his father was diagnosed with tongue cancer in 1986 in Iran.[217] He requested his father's medical records in 2011 but was told that there was no record of his father being a patient.[218] The witness instructed solicitors to assist him with obtaining the records. On 31 July 2017 the solicitors sent a letter to the Health Records Department of the hospital, attaching copies of his father's identification and setting out alternative spellings of his father's name.[219] The Trust responded and stated that they could not trace his father.[220] The witness then approached his MP, who wrote to the Chief Executive of the hospital.[221] The hospital Trust responded and the witness states that:

'*and this time, claimed that there was an entry for my father on their previous computer system, but that entry indicated that the medical file was placed into a storage library in 1993 and subsequently destroyed in 2017.*[222]*I could not believe how they had suddenly been able to identify my father and located his medical records after denying that he was ever a patient at [the hospital] for so long. I could not believe that they had then destroyed those records after I had spent such a long time attempting to request them. I think it is suspicious that it was in the same year that my MP wrote to them that my father's medical records were destroyed.'*[223]

119. It appears that the reason for this was because the hospital had a different spelling for his father's surname and the wrong date of birth listed.[224] The witness states that the hospital was then able to list the dates of the transfusions as well as the unit numbers and component types he received.[225] However, he has never personally received these records and believes that there is a cover up in place.[226] His application to EIBSS and subsequent appeal were unsuccessful.[227]

---

[216] WITN0890001
[217] §§4-5 of WITN0890001
[218] §24 of WITN0890001
[219] WITN0890002
[220] WITN0890003
[221] WITN0890004
[222] WITN0890005
[223] §28 of WITN0890001
[224] §29 of WITN0890001
[225] WITN0890006
[226] §58 of WITN0890001
[227] §55 of WITN0890001

120. An affected mother attempted to obtain her late son's medical records from the Queen Elizabeth Hospital, Birmingham. He died in 1995 when he was only 25 years old.[228] She had originally obtained his records and successfully applied to the Skipton Fund in around March 2011.[229] In around 2013 she then found out about the second stage payment for the Skipton Trust. She was told by Skipton she needed to supply medical records. She queried this because she had previously supplied such records. When she contacted the Queen Elizabeth Hospital in April 2013 she was told that the medical records had been destroyed. She was told that '*they had moved to a smaller office and could not accommodate all the records*.'[230] Her application for the second stage payment was successful after support from Dr Wilde.[231]

121. Another example of records being available and then subsequently destroyed is that of a man, who was diagnosed with cardiomyopathy and myocarditis in 1984. He tested positive for HBV in 1987.[232] His solicitors requested medical records from Northwick Park Hospital and were told that Trust was unable to supply the records as retention period had passed and they no longer held records.[233] He describes this as '*very strange*' because his medical records were provided to his previous solicitors in 2018.[234]

Records subsequently found

122. The Inquiry has received evidence from infected individuals and their affected family members about records which were said to be destroyed but were in fact subsequently found. Three examples are set out below.

123. A man with haemophilia, who commenced factor VIII treatment in 1978,[235] was treated at the Manchester Royal Infirmary and Treloars school.[236] In 2017 he obtained his medical

---

[228] §2 of WITN1616001
[229] §42 of WITN1616001
[230] §43 of WITN1616001
[231] WITN1616009
[232] §10 of WITN2638001
[233] §41 of WITN2638001
[234] §41 of WITN2638001
[235] §9 of WITN1379001
[236] WITN1379001

records from his solicitors. He had previously been told that his records had been destroyed approximately 8 years after his last attendance at the Manchester Royal Infirmary:

'*At the time of my request they did acknowledge that my records should have been kept due to my haemophilia and my having received blood products but that they had been destroyed in error due to a failure in the Trust's processes.*'[237]

124. A woman, who received a blood transfusion in around October 1983 for a bladder condition,[238] was told by telephone that her records from St Thomas' Hospital had been destroyed.[239] However, she states that her nephew had a '*temporary job at DoH in the late 1990s, his role had been to transfer old records to microfilm. At that time he had picked up my notes and had recognised my surname as it is quite unusual. He had copied them to microfilm. Once we knew this, we asked the GP to request the requests, miraculously the records turned up.*'[240] She was able to use these records to get the first stage of the Skipton Fund: '*I don't know what we would have done if we had not been able to get the records. I could not work and I was too ill to be left by myself... Without the money from the Skipton Fund how could we have survived?*'[241]

125. A woman, whose husband was diagnosed with HCV in 1992 and died in 2018,[242] has made three statements to the Inquiry. After applying for her late husband's records from the Dundee Royal Infirmary, she received 11 volumes of medical records. These have been reviewed by the Inquiry's investigators.[243] Of these 11 volumes, there was no volume 5. The witness then contacted her husband's nurse and obtained volume 5.[244] She states: '*Upon inspection of this missing file, I have been informed that there is no highlighted or marked area of interest, as I had previously been informed by [her husband's haemophilia nurse]. I have no idea why this file was not made available the first time of asking.*'[245]

---

[237] §3 of WITN1379001
[238] §5 of WITN1932001
[239] §§82-83 of WITN1932001
[240] §83 of WITN1932001
[241] §83 of WITN1932001
[242] §9 of WITN0640001
[243] §2 of WITN0640005
[244] §6 of WITN0640018
[245] §7 of WITN0640018

126. A woman was infected with HCV after receiving a blood transfusion at the Poole General Hospital on 27 March 1988 after the birth of her first child.[246] She attempted to obtain her medical records in May and June 2015 but was told that her records were unavailable.[247] She asked whether her records had been destroyed or transferred to another medium, but states that she did not receive answers to these questions.[248] On the second occasion she was sent maternity records in relation to her youngest child.[249] She then applied to her GP practice for her medical records and she received a telephone call from the receptionist that some of her records had been located but records covering 1988 could not be found.[250] She states that:

'A few days later I received a phone call ... informing me that my missing records had been found by [a GP's] daughter at the back of a cupboard in the basement. We were delighted although we thought it strange that they were separate from my other GP records.'[251]

127. She states that although the records were nearly 300 pages long, there is no reference within them to her having a blood transfusion in 1988. [252] She was nonetheless successful in her application to the Skipton Fund.[253]

The quality of medical records

128. Infected individuals and their affected family members have raised concerns about inaccuracies in their medical records. Broadly, these fall into two main categories: (i) inconsistency between what is recorded in the notes and the information that was given, or not given, to a patient; and (ii) inaccurate information being recorded in the records. The available evidence suggests that patients have struggled to get inaccurate information altered in their medical records.

---

[246] §3 of WITN2051001
[247] §67 of WITN2051001
[248] §67 of WITN2051001
[249] §67 of WITN2051001
[250] §69 of WITN2051001
[251] §70 of WITN2051001
[252] §71 of WITN2051001
[253] §118 of WITN2051001

Inconsistency between oral information and what is recorded in medical records.

129. Some witnesses have highlighted to the Inquiry that, upon reviewing their medical records, those records contain different information to what individuals have been told, or not told, orally by treating clinicians. To date, the Inquiry has heard a significant amount of evidence from infected individuals and their affected family members about communication issues with clinicians; that evidence is not repeated here. However, some examples of conflicting evidence between what individuals were told, or not told, orally and what is recorded in their medical records are set out below.

130. One woman received factor IX at the Colchester General Hospital in 1982 following a tooth extraction.[254] She was subsequently diagnosed with mild haemophilia B and was referred to the London Hospital, Whitechapel.[255] In 1991 she received a letter that stated she had been infected with HCV.[256] When she saw her medical records she found letters that suggest she was not informed about her infection earlier despite the fact her treating clinicians were aware of it. A letter from Dr Colvin, dated 25 April 1982, stated: '*I suppose we should assume that she has on-A non-B hepatitis, though I do not propose to tell her this as she is extremely well*'.[257] In another letter from Dr Colvin, dated 10 February 1982, he wrote: '*As you know there was some evidence of sub-clinical non A non B hepatitis following her treatment last year but we decided to turn Nelson's eye to this...*'[258] The letter goes on to say:

'*The present attack could conceivably be due to a recurrence of the previous hepatitis or might be related to [her son's] home treatment... When [she] is better we will probably need to go into this in a little more detail but in the meantime if you are able to get a sample from [her son] that might be quite helpful*'.[259]

131. There is no evidence that the witness was told about the hepatitis until she received the letter in 1991.[260]

---

[254] WITN1768001; WITN1768002
[255] §4 of WITN1768001
[256] §8 of WITN1768001
[257] WITN1768003
[258] WITN1768004
[259] WITN1768004
[260] Dr Colvin was approached for a response to this criticism but elected not to respond.

132. In June 1981 a man was involved in a serious motorcycle accident and underwent surgery at Harrogate District Hospital.[261] He believes that he received a blood transfusion because of the extensive nature of his injuries.[262] However, he has received conflicting and confusing information about whether he received blood products. Following his surgery, he states that he became addicted to prescription painkillers and this led to further substance abuse, including the use of intravenous drugs.[263] In 2004 he was diagnosed with HCV after offering his sperm to a lesbian couple.[264] In 2009 he contacted the hospital to see if he had a blood transfusion in 1981. On 25 March 2009 the witness received a letter from Mrs GRO-D of the Harrogate and District NHS Foundation Trust, which stated that he received no blood products during his June 1981 admission.[265]

133. The witness subsequently ran into the surgeon who performed the surgery in the post office. The surgeon did not recall the specific surgery but the witness asked him if it was likely he had received blood as his leg had been '*shattered*':

'*He said that people do not understand that bones bleed and I would have been bleeding profusely so I would have required blood and that it would have been absolutely necessary to have a blood transfusion.*'

134. The witness asked his GP about whether he had received blood. On 22 April 2016 the Harrogate and District NHS Foundation Trust stated that they had traced historic transfusion records which suggested that a patient with the same name as the witness received 4 units of blood on 16 August 1981:

'*The records have no other identifiers (just first name and surname) but in view of the specific date given by the patient it can safely be assumed that he is the [patient] in the document.*

I have included a copy of the blood bank register for your information. It has the donor numbers of the units on'.[266]

[261] WITN2792001
[262] §4 of WITN2792001
[263] §5 of WITN2792001
[264] §6 of WITN2792001
[265] WITN2792002
[266] WITN2792003

135. The witness made a complaint and the Trust produced a report setting out the Trust's investigation into why the witness received conflicting information.[267] The report states that the witness did not, in fact, receive a blood transfusion and the conflicting information was due to human error. It states that blood transfusion records were:

'*manual entries in a Blood Bank Register at the time... the register shows that the blood above was returned to stock and not used during your care. This was common practice in the register, with many cross matched units returned to stock.*

When the request came to Mrs GRO-D *in 2009, Mrs* GRO-D *reviewed the information in the Blood Bank Register and wrote a letter to you confirming the blood which had been cross-matched for you, was not used...*'[268]

136. The witness' position is that he has never seen any evidence to confirm that the blood was actually destroyed.[269] In a second witness statement to the Inquiry the witness states that in 2016 he received a call from a man at the hospital to apologise for the clerical error:

'I can no longer recall his name, but this man was in tears and he wanted to apologise to me personally for the distress he had caused to me. He swore on his children's lives that it was due to his clerical error that I had been informed that I had had a blood transfusion, when I had not. This man offered to meet me to show my medical records. At the time, I felt sorry for the man, I accepted his apology and left it at that. However in retrospect, I wonder if I had been emotionally manipulated.

What does not ring true to me, is that in connection with my enquiry as to why I was told first that I had not had a transfusion, then years later that I had and then again that I had not, I was only told of women's names that were involved, Mrs GRO-D*, Mrs* GRO-D *and Ms* GRO-D*.*'[270]

Inaccuracy

137. Many individuals have expressed concerns to the Inquiry that their medical records are inaccurate. Some examples are set out below.

138. The Inquiry received a statement from a man who suffered a traumatic amputation of his thumb as a child.[271] He received a blood transfusion and blood products and was later

[267] WITN2792004
[268] WITN2792004
[269] §12 of WITN2792001
[270] §§5-6 of WITN2792006
[271] WITN1899001

diagnosed with HCV. He has described finding out that his medical records contained '*many falsehoods*' such as that he was '*married, had two kids; false teeth and was an intravenous drug user!*'[272] He states that his request was granted in 2007 and the references were '*expunged*' from his records.[273]

139. Another man, who underwent significant abdominal surgery in 1974, has raised concerns about the accuracy of his records. There is a note in his medical records which states that he could have been infected by his mother and sister who are said to have HCV. He states that this is not correct:

'*I think that this happened at Homerton Hospital when I asked how I could have become infected with hepatitis C. I think that this person misheard my response to her question about whether any sibling had become infected.*'[274]

140. A widow, whose husband died in 2013, has raised concerns about the accuracy of her late husband's records.[275] Within his records is an entry dated 11 December 1981, which set out a '*flare up of symptoms*' around two weeks after he received NHS concentrate.[276] However, an identical entry is recorded in the man's father's medical records.[277] The two men shared the same name. In her oral evidence to the Inquiry the witness put it in these terms: '*How can you have two separate patients with exactly the same comments? That's my question.*'[278] She further stated:

'*It looks like this entry has been cut and paste like a piece of paper over the top of it which concerns me too because I didn't get the originals, I had scans. So I couldn't look and investigate that any further.*'[279]

---

[272] §34 of WITN1899001
[273] §34 of WITN1899001
[274] §41 of WITN1967001
[275] WITN1001001
[276] WITN1001004
[277] WITN1001004. The Inquiry has received a statement from Professor Lee who first saw the man's father in November 1983: WITN0644038.
[278] P. 112 of INQY1000038
[279] P. 113 of INQY1000038

Alcohol

141. Many witnesses have expressed concerns that their, or their family member's, records contain inaccurate references to alcohol use. This most commonly arises for those with HCV who have experienced GPs and hospital clinicians link the source of their HCV infection to excessive alcohol use. Some examples are set out below.

142. During her oral evidence to the Inquiry, a widow, whose husband died in 2013, was asked about references in her late husband's medical records to excessive alcohol intake being the cause of his liver problems. She was asked about whether that was accurate and stated:

'No, not at all. I was horrified when I read that. I have never, ever seen Angus with a beer in his hand, a spirit in his hand. We have -- he was not a pub visitor. He hated pubs, wine bars, nightclubs, and indeed when we used to go on holiday we would frequently fall out because I would want to go to something special after and he would be adamant, "No, we're going back to the room by 10.30", and there would be in the most exotic location and he wanted to go back to the room. In the whole time that I knew ... he would like a glass of wine, we'd cook together and have a glass of wine and go out for meals and have a glass of wine but he was not the type of person that would go out drinking, not at all.'[280]

143. The Inquiry has received a statement from Professor Lee, who first saw the witness' husband in 1990.[281] On the issue of whether Professor Lee attributed this patient's HCV to his alcohol intake, Professor Lee has told the Inquiry:

'*I would never have attributed the cause of [his] HCV as being due to alcohol. However, I did advise all patients with HCV infection that alcohol consumption in any amount may cause or exacerbate damage to the liver and this would add to any damage caused by HCV infection. I documented the information that [he] gave to me about his alcohol consumption in the notes.*'[282]

144. The witness told the Inquiry:

[280] P. 118 of INQY1000038
[281] WITN0644023
[282] §23 of WITN0644023

'*It seems to be habitual that clinicians like to write that somebody has a problem with drink and that's why they have the cirrhosis. You hear this in the hearings and also they actually did this to – they wrote this in [his] father's notes at all and I have to say I never ever saw [his] father ever drink at home, ever, never did, and he hardly went out the house. So it seemed to me that one clinician write in something and they all tend to pick up on it and decide to continue to write that afterwards.*'[283]

145. Professor Lee has addressed the family's criticism about alcohol in the following terms:

'*Witness W1002 states that there is a lot of reference in [the patient's] records to him drinking a lot of alcohol which is not true. The records represent an accurate note of the history provided by [the patient] to his treating doctors. Alcohol is a known factor in the causation and progression of liver disease and it is important to be aware of a patient's level of alcohol consumption and give advice accordingly.*'[284]

146. Another example of contested references in medical records to excessive alcohol use is provided by the wife of a man, who had a metal plate inserted into his ankle at St Thomas' Hospital following a road traffic accident in 1978.[285] She refers to an entry in his GP records of 1 August 1990 which records:

'*The low WCC and low platelet count may be from hypersplenism related to liver disease which I think is related to his previous alcohol abuse. He used to drink up to 15 pints plus 2-3 bottles of wine a week over many years...I have advised him to continue to remain a teetotaller...*'[286]

147. His wife contests this: '*This is not accurate. While [her husband] did used to drink in a work environment, he was never an alcoholic and by the time of those tests, had stopped drinking entirely. In addition, at no time in his life has he ever "enjoyed" a pint; coeliacs and beer don't mix.*'[287] She states that he was not informed of his infection with HCV until 1999 despite the existence of cirrhosis.[288]

148. A woman, who was infected with HCV, received a transfusion on 21 June 1980 following childbirth.[289] Her medical records evidence the fact of transfusion and the fact

[283] P. 119 of INQY1000038
[284] §88 of WITN0644038
[285] §3 of WITN2026001
[286] WITN2026003
[287] §11 of WITN2026001
[288] §§13-14 of WITN2026001
[289] §6 of WITN0511001

she developed jaundice in 1980,[290] which was described in her medical records on 8 August 1980.[291] She underwent investigations in 2016 and a clinician provided a diagnosis of a fatty liver with an impression of '*likely secondary to fatty liver combination of overweight and alcohol in the past.*'[292] The witness disputes this reference to alcohol use and sought a second opinion.[293] That second clinician provided a differential diagnosis of '*non-alcoholic fatty liver disease*' as well as a previous HCV infection.[294]

149. An affected widow, whose husband was co-infected with HIV, HBV and HCV and died from liver cancer in 1993,[295] has queried the references to alcohol in her husband's medical records.[296] She states that she had not previously seen these records and was '*unaware of their existence and content*' until she obtained his records.[297] She states that her husband '*very rarely consumed alcohol. He was not a drinker*'. Her view is that the treating clinician '*fabricated*' reports of alcohol consumption.[298] She describes their social life as being '*non existent*' because they ran a business together from home and had young children. She describes her husband as having '*the odd glass of wine at Christmas. The alcohol in the house remained untouched from one year to the next.*'[299] She states that in 22 years of marriage she had never seen her husband '*worse for wear through drink*'.[300]

150. The Inquiry has received a response from the man's treating clinician: '*I would record what alcohol the patient told me they drank and also refer to any relevant reports of their alcohol consumption made by nurses and other staff and family members who had been involved in the patient's care. I would not have had any reason to record any other alcohol consumption and would never have considered fabricating this as doing so would not have contributed positively to the patient's care or their survival.*'[301]

---

[290] §6; §9 of WITN0511001
[291] WITN0511002
[292] WITN0511004
[293] §15 of WITN0511001
[294] WITN0511005
[295] §2 of WITN1183001
[296] §30 of WITN1183001
[297] §30 of WITN1183001
[298] §30 of WITN1183001
[299] §31 of WITN1183001
[300] §33 of WITN1183001
[301] §8 of WITN3740001

UKHCDO records

151. The Inquiry has received a significant amount of evidence from infected and affected individuals about errors and omissions in UKHCDO records. Some examples are set out below.

(a) One man, who was coinfected with HIV and HCV, has obtained his UKHCDO records which show "*#Error*" for an entry in 1976 and an undated entry.[302] He has concerns about the overall accuracy of the UKHCDO records because the database lists the '*date first positive*' as 15 January 1985.[303] However, he attended for testing in August 1985 and the sample date is listed as 15 September 1985. He does not know if that is a transcription error or another test which he was/is not aware of.[304]

(b) The Inquiry received oral evidence from a man whose medical records suggest that he was first positive for HIV on 28 April 1985.[305] However, his UKHCDO records lists 1 January 1999 as the date he was first diagnosed.[306]

(c) The Inquiry received oral evidence from a man whose UKHCDO records do not record any factor IX treatment given in 1978. He first received factor IX in around May 1978 at the Brooke Hospital in south-east London. He received seven bottles of factor IX over two days. It was subsequently confirmed that he did not have a factor IX deficiency but a factor VIII deficiency.[307] His UKHCDO records show treatment with factor VIII in 1988 but not the earlier treatment.

(d) One widow describes her husband's UKHCDO records as '*farcical.*'[308] The date of her husband's first HIV diagnosis is listed as October 1984-1985 whereas the ELISA test indicates this was August 1984.[309] The UKHCDO record states that her husband was

[302] WITN1122002
[303] WITN1122018
[304] P. 17 of INQY1000045
[305] P. 10 of INQY1000042
[306] P. 2 of WITN1387013
[307] P. 70 of INQY1000016
[308] P. 91 of INQY1000040
[309] P. 91 of INQY1000040

not seen in 2004 and 2005: '*well, since he had been cremated for nearly seven years by then it's hardly a surprise.*'[310]

(e) One witness, who was wrongly treated as though he had a clotting factor deficiency[311] received fresh frozen plasma, cryoprecipitate and factor VIII concentrates on 4 September 1978[312] and was told by the UKHCDO that his record is completely blank:

'*They said they would have to come back to me, because they had to look on their computerised system, and then I did have correspondence saying that they found nothing. All it had was my name, but there was nothing. It was blank. Four pages of blank paper. And then they said that they will go through their paper archives, which again has come back as nothing.*'[313]

This witness describes being told by UKHCDO that their records were '*only as good as the information that was given to them by the treatment hospital and that it was a breach of protocol for them not to have been informed.*'[314] The witness has been unable to obtain the batch numbers of the blood products he received.

152. Other witnesses have made observations about the challenges of obtaining UKHCDO records. For example, one widow explained the difficulties she has had obtaining her husband's UKHCDO records:

'*I have applied to the UKHCDO for their records probably two/three times. I phoned them up and all I've been provided with is a sheet about, you know, that long (indicated), four or five treatments for his entire life. It is so wrong that we, as the victims, cannot get co-operation from these official bodies and have to rely on solicitors and legal people to do it. You know, I'm so impressed that you got that because I battled for ages and couldn't get anything.*'[315]

153. She was able to obtain a list of products from the West Midlands Regional Health Authority which sets out a different list of products received.[316]

---

[310] P. 91 of INQY1000040
[311] When in fact he had Ehlers-Danos Syndrome
[312] §1 of WITN0653009
[313] P. 39 of INQY1000043
[314] §74 of WITN0653001
[315] P. 39 of INQY1000037
[316] Compare: WITN1564011 and WITN1564012

154. Some witnesses have highlighted to the Inquiry that they were contacted by UKHCDO after further records were found. In a July 2019 letter from Professor Charles Hay, Director of the National Haemophilia Database, it was explained that medical records from paper archives had been missed out:

'*on a recent inspection of the paper archive we discovered that some details, from paper forms submitted to the database in the seventies through to the nineties, were archived but not entered into the electronic record. These forms were submitted many years ago by your Haemophilia Centre when the database was held in Oxford before paper reporting was phased out in 2000...*

We apologise unreservedly that you were not sent all the information after your initial request and for any distress or difficulties this may have caused. Please be aware that some paperwork had other names on it in addition to yours, and therefore these parts of the records have been blacked out to preserve confidentiality.'[317]

Missing records

No explanation for missing records

155. In some circumstances individuals and hospital trusts / health boards have not been able to ascertain what happened to missing medical records.

156. For example, the Inquiry has received a statement from a man who underwent a combined septoplasty and rhinoplasty on 17 August 1987 at the Queen Mary's Hospital in Roehampton.[318] He has confirmation of his admission to and discharge from the hospital.[319] He attempted to obtain a complete set of his medical records:

'*I called the hospital and also sent them a letter to try and get my medical records. I rang the hospital on a couple of occasions and had a conversation with a woman from the hospital. I ultimately received a letter back from the hospital which stated that after an extensive search they could not find my medical records.*'[320]

[317] P2 of WITN1389005
[318] §7 of WITN0943001
[319] WITN0943002
[320] §106 of WITN0943001

157. That letter, from 2015 on behalf of the St George's University Hospitals NHS Foundation Trust, states that '*despite extensive searches we have been unable to trace your medical records relating to your stay here in 1981.*'[321]

158. The witness states that he was only able to obtain a '*couple of letters*' from his former and current GP. One GP commented that '*given the operation I had, it was unusual that there were so few documents and that I should have had a bigger file.*'[322]

159. A woman with severe von Willebrand's disease, who was diagnosed in 1975, was treated at the Manchester Children's Hospital, the Manchester Royal Infirmary, the Withington Hospital and the Queen Elizabeth Hospital, Birmingham.[323] She was diagnosed with HCV in 1993 aged 18 when being treated at St Thomas' hospital for some surgery.[324] She has been unable to discover when she was tested for HCV. She:

> '*tried to get copies of my notes from RMCH from my entire childhood with the help of my specialist nurse. However, having said, "yes, no problem, leave it with me," she then rang us back to say my notes had, "gone down a black hole" and she could not understand it...*'[325]

Missing records: a specific procedure or appointment

160. Infected individuals and their affected family members have raised concerns about the existence of gaps in their medical records in relation to a specific procedure or appointment. For some, this has caused particular concern that their records have been purposefully tampered with or key records removed.

161. An example of missing records for a specific procedure is provided by the wife of a man, who had a metal plate inserted into his ankle at St Thomas' Hospital following a road traffic accident in 1978.[326] He was '*in hospital for quite some time – weeks rather than*

---

[321] WITN0943004
[322] §107 of WITN0943001
[323] WITN1168001
[324] §12 of WITN1168001
[325] §13 of WITN1168001. See also her oral evidence to the Inquiry on 18 October 2019: p. 95 of INQY1000044
[326] §3 of WITN2026001

days.'[327] There are no medical records relating to this procedure.[328] Within his medical records is a document entitled '*Integrated Care Pathway for Nurse-led treatment of Hepatitis C Patients*.'[329] Within that document the question of '*blood transfusion prior to 1991*' has been ticked and handwritten next to it is: '*leg operation. ?? yrs [sic] ago*'. The application to the Skipton Fund was initially rejected.[330] An appeal was successful in 2007.[331]

162. Another example of a specific appointment missing from medical records is that of a man who was coinfected with HIV and HCV. He was informed of his diagnosis with HIV in 1985 via a letter, after he had attended for testing. He has kept a copy of that letter.[332] In his witness statement he stated: '*Interestingly I have been unable to locate a copy of the letter in the medical records that have been provided to me.*'[333]

163. Another example of missing records related to specific appointments is that provided by a woman, whose husband was infected with HIV and HCV as part of treatment for severe haemophilia at the Royal Free Hospital. She has described that there is no reference of her husband's attendances at the hospital in February 1985 when he received his diagnosis of HIV.[334] She states that he attended one appointment where he and his father were told that he did not have AIDS and then he attended a week later to be told by Dr Kernoff the opposite and that he was in fact infected. Neither appointment appears in his medical records. The witness states:

'*These records must have been removed from [his] notes. There is nothing contained within the medical records between 24 September 1984 to 8 March 1985.*'

164. She is further concerned that medical records within her late husband's records have been doctored. She attended an appointment to discuss genetic counselling and to discuss the AIDS diagnosis on 9 March 1985.[335] The witness states that the first three lines at the

[327] §3 of WITN2026001
[328] §4; §54 of WITN2026001
[329] P. 4 of WITN2026008
[330] §§46-47 of WITN2026001
[331] §49 of WITN2026001
[332] WITN1122004
[333] §12 of WITN1122001
[334] §10- §12 of WITN1578001
[335] §12 of WITN1578001

top right-hand side of the page of the medical records for this attendance appear to have been tipex-ed out.[336]

165. The Inquiry has received a statement from a man who underwent surgery in June 1984 at the North Middlesex Hospital (formerly the Prince of Wales Hospital) for a perforated duodenal ulcer.[337] He has been left with a visible keloid scar, which is approximately 12 inches in length.[338] After the procedure and his recovery in intensive care, he was told that the surgery had not gone well and that he had required multiple blood transfusions. He recalls seeing blood bags attached to his arm and blood being transfused into him.[339] He further recalls that a clinician told him post-operatively that he had received blood. However, he has not been able to obtain any medical records that confirm he received blood. When he requested his medical records, he found that two pages were missing: '*they are pages 20 and 21 of a set that I have received*'.[340] He was diagnosed with HCV in 2013.[341] He has been unable to obtain any funds from the Trusts and Schemes because he is unable to prove that he received blood.[342]

166. The Inquiry has received a statement from the widow of a man who underwent a gastroenterostomy and partial gastrectomy on 25 February 1987 at the Frimley Park Hospital, Surrey. She has not been able to obtain medical records that conclusively evidence any transfusion but has received payments from the Skipton Fund:

'*I find it hard to believe that there are only 30 pages of medical records available... at Frimley Park Hospital and that these records do not record specifically the facts that he had a blood transfusion… The notes document the following information: 'x match 20 (HB 9.3)' on 15 March 1987 and "2 litres x 12 hours" on 26 February 1987. I assume that these entries referred to blood and provision of it*'.[343]

[336] WITN1578003. This is difficult to see on the photocopied record.
[337] §3 of WITN1967001
[338] §3 of WITN1967001
[339] §3 of WITN1967001
[340] §3 of WITN1967001
[341] §8 of WITN1967001
[342] §32 of WITN1967001
[343] §43 of WITN1977001. See also §8 for concerns about GP records.

Missing records: specific years missing

167. In addition to instances where individual appointments or records pertaining to a specific procedure are missing, the Inquiry has received examples of individuals and their family members who have been unable to trace any records relating to whole years of treatment. Some examples are set out below.

168. The affected partner of a man, who died in 2002, has provided a statement to the Inquiry with input from the notes written by his parents.[344] He had severe haemophilia and was treated from the age of 4.[345] In 1984, when he was 11 years old, his parents were told that he had contracted HIV through infected blood products.[346] In order to produce the statement for the Inquiry, the witness applied to obtain his medical records: '*when I spoke with the administrative staff at the [hospital] I was assured that [his] notes would not have been destroyed.*'[347] She described herself being '*initially optimistic when two substantial packages arrived*'. She received in excess of 700 pages. However, the bulk of these are "*green cards*"[348] and the medical records are incomplete:

> '*Having reviewed every page it is clear, however, that the records are incomplete. There are a number of years between 1977 and 1991 that do not feature at all in respect of "green cards" which, given [his] severe haemophilia status, cannot be accurate.*'[349]

169. In particular, there are no copies of green cards in 1983 or 1984; these are obviously significant years in relation to his HIV infection.

170. The Inquiry has received a statement from a person with severe haemophilia who was treated at the Newcastle Haemophilia Centre at the Royal Victoria Infirmary, under the care

---

[344] WITN0870001

[345] §5 of WITN0870001

[346] §6 of WITN0870001. He was later also diagnosed with HCV.

[347] §12 of WITN0870001

[348] §12 of WITN0870001. Green cards which were completed by medical staff, his parents and himself to record the blood products administered.

[349] §12 of WITN0870001

of Dr Peter Jones.[350] He states that he has no records, other than UKHCDO records, from the beginning of 1985 to the end of 1986.[351] He states that he was:

'*first alerted to this by a firm of lawyers in the USA when I was involved in the American litigation. I phoned the Newcastle Health Authority to see if they had been misplaced. I was then told that they had been sent to be copied and were lost. If that we true, I do not understand why it is that the two most important years are amongst those missing.*'[352]

171. The witness' father has provided a statement to the Inquiry about his other son, who also had haemophilia and who was infected with HCV and died of a haemorrhage aged 6 in 1978.[353] He states that he was told that his late son's medical records had been destroyed 8 years after his death. However, in a letter, dated 8 February 2012, a consultant haematologist wrote to the Skipton Fund that it was very likely that the boy was infected with HCV and referred to abnormal liver function test results on 24 February 1977.[354] The boy's father therefore questions how the hospital was able to provide that information to the Skipton Trust if the records have been destroyed.[355]

172. The Inquiry has received a statement from a woman with haemophilia, who was treated at the Leeds General Infirmary under the care of Dr Kernoff in the early 1970s.[356] Her medical records contain correspondence from 1977 between Dr Kernoff and Dr Rizza of the Oxford Haemophilia Centre about the prospects of her having a child without haemophilia.[357] In around 1977 to 1979 the witness trapped her finger in a door and attended the A&E department of Leeds General Infirmary. She states that she:

'*told the hospital that Dr Kernoff was my treating consultant there and was advised that Dr Kernoff had gone to do research in America. I asked if my medical records could be recovered and transferred to another consultant, and it was explained that Dr Kernoff had taken my records with him. The implication was that he had wanted to use them for his research in the field. They suggested that I go to St James' Hospital for treatment as that was where the haemophiliac clinic is.*'[358]

---

[350] §4 of WITN1521001
[351] §40 of WITN1521001
[352] §40 of WITN1521001
[353] WITN1519001
[354] WITN1519002
[355] §23 of WITN1519001
[356] §7 of WITN1879001
[357] WITN1879003; WITN1879004
[358] §12 of WITN1879001

173. In a letter, dated 2 November 1981, her GP Dr Anderson wrote to Dr Swinburn at the haemophilia clinic: '*some of her notes appear to be missing from her files*'.[359] However, the witness does have the medical records that prove her infection with HCV, including batch numbers and a handwritten record from 1982 that she contracted non-A non-B hepatitis from an amniocentesis procedure in August 1982.[360]

Specific type of records missing

174. The Inquiry has received examples from infected individuals and their affected family members about medical records not containing a specific type of record or medical discipline. One example is that of an affected father, whose son was infected with HIV and HCV.[361] His son was treated at three different hospitals. He applied for his son's records in order to appeal a negative decision from the Skipton Trust.[362] Having obtained the records he describes being '*struck by the total lack of reference to or information about his HIV status in his notes from York District Hospital*'. There is only a single haematology letter from 1979 to 1988:[363]

> '*His other notes are there, for example his paediatrics and orthopaedics, it is only haematology that is missing. It is our belief that records relating to [his] HIV have been purposefully removed or destroyed.*'[364]

175. A man, who was infected with HIV and HCV, as a result of his haemophilia treatment at Yorkhill Hospital and Raigmore Hospital, states that he has not been provided with a full set of medical records.[365] He has not received a full copy of the batch numbers of products, the test result that confirmed his HIV diagnosis and the notes of his parents' attendance when they received his HIV diagnosis. He also states there are a number of records that are blacked out and/or illegible.[366]

---

[359] WITN1879005
[360] §18; §22; §23 of WITN1879001
[361] WITN0995001
[362] §56 of WITN0995001
[363] §58 of WITN0995001
[364] §58 of WITN0995001
[365] WITN2149001
[366] §46 of WITN2149001; WITN2149004

176. Some witnesses who have been unable to obtain information about the batch numbers of blood products have made requests to blood banks to see if such records are held there. Manchester University NHS Foundation Trust has provided a response to such a request and stated that blood banks must only retain data needed for full traceability for at least 30 years from the point of receipt and there is no obligation for a blood bank to keep such records indefinitely.[367]

Impact of missing records

177. For individuals who have been unable to obtain their own, or family members' records, one of the key impacts is being unable to ascertain when, where and how and infection arose. Some examples are set out below.

178. The Inquiry received a witness statement from an affected daughter.[368] Her father died in 2010 and HCV is listed, along with other conditions, on his death certificate.[369] She believes he may have received a transfusion as a result of a goitre operation in around 1975 or 1976 at the Queen Elizabeth Hospital's predecessor in London.[370] She recalls visiting him in hospital after the surgery when she was about 8 years' old. She applied for her father's medical records after completing a Skipton application form she found in his records after he died.[371] She was told there were no pre-1991 records available. She received a letter from Dr McNair of the Lewisham and Greenwich NHS Trust which stated that, having reviewed her father's medical records, he could find no evidence that he had a blood transfusion or received any other blood product.[372] He stated:

'*There does appear to have been a gap in his medical records from 1986 to 1998 and naturally if you are aware that he received a blood transfusion at another hospital prior to routine testing for hepatitis C in blood products in 19991 then you should take the application form to a doctor at that hospital.*'

[367] LDAY0000001
[368] WITN2011001
[369] WITN2011004
[370] §4 of WITN2011001
[371] §39; §41 of WITN2011001
[372] WITN2011011

179. Her application, and subsequent appeal to the Skipton Fund, were both unsuccessful due to the absence of medical evidence. The witness has queried how Dr McNair was able to refer to a gap in her father's medical records as she '*still not been granted any access to records pre-1991 so didn't know how Dr McNair had been able to review them*.' She has been told that she is not able to access these records because, under the Access to Health Records Act 1990 because the records were made prior to November 1991.[373]

180. For the impact of missing records on Look Back exercises, see the Inquiry's presentation dated October 2021.[374]

Significant interference in medical records

181. The Inquiry has received some accounts from infected individuals and their affected family members that raise serious issues of intentional interference in medical records. This section of the presentation sets out the available evidence and the investigations undertaken by the Inquiry in relation to these allegations.

182. An affected mother has provided written and oral evidence to the Inquiry about her son's infection with HCV and his death in 2012.[375] Her son was initially treated at Great Ormond Street Hospital from 1976. He first received factor VIII on 3 November 1980 due to a lack of availability of cryoprecipitate and notwithstanding his parents' expressed concerns about the safety of American blood products.[376] In 1985 his care moved to the Royal Free Hospital after GOSH wanted to switch his treatment to American factor VIII.[377] His mother gives the following account:

> '*We returned to GOSH the same day but they refused to give us the file with Nick's medical notes. I don't remember who it was at GOSH that refused to hand over his records. However, about 2 weeks later a nurse from Great Ormond Street rang me at work and said if we'd like to meet her she would give me Nick's file. She met us in the street. Although I recognised her at the time I can't remember her name now. I took the medical records to the Royal Free. I thought they were complete but I couldn't have known for sure. I don't remember looking through them until we got to the Royal Free*

[373] WITN2011018
[374] See p. 13 onwards of INQY0000310
[375] WITN0282001 and INQY1000007
[376] §24 of WITN0282001
[377] §35 of WITN0282001

as I thought it was the right thing to do. We looked at the notes with the head nurse of the haemophilia department at the Royal Free whose name was Christine Harrington. There was a dated page with tramlines scrawled across, within which was written in large letters, "neurotic mother". I recognised that this entry was from the day I kicked up such a fuss about refusing to allow Nick to be given American factor VIII in early 1980.'[378]

183. After her son died, she applied for his medical records but the "*neurotic mother*" note was missing. She states that she '*rue[s] to this day that I wasn't savvy and didn't photocopy the notes*.' She states that she only received the records after:

'*a bit of a struggle but at least I managed to obtain them. It took several physical meetings over the course of a month to eventually obtain both sets of records. That is when I first realised entries were missing. I have not been able to trace any testing for hepatitis or HIV within the GOSH records however, within the Royal Free records it is very apparent that Nick was regularly tested for both.*'[379]

184. The Inquiry obtained a statement from Debra Pollard, Lead Nurse Specialist within the Haemophilia and Thrombosis Centre at the Royal Free, in response to the treatment matters.[380] It has also received a statement from Dr Eleanor Goldman,[381] Professor Graham Foster[382] and two statements from Professor Christine Lee.[383] None of these statements assist as to the circumstances in which this reference in his medical records was removed. A response is awaited from Great Ormond Street Hospital for Children NHS Trust.

185. The Inquiry has not been able to establish any further details as to the circumstances in which this document was removed.

186. Another example of a specific item being removed from a patient's medical records is provided by a man infected with HBV and HCV as a result of treatment for his severe haemophilia A.[384] He was treated at the Royal United Hospital in Bath ("RUH") with factor VIII from the late 1970s.[385] He states that his mother kept '*meticulous*' home treatment

[378] §36 of WITN0282001
[379] §47 of WITN0282001
[380] WITN3094001
[381] WITN3067001
[382] WITN3042001
[383] WITN0644001 and WITN0644057
[384] WITN1013001
[385] §9 of WITN1013001

records.[386] He states that the records he received from the RUH are '*generally comprehensive*'. However, the man recalls attending an appointment in the 1990s and reading a letter from a pharmaceutical company offering to donate money to the hospital charity if their product was used: '*it was clearly on display in my file and I remember reading it upside down across the desk during a clinic review.*' However, when he received his records, he was unable to find that letter.[387]

187. The Inquiry has obtained a statement from the RUH, which confirms that the Trust has been unable to find a copy of this letter in the witness' medical records. The Inquiry has not been able to establish any further details as to the circumstances in which this letter was removed.

188. The Inquiry has received a statement from a woman who had a blood transfusion on 23 May 1986.[388] She states that she was told by the ward sister that she needed to have a transfusion in the early stages of labour due to anaemia.[389] She recalls that she had a cannula inserted and she was '*hooked*' up to blood and the transfusion was started.[390] Her recollection is that the transfusion was then stopped by a nurse before it was finished and she was told she needed to go for an ultrasound.[391] She was diagnosed with HCV in 2016.[392] When she requested her medical records for the purpose of applying to the Skipton Fund[393] she was told some of her medical records were missing:

'*There are no records for the day of my transfusion, 23 May 1986. There are doctors[s] notes for the 19th, 20th, 21st, 22nd May and then for 24th May until I was discharged. There are no nursing notes for any part of the admission. There is nothing in my records which confirms that I had a blood transfusion on 23rd May 1986, or that I had an ultrasound on that day.*

The discharge letter from my hospital admission in 1986 is ticked to say that I did not have anaemia. It is this that worries me most; I feel that the reason that I needed a blood transfusion has been hidden. It is as if they distorted the truth to cover up what they were doing...'[394]

---

[386] §12 of WITN1013001
[387] §95 of WITN1013001
[388] WITN1921001
[389] §3 of WITN1921001
[390] §4 of WITN1921001
[391] §4 of WITN1921001
[392] §13-§14 of WITN1921001
[393] Her application was successful.
[394] See also her oral evidence to the Inquiry on 10 May 2019 on p. 85-6 of INQY1000008.

189. The witness made a complaint to the Trust. During her oral evidence to the Inquiry on 10 May 2019 she explained:

'*I actually went up to the hospital in person, went to the reception desk and asked them to bring somebody down from the office to hand them my complaint letter and all a sudden they instantly found everything, except for the notes.*

It took, all in all, about ten months from initial request for them to supply me with notes that they said they'd got and a letter to say that they thought that, due to the timescale and the building moves, that any letters from that time, except for the ones that I got either side of that, had been destroyed or lost and they've never come up with the day of the 23rd'.[395]

190. In her written account to the Inquiry she states:

'*They were quite offensive towards me until my local MP got involved to help encourage them to make notes available or agree what had happened to them. Eventually in September 2017 the Trust agreed that my notes were missing...I now realise that some of my notes will never be available.*'[396]

191. In a letter, dated 20 September 2017, the Trust has stated that a '*thorough search and investigation*' was undertaken to try and find '*any additional and/or secondary filing which may contain information in respect of a blood transfusion*' in May 1986.[397] No such documents were found. The letter states that following the witness' complaint another search was done '*to ensure every avenue had been explored*'. However, that second search did not find any further records or information. The reason given by the Trust was that:

'*…any secondary filing/documentation which may have existed relating to your admission some thirty two years ago has almost certainly been destroyed due to the length of time which has now passed.*'

192. One man, who suffers from moderate haemophilia B and was treated at the Edinburgh Royal Infirmary, gave an account in his oral evidence to his medical records being destroyed in the 1990s.[398] He gave the following account in his oral evidence to the Inquiry.

'When I got my notes, most folk would think, for God's sake, it was a massive box with reams of documents. But I thought that looks awful wee, because whenever I was in the

[395] P. 86 of INQY1000008
[396] §72 of WITN1921001
[397] WITN1921002
[398] §22 of WITN2168001

hospital there was a blooming trolley that used to come with "Hutchison/Hutchison", it was all me. And that, on the box I received was about that (Indicates). And all the time from when I was a teenager right until a certain point they're gone, years and years. And being a haemophiliac you'd think the previous history would be very relevant, you know, you wouldn't destroy notes. But I do know that notes were destroyed in an inappropriate manner.

I went to the Old Royal Infirmary for an appointment and I became very friendly with the receptionist, and she said to me, "Myles, I shouldn't tell you this, but I have to, my conscience is getting me." She goes, "I know one of the nurses is up the stairs just now and they're up to something." And I went, "What?" She goes, "They're destroying your notes." I said, "Maybe it's just the old ones they're getting rid of." She goes, "No, these are notes you have to keep in your records." Anyway, I went and seen the nurse when I went through for my usual gallons of blood test, and I says, "Why were you destroying my notes? The receptionist said." And she goes "Well, she should mind her own business in the first place." And she goes, "They are getting transferred onto CDR" – you know, at the time it was CDs, I think -- "... and they are not relevant, it's just notes we keep aside for the doctors' comments, things like that." And I says, "All right, so there's not going to be a big space in my files or anything?" She goes, "No, no, no, no, it's nothing like that."

And so when I got my medical files I wasn't surprised when there was a massive gap, because it was happening right in front of me, basically, while I was attending the Old Royal Infirmary.'[399]

193. In response to the criticisms raised in this witness' statement, Professor Ludlam was approached for a response and provided a response.[400] In relation to the witness' comments on medical record destruction, Professor Ludlam states:

'*I do not know the present status of his medical case notes, but I made strenuous efforts to maintain patient records especially in relation to treatments and potential infections. I know of no evidence that records were shredded nor was it practice to 'destroy things after a certain amount of time.*'[401]

194. Professor Ludlam has further stated:

'*the hospital developed a haematology record keeping computer system in the early mid-1980s. This recorded basic demographic information, diagnosis and laboratory data, and for those with haemophilia in addition their immune and virology results. The haemophilia information was stored in this way separate from the case notes partly to preserve confidentiality and also because the immune and virology results were sent from the laboratories on specifically designed forms for the purpose of reporting the specialist results.*

[399] P. 133 - 135 of INQY1000048

[400] WITN3428026 and WITN3428001

[401] §26 of WITN3428026

Most routine hospital laboratory report forms were designed to be filed in patients notes. Some of the investigations we carried out on people with haemophilia were very specialised and those investigations were specifically set up for monitoring this group of individuals. As the results of these investigations were not standard laboratory reports and they were not filed in the paper case notes but instead the results were entered into the haematology / haemophilia computer system.'[402]

195. Other patients treated by Professor Ludlam have raised concerns Professor Ludlam kept a separate file regarding patients' HIV/AIDS infections.[403] In relation to the question of keeping separate files on haemophilia patients with HIV/AIDS, Professor Ludlam's evidence is:

'*For those patients who were anti-HTLVIII positive I kept short "thumbnail" sketches of pertinent clinical information along with laboratory findings… I kept a small number of notes (no more than a single sheet of paper for each patient) separate from the main hospital case records in relation to people with haemophilia who came to see me early in 1985 in response to the December 1984 meeting, the circulate letter written to all patients and the encouragement of the haemophilia staff to inquiry about their anti-HTLVIII status. These notes were kept separate because as a team we decided at this time that we would not make any record related to HTLVIII or AIDS in the patients' notes because of discrimination against positive patients even with the hospital.'*[404]

JENNI RICHARDS KC

KATHERINE SCOTT

SARAH FRASER BUTLIN

TAMAR BURTON

Inquiry Counsel Team

September 2022

[402] §109 of WITN3428027

[403] See for example, §13 of WITN2190001

[404] §§110-111 of WITN3428027