SMALLER HAEMOPHILIA CENTRES PRESENTATION

COVENTRY (CENTRE 21)

Directors

1. The directors of the Haemophilia Centre at Coventry ("Coventry Hospital") during the 1970s-80s included Dr N Keith Shinton (later Professor Shinton) and Dr Maurice John Strevens. Dr Strevens has provided a written statement to the Inquiry dated 13 May 2021.[1] Dr Strevens and Professor Shinton were co-directors of the Haemophilia Centre from 1979 to 1991. When Professor Shinton retired, Dr Strevens became the sole Director of the Centre from 1991 to 2005.[2]

2. Dr Strevens spent time training in the treatment of bleeding disorders from 1975 to 1979 at Sheffield Hospital with Professor Preston.[3] He then became a Haematology Consultant in Coventry from 1979 to 2005.[4] Within the service for patients with haemophilia, his duties were shared with Dr Shinton.[5] Professor Shinton retired from clinical practice in around June 1990.[6]

3. The facilities at Coventry Hospital in 1974 were noted in "*Treatment of Haemophiliacs Summary of Workload 1974*" for the West Midlands Regional Health Authority:[7]

> "*Facilities*
>
> *(i) 24 hour telephone advisory service (not always consultant)*
>
> *(ii) Specialist consultant service for surgical, dental, physiotherapy and social care*
>
> *(iii) Home therapy for students at Hereward College*

[1] WITN3808005
[2] WITN3808005 para 7.1-7.2
[3] WITN3808005 para 2.11
[4] WITN3808005 para 2.16
[5] WITN3808005 para 2.18
[6] SHIN0000006 p. 3
[7] SHIN0000045 p. 5

(iv) Reference Laboratory service for factor assays, inhibitors titres etc.

(v) Education facilities for patients, medical and para-medical staff

(vi) *Available factor concentrates: cryoprecipitates, freeze-dried factor VIII and freeze-dried factor IX*"

Status of Haemophilia Centre, Relationship with other Haemophilia Centres and Relationship with Blood Transfusion Centre

4. The Haemophilia Centre at Coventry & Warwickshire Hospital was based at the Department of Haematology, Coventry & Warwickshire Hospital, Stoney Stanton Road, Coventry CV1 4FH.[8] It was Haemophilia Centre Number 21. Dr Strevens summarised:[9]

> "*5.7. When I started in 1979 there were around five hospitals in Coventry. The services were coordinated with some hospitals providing general services and others more specialised. During the 80's most of these hospitals closed, their services becoming more centralized on two sites - the Coventry and Warwickshire Hospital near the centre of town and the relatively new Walsgrave Hospital around four miles from the city centre. The anachronism was that the A and E unit was at the C and W site while most of the specialist services (medicine, surgery, cardiology etc) were four miles away. The arrangement was far from satisfactory and eventually all services were moved to Walsgrave in the 1990s and the Coventry and Warwickshire Hospital closed.*"

5. The Coventry & Warwickshire Hospital closed in July 2006 and was replaced by University Hospital Coventry on the site of the former Walsgrave Hospital.[10]

[8] DHSC0002263_005
[9] WITN3808005 para 5.7
[10] https://warwick.ac.uk/fac/arts/history/chm/outreach/cwhp/events/onelastlook/sites/closure

6. In 1975/1976, Coventry Hospital was part of the West Midlands Regional Health Authority.[11] Other Haemophilia Centres in the West Midlands Region included Birmingham Queen Elizabeth's, Birmingham Children's, Hereford, Shrewsbury, Staffordshire (Stoke-on-Trent), Worcester and Wolverhampton.

7. Dr Strevens explained the status of Coventry Hospital as follows:[12]

> *"5.1. As haemophilia services evolved, the Coventry Centre was designated as a 'Haemophilia Centre' with 'Comprehensive Care' being provided by Birmingham Queen Elizabeth Hospital for adults and the Children's Hospital for children.*
>
> *5.2. I worked in close collaboration with the Birmingham centres. Where there were gaps in our service provision such as genetic counselling and more complex diagnostic analysis I was free to refer to the Birmingham centres but Birmingham was over 20 miles from Coventry and whenever possible I felt that it was better to offer services locally. If patients would prefer to go to the Birmingham centres I would be happy to refer although I do not remember this happening.*
>
> *5.3. Surgery was an issue. According to our designation patients should be referred to the Comprehensive Care Centres in Birmingham. If patients required surgery I always discussed this with my Birmingham colleagues and the response was usually to proceed with the surgery in Coventry."*

8. The West Midlands Region was supplied by the Regional Transfusion Centre in Edgbaston, Birmingham. Dr Strevens stated:[13]

[11] OXUH0000863_002
[12] WITN3808005 paras 5.1-5.3
[13] WITN3808005 para 6.1

> *"6.1. A/B: The Regional Transfusion Centre was in Birmingham where all blood supplies came from supplying the whole of West Midlands Region. As far as I can remember this included the distribution of factor eight products from BPL. After Trusts were established the supply of blood products remained unchanged. The funding of specialist blood products was an issue. Any Trust with a haemophilia centre would have to deal with serious financial risks. Trusts were expected to live within a budget but with so much expenditure focused on a handful of patients expenditure could vary widely from one year to another because of major problems occurring in one or two patients. The solution was that funding for haemophilia was retained at Regional level"*

9. Dr Shinton regularly attended meetings of the West Midlands Regional Health Authority Working Party on the Treatment of Haemophiliacs ("Working Party") including on 14 May 1974,[14] 18 December 1975,[15] 13 May 1976,[16] 22 November 1976,[17] 23 May 1977,[18] 21 November 1977,[19] 15 May 1978,[20] 4 December 1978,[21] 14 May 1979,[22] 3 December 1979,[23] 19 May 1980,[24] 8 December 1980,[25] 22 June 1981,[26] 23 November 1981,[27] 28 June 1982,[28] 6 December 1982,[29] 27 June 1983,[30] 5 December 1983,[31] 14 May 1984,[32] 29 October 1984,[33] 17 December 1984,[34] 15

[14] SHIN0000046
[15] SHIN0000045
[16] SHIN0000044
[17] SHIN0000043
[18] SHIN0000042
[19] SHIN0000041
[20] SHIN0000040
[21] CBLA0000882
[22] SHIN0000038
[23] SHIN0000037
[24] SHIN0000036
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[28] SHIN0000032
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[30] SHIN0000030
[31] SHIN0000029
[32] SHIN0000028
[33] SHIN0000027
[34] SHIN0000026_002

February 1985,[35] 13 May 1985,[36] 29 July 1985,[37] 2 December 1985,[38] 24 March 1986,[39] 14 July 1986,[40] 13 October 1986,[41] 10 November 1986,[42] 2 March 1987,[43] 6 April 1987,[44] 27 July 1987,[45] 14 September 1987,[46] 30 November 1987,[47] 16 May 1988,[48] 18 July 1988,[49] 17 October 1988,[50] 13 February 1989,[51] 10 April 1989,[52] 6 November 1989,[53] 5 February 1990,[54] 24 January 1991,[55] 11 March 1991,[56] and 5 February 1992.[57] Dr Shinton sent his apologies for meetings on 15 December 1986,[58] and 16 July 1990.[59]

10. Dr Strevens also attended meetings of the Working Party on 6 December 1982,[60] 29 July 1985,[61] 2 December 1985,[62] 24 March 1986,[63] 14 July 1986,[64] 13 October 1986,[65] 10 November 1986,[66] 15 December 1986,[67] 6 April 1987,[68] 27 July 1987,[69] 30

[35] SHIN0000025
[36] SHIN0000024
[37] SHIN0000023
[38] SHIN0000022
[39] SHIN0000021_001
[40] SHIN0000020
[41] SHIN0000019
[42] SHIN0000018_001
[43] SHIN0000016
[44] SHIN0000015_001
[45] SHIN0000014
[46] SHIN0000013
[47] SHIN0000012
[48] SHIN0000011_002
[49] SHIN0000010
[50] SHIN0000009
[51] SHIN0000008
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[58] SHIN0000017
[59] SHIN0000004
[60] SHIN0000031
[61] SHIN0000023
[62] SHIN0000022
[63] SHIN0000021_001
[64] SHIN0000020
[65] SHIN0000019
[66] SHIN0000018_001
[67] SHIN0000017
[68] SHIN0000015_001
[69] SHIN0000014

November 1987,[70] 17 October 1988,[71] 13 February 1989,[72] 10 April 1989,[73] 6 November 1989,[74] 5 February 1990,[75] 16 July 1990,[76] 24 January 1991,[77] and 5 February 1992.[78]

11. At a meeting of the Working Party on 14 May 1974,[79] an earlier agreement that "*five satellite centres should be established at Stoke-on-Trent, Coventry, Worcester, Shrewsbury and Wolverhampton for the treatment of haemophiliacs with cryoprecipitate*" was noted.[80] It was requested and unanimously agreed "*that Hereford should be included in the list of designated centres for the treatment of haemophilic patients*".[81] The Chair, Sir Edward Wayne, summarised the views of those present:

> *"(1) That the five existing satellite centres should remain in being, and that Hereford should be recognised as a sixth centre for the treatment of haemophiliacs. The designated consultant at each centre would be responsible for establishing recommended standards of medical and technical cover for the care of haemophiliacs.*
>
> *(2) That cryoprecipitate should be retained for use as the main form of treatment for the present.*
>
> *(3) That the eventual distribution and use of freeze-dried factor VIII concentrate should follow the same pattern as the existing system used for cryoprecipitate.*
>
> *(4) That an emergency reserve of freeze-dried factor VIII be kept at the Queen Elizabeth Hospital, Birmingham.*

[70] SHIN0000012
[71] SHIN0000009
[72] SHIN0000008
[73] SHIN0000007
[74] SHIN0000006
[75] SHIN0000005
[76] SHIN0000004
[77] SHIN0000003
[78] SHIN0000001
[79] SHIN0000046
[80] SHIN0000046
[81] SHIN0000046

(5) That the Working Party currently assembled should meet at regular intervals of six or 12 months. At such meetings, the designated Consultants should supply details of the number of patients treated, and of the facilities available and the type of treatment."

12. Dr Shinton was appointed Chair of the Working Party at a meeting on 4 December 1978.[82] The Working Party met regularly throughout the 1970s-1980s to discuss, amongst other things, the supply and distribution of blood products in the West Midlands Region. At a meeting of the West Midlands RHA Working Party on 6 December 1982,[83] it was noted that:[84]

> "*Dr Ala reported that at present there was an excess supply of cryoprecipitate, possibly due to over-stocking in anticipation of a reduced supply of Factor VIII concentrate from BPL. He understood that the BPL would be resuming normal production soon and the situation should revert to normal. The shortfall in supply of Factor VIII from the BPL had been made up by greater purchases of commercial factor VIII and the stock had not been taken up by increased use of cryoprecipitate....*"

13. Dr Shinton chaired a meeting of the West Midlands RHA Working Party on 14 May 1984.[85] It was noted from the annual statistics and supply expected from of BPL, that there could be a shortfall of 3.5 million units of factor VIII to be made up from commercial sources.

14. Coventry Hospital, along with other Haemophilia Centres in the West Midlands Region, was part of the Oxford Haemophilia Supraregion. Dr Shinton attended meetings of Haemophilia Centre Directors and Blood Transfusion Centre Directors within the Oxford Haemophilia Supraregion on 26 July 1976,[86] and 19 June 1978,[87]

[82] CBLA0000882
[83] SHIN0000031
[84] SHIN0000031 p. 2
[85] SHIN0000028
[86] CBLA0000391
[87] OXUH0003752_005

At the meeting on 26 July 1976,[88] it was recorded that the "*Oxford Haemophilia Reference Centre had responsibility for the care of haemophiliacs in the Health Authority Regions:- West Midlands, Oxford, Wessex, the South West and Northern Ireland*". It appears that a further meeting was scheduled for 22 October 1985,[89] and Dr Strevens confirmed his intended attendance by letter dated 24 September 1985,[90] but minutes of the meeting have so far not been located.

Number of Patients Registered and/or Treated at the Centre

15. According to a note on "*Treatment of Haemophiliacs Summary of Workload 1974*" for the West Midlands Regional Health Authority,[91] the number of patients registered at Coventry Hospital in 1974 was 60. 30 patients (23 with haemophilia, 2 with Christmas disease, and 5 with von Willebrand's disease) attended for treatment.[92]

16. A list of Haemophilia Centres in around 1975 suggests that there were 30 patients with haemophilia A at Coventry Hospital.[93]

17. At a meeting of the West Midlands RHA Working Party on 13 May 1976,[94] "*Dr Shinton referred to the concentration of haemophilic patients in the Hereward College in Coventry from outside the Region, and said that his AHA were very concerned about the costs involved in treating these patients with Factor VIII.*"

18. According to Dr Strevens:[95]

> "*In summary we provided direct ongoing care for around 30 patients who almost certainly were on home treatment and regular prophylaxis. The number did not change significantly during my time in Coventry.*"

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[88] CBLA0000391
[89] OXUH0003752_026 and OXUH0003752_002
[90] OXUH0003752_009
[91] SHIN0000045
[92] SHIN0000045 p. 5
[93] OXUH0000863_002
[94] SHIN0000044
[95] WITN3808005 para 9.1

19. In the following years, the numbers of patients registered and/or treated at Coventry Hospital from the available evidence in the Annual Returns were as follows:

20. 1976: The Annual Returns for 1976, signed by Dr Shinton and Dr Cotter, show that the Centre treated 33 patients with haemophilia A, including 1 patient with factor VIII antibodies, 3 patients with Christmas disease, and 5 patients with von Willebrand's disease.[96] It appears that at least 13 registered patients were on regular home therapy.[97]

21. 1977: The Annual Returns for 1977, signed by Dr Cotter and Dr Shinton, show that the Centre treated 29 patients with haemophilia A, including 2 patients with factor VIII antibodies, 4 patients with Christmas disease, and 8 patients with von Willebrand's disease.[98] It appears that at least 11 registered patients were on regular home therapy.[99]

22. 1978: The Annual Returns for 1978, signed by Dr Shinton and Dr Cotter, show that the Centre treated 27 patients with haemophilia A, including 1 patient with factor VIII antibodies, 3 patients with Christmas disease, and 10 patients with von Willebrand's disease.[100] It appears that at least 9 registered patients were on regular home therapy.[101]

23. 1979: The Annual Returns for 1979, signed by Dr Shinton, show that the Centre treated 26 patients with haemophilia A, including 1 patient with factor VIII antibodies, 2 patients with Christmas disease, and 6 patients with von Willebrand's disease.[102] It appears that at least 8 registered patients were on regular home therapy.[103]

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[96] HCDO0001071
[97] HCDO0001071
[98] HCDO0001152
[99] HCDO0001152
[100] HCDO0001249
[101] HCDO0001249
[102] HCDO0001317
[103] HCDO0001317

24. 1980: The Annual Returns for 1980, signed by Dr Strevens and Dr Shinton, show that the Centre treated 24 patients with haemophilia A, 4 patients with von Willebrand's disease, and 3 patients with haemophilia B.[104]

25. 1981: The Annual Returns for 1981, signed by Dr Strevens, show that the Centre treated 30 patients with haemophilia A, 2 patients with von Willebrand's disease, and 2 patients with haemophilia B.[105]

26. 1982: The Annual Returns for 1982, signed by Dr Strevens and Dr Shinton, show that the Centre treated 25 patients with haemophilia A, 3 patients with von Willebrand's disease, and 2 patients with haemophilia B.[106]

27. 1983: The Annual Returns for 1983, signed by Dr Strevens, show that the Centre treated 25 patients with haemophilia A, 2 patients with von Willebrand's disease, and 3 patients with haemophilia B.[107]

28. 1984: The Annual Returns for 1984, signed by Dr Strevens. show that the Centre treated 22 patients with haemophilia A, 6 patients with von Willebrand's disease, and 5 patients with haemophilia B.[108]

29. 1985: The Annual Returns for 1985, signed by Dr Strevens and Professor Shinton, show that the Centre treated 20 patients with haemophilia A, 0 patients with von Willebrand's disease, and 5 patients with haemophilia B.[109]

30. 1986: The Annual Returns for 1986, signed by Professor Shinton and Dr Strevens, show that the Centre treated 24 patients with haemophilia A, 1 patient with von Willebrand's disease, and 6(?) patients with haemophilia B.[110]

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[104] HCDO0001414
[105] HCDO0001512
[106] HCDO0001614
[107] HCDO0001711
[108] HCDO0001806
[109] HCDO0001898
[110] HCDO0000306_026

31. 1987: The Annual Returns for 1987, signed by Professor Shinton and Dr Strevens, show that the Centre treated 23 patients with haemophilia A, 5 patients with von Willebrand's disease, and 8 patients with haemophilia B.[111]

32. Data from Coventry Hospital was contributed by Dr Shinton and Dr Strevens to published studies including: "*Haemophilia Treatment in the United Kingdom from 1969 to 1974*" by Rosemary Biggs,[112] and "*Treatment of haemophilia and related disorders in Britain and Northern Ireland during 1976-80*" by C R Rizza and Rosemary J D Spooner.[113]

Treatment policies and blood product usage

33. The Annual Returns show that Coventry used the following blood products in the following years:

34. 1976: To treat 33 haemophilia A patients, the Centre used:[114]

    a. 7,712 bottles / 539,840 units of cryoprecipitate;
    b. 222 bottles / 56,750 units of Armour Factor VIII (Factorate);
    c. 66 bottles /16,500 units of Hyland Factor VIII (Hemofil); and
    d. 200 bottles / 84,435 units of Immuno Factor VIII (Kryobulin);

35. To treat 3 patients with Christmas disease, the Centre used 39 bottles / 24,960 units of NHS factor IX.[115] To treat 5 patients with von Willebrand's disease, the Centre used 299 bottles / 20,930 units of cryoprecipitate.[116]

36. 1977: To treat 29 haemophilia A patients, the Centre used:[117]

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[111] HCDO0002084
[112] PRSE0004645
[113] HCDO0000586
[114] HCDO0001071
[115] HCDO0001071
[116] HCDO0001071
[117] HCDO0001152

a. 4,642 bottles / 324,940 units of cryoprecipitate;
b. 860 bottles / 191,970 units of NHS factor VIII;
c. 1,159 bottles / 340,407 units of Armour Factor VIII (Factorate); and
d. 66 bottles /26,340 units of Hyland Factor VIII (Hemofil).

37. To treat 4 patients with Christmas disease, the Centre used 65 bottles / 35,925 units of NHS factor IX.[118] To treat 8 patients with von Willebrand's disease, the Centre used 218 bottles / 15,260 units of cryoprecipitate.[119]

38. 1978: To treat 27 haemophilia A patients, the Centre used:[120]

a. 8 bottles / 560 units of cryoprecipitate; and
b. 1,916 bottles / 438,799 units of NHS factor VIII.

39. It does not appear that any commercial products were used to treat haemophilia A patients in 1978. To treat 3 patients with Christmas disease, the Centre used 117 bottles / 64,490 units of NHS factor IX.[121] To treat 10 patients with von Willebrand's disease, the Centre used 136 bottles / 9,520 units of cryoprecipitate and 9 bottles / 2,215 units of NHS factor VIII.[122]

40. 1979: To treat 26 haemophilia A patients, the Centre used:[123]

a. 1,714 bottles / 414,860 units of NHS factor VIII;
b. 80 bottles / 23,544 units of Armour Factor VIII (Factorate);
c. 25 bottles / 17,250 units of Hyland Factor VIII (Hemofil); and
d. 410 bottles / 147,640 units of Immuno Factor VIII (Kryobulin).

[118] HCDO0001152
[119] HCDO0001152
[120] HCDO0001249
[121] HCDO0001249
[122] HCDO0001249
[123] HCDO0001317

41. To treat 2 patients with Christmas disease, the Centre used 52 bottles / 49,800 units of NHS factor IX.[124] To treat 6 patients with von Willebrand's disease, the Centre used 86 bottles / 6,020 units of cryoprecipitate and 8 bottles / 2,080 units of NHS factor VIII.[125]

42. 1980: To treat 24 haemophilia A patients, the Centre used:[126]

    a. 101,285 units of NHS factor VIII in hospital and 191,505 units of NHS factor VIII for home treatment;
    b. 71,200 units of Armour Factor VIII (Factorate) in hospital and 176,615 units of Armour Factor VIII (Factorate) for home treatment;
    c. 1,740 units of Immuno Factor VIII (Kryobulin) in hospital and 5,800 units of Immuno Factor VIII (Kryobulin) for home treatment.

43. To treat 3 patients with haemophilia B, the Centre used 39,955 units of NHS factor IX in hospital and 19,275 units of NHS factor IX for home treatment.[127] To treat 4 patients with von Willebrand's disease, the Centre used 4,410 units of cryoprecipitate and 735 units of NHS factor VIII in the hospital.[128]

44. 1981: To treat 30 haemophilia A patients, the Centre used:[129]

    a. 630 units of cryoprecipitate in hospital;
    b. 188,465 units of NHS factor VIII in hospital and 274,985 units of NHS factor VIII for home treatment; and
    c. 29,338 units of Armour Factor VIII (Factorate) in hospital and 111,815 units of Armour Factor VIII (Factorate) for home treatment.

[124] HCDO0001317
[125] HCDO0001317
[126] HCDO0001414
[127] HCDO0001414
[128] HCDO0001414
[129] HCDO0001512

45. To treat 2 patients with haemophilia B, the Centre used 13,980 units of NHS factor IX in hospital and 10,595 units of NHS factor IX for home treatment.[130] To treat 2 patients with von Willebrand's disease, the Centre used 3,360 units of cryoprecipitate in the hospital.[131]

46. 1982: To treat 25 haemophilia A patients, the Centre used:[132]

    a. 94,035 units of NHS factor VIII in hospital and 329,965 units of NHS factor VIII for home treatment; and
    b. 141,931 units of Armour Factor VIII (Factorate) in hospital and 380,990 units of Armour Factor VIII (Factorate) for home treatment.

47. To treat 2 patients with haemophilia B, the Centre used 32,070 units of NHS factor IX in hospital and 28,230 units of NHS factor IX for home treatment.[133] To treat 2 patients with von Willebrand's disease, the Centre used 9,660 units of cryoprecipitate, 1,525 units of NHS factor VIII, and 735 units of Armour Factor VIII (Factorate) in hospital.[134]

48. 1983: To treat 25 haemophilia A patients, the Centre used:[135]

    a. 560 units of cryoprecipitate in hospital;
    b. 35,150 units of NHS factor VIII in hospital and 522,275 units of NHS factor VIII for home treatment; and
    c. 18,600 units of Armour Factor VIII (Factorate) in hospital and 104,145 units of Armour Factor VIII (Factorate) for home treatment.

49. To treat 3 patients with haemophilia B, the Centre used 37,780 units of NHS factor IX in hospital and 34,895 units of NHS factor IX for home treatment.[136] To treat 2

[130] HCDO0001512
[131] HCDO0001512
[132] HCDO0001614
[133] HCDO0001614
[134] HCDO0001614
[135] HCDO0001711
[136] HCDO0001711

patients with von Willebrand's disease, the Centre used 1,400 units of cryoprecipitate in hospital.[137]

50. 1984: To treat 22 haemophilia A patients, the Centre used:[138]

    a. 2,240 units of cryoprecipitate in hospital;
    b. 78,165 units of NHS factor VIII in hospital and 456,180 units of NHS factor VIII for home treatment;
    c. 48,020 units of Armour Factor VIII (Factorate) in hospital and 22,000 units of Armour Factor VIII (Factorate) for home treatment; and
    d. 5,000 of Immuno FEIBA in hospital.

51. To treat 5 patients with haemophilia B, the Centre used 22,475 units of NHS factor IX in hospital and 53,935 units of NHS factor IX for home treatment.[139] To treat 2 patients with von Willebrand's disease, the Centre used 2,380 units of cryoprecipitate in hospital.[140]

52. 1985: To treat 20 haemophilia A patients, the Centre used:[141]

    a. 12 bags of cryoprecipitate in hospital;
    b. 15,360 units of NHS factor VIII in hospital and 140,525 units of NHS factor VIII for home treatment; and
    c. 47,180 units of Armour Factor VIII (Factorate) in hospital and 381,445 units of Armour Factor VIII (Factorate) for home treatment.

53. To treat 5 patients with haemophilia B, the Centre used 13,530 units of NHS factor IX in hospital and 87,460 units of NHS factor IX for home treatment.[142]

[137] HCDO0001711
[138] HCDO0001806
[139] HCDO0001806
[140] HCDO0001806
[141] HCDO0001898
[142] HCDO0001898

54. 1986: To treat 24 haemophilia A patients, the Centre used: [143]

a. 14,855 units of NHS factor VIII in hospital and 222,895 units of NHS factor VIII for home treatment;
b. 24,140 units of Alpha Factor VIII (Profilate) in hospital and 122,760 of Alpha Factor VIII (Profilate) for home treatment;
c. 73,790 units of Armour Factor VIII (Factorate) in hospital and 267,045 units of Armour Factor VIII (Factorate) for home treatment;
d. 16,000 units of FEIBA; and
e. DDAVP.

55. To treat 6 patients with haemophilia B, the Centre used 1,570 units of NHS factor IX in hospital and 98,930 units of NHS factor IX for home treatment.[144]

56. 1987: To treat 23 haemophilia A patients, the Centre used:[145]

a. 8,425 units of NHS factor VIII in hospital and 144,525 units of NHS factor VIII for home treatment;
b. 42,940 units of Alpha Factor VIII (Profilate) in hospital and 781,760 units of Alpha Factor VIII (Profilate) for home treatment;
c. 39,620 units of Cutters Factor VIII (Koate) in hospital and 127,820 units of Cutters Factor VIII (Koate) for home treatment; and
d. 32 units of DDAVP.

57. To treat 5 patients with von Willebrand's disease, the Centre used 41 units of cryoprecipitate, and 6 units of DDAVP in hospital. To treat 8 patients with haemophilia B, the Centre used 9,255 units of NHS factor IX in hospital and 74,780 units of NHS factor IX for home treatment.[146]

[143] HCDO0000306_026
[144] HCDO0000306_026
[145] HCDO0002084
[146] HCDO0002084

58. According to Dr Strevens, the principles governing the use of blood products were as follows:[147]

> "*10.1. The general principles of treatment were that all blood products should be avoided if possible. DDAVP or Cryoprecipitate should be used in preference to factor concentrate if practical and safe. This would only be practical for patients with mild disease and especially if they had never been exposed to factor concentrates. UK concentrate should be used in preference to American products although this had to be tempered by the severely limited amount of UK concentrate relative to demand. Finally attempts would be made to limit the number of different suppliers of American products - subject to availability.*
>
> *10.2. As far as I can remember all products were supplied from Birmingham (I think the transfusion centre). I think the Birmingham Centre directors devised the purchasing policy and I am confident that they would have been based on the principles outlined above.*
>
> *10.3. In practice this meant that children were supplied with BPL products and adults received American products. Further information about the annual usage of factor products in Coventry would be available from UKHCDO annual returns records. As far as I can remember selection of products was done at a regional level. My colleagues in Birmingham would have been involved in the process.*
>
> *10.4. Once a quality standard had been agreed I would not have thought that cost was a significant issue.*"

59. Regarding heat-treated products, Dr Strevens stated:[148]

[147] WITN3808005 paras 10.1 to 10.4
[148] WITN3808005 paras 11.2

"*11.2. Following the development of tests for HIV, the degree of contamination of concentrates became apparent and so we switched to heat treated products as quickly as possible. Then as genetically engineered products became available and were shown to be safe and effective we switched to these products. All of this was done in the light of UKHCDO advice and implemented through our regional directors.*"

60. Dr Strevens was not aware of the hospital having any involvement in the purchase of therapeutic materials. He stated that "*neither myself nor my colleagues in the Centre were involved in the purchasing decisions being made with respect to the products we used*".[149]

61. Regarding home treatment, Dr Strevens stated that: [150]

"*15.1. In the 1970s, prior to factor eight concentrates, cryoprecipitate was the treatment of choice for bleeding episodes. Patients would need to come to the hospital and the frozen cryoprecipitate - around 4 - 8 bags had to be melted in a water bath. This was then infused into the patient. The issue was that the whole process would take at least an hour from the recognition of a bleed to the administration of the cryoprecipitate. By that time the joint was often swollen and inflamed. Several days rest would be required together with repeat treatments. This often led to 'target joints' where repeated bleeds into the same joint eventually led to arthritis and lifelong disability. The big advantage of freeze dried concentrates was that the product could be at home by patient or parent which led to treatment being given far more quickly as a result, it quickly became apparent that target joints were much less common, patients were not getting arthritis and were able to live a much more normal life. Even before prophylaxis was introduced having a treatment before they undertook an activity that had a high risk of inducing a bleed was a sensible use of factor eight and eventually led to prophylaxis and the understanding*

[149] WITN3808005 paras 12.2
[150] WITN3808005 paras 15.1-15.2

that even small doses of factor concentrate could keep many patients bleed free and led to them being able to lead an almost normal life. I cannot emphasise enough the importance of the introduction of factor concentrates on the lives of patients with severe haemophilia.

15.2 I am aware that some patients in some centres used cryoprecipitate at home. I do not think this was a practical consideration for most patients".

62. The home treatment policy with factor concentrates was firmly established by the time Dr Strevens started working in Coventry in 1979:[151]

"*17.1. As stated previously home treatment with concentrates was firmly established when I started working in Coventry and this naturally evolved into prophylaxis. Cryoprecipitate was never considered as an alternative to concentrates in the context of home treatment.*

17.2. Cryoprecipitate was always considered the treatment of choice for patients with mild/moderate disease who required infrequent treatment of limited duration and non- life threatening severity. Whenever possible these treatment decisions would involve a consultant haematologist - day or night. This was regarded as particularly important for patients who had never previously received concentrate.

17.3. This policy did not change while I was at Coventry."

63. Dr Strevens added that it was considered that all patients should be offered home treatment:[152]

"*18.1. When I started in Coventry in 1979 the policy of home treatment was firmly established. It was felt that all patients should be offered home*

[151] WITN3808005 paras 17.1-17.3
[152] WITN3808005 para 18.1

treatment as quickly as possible - especially in children, with a view to preventing the life changing arthritic complications, which inevitably followed hospital based treatments. Home treatment also meant that patients, especially children, could live a much more normal life. Please see my answer to question 15 for further detail."

64. According to Dr Strevens, the Centre's home treatment policy naturally progressed to prophylactic treatment:[153]

"*I refer to my answer to question 15. As I stated the progression from home treatment to prophylaxis was almost a natural progression. What surprised me was how little treatment was needed to suppress the majority of bleeds. It was a virtuous circle – as bleeds were prevented, joints became healthier which led to lower prophylactic dose requirements. The concern was that factor requirements would rocket but as far as I remember that didn't happen.*"

65. Regarding the treatment of children, Dr Strevens stated:[154]

"*20.1. As a general policy factor concentrates would always be avoided in children with mild or moderate disease and to reinforce this no factor concentrate was issued from the blood bank without the involvement of a haematologist.*"

66. In relation to the provision of information to patients, Dr Strevens stated that:[155]

"*Advice given would have been on an individual basis. They would have been warned about Hepatitis B and they would have been offered vaccination prior to commencing therapy. Giving advice about HCV or HIV would have been difficult from around 1983 - 1985/6 when there were emerging suspicions of*

[153] WITN3808005 para 19.1
[154] WITN3808005 paras 20.1
[155] WITN3808005 para 38.1

AIDS being transmitted via blood products and non A non B not being the benign infection it was once thought to be."

67. An Inquiry witness described how her brother, who had severe haemophilia A, was treated by Dr Strevens at Walsgrave Hospital.[156] The witness' brother was also treated at the Birmingham Children's Hospital and Coventry & Warwickshire Hospital.[157] He was treated with cryoprecipitate and factor VIII.[158] He started home treatment once factor VIII became available and injected himself several times each week for a number of years.[159]

68. The patient's mother was adamant that she never received any warnings as to any potential risks associated with using factor VIII.[160] The witness does not believe that her brother gave 'informed consent to his treatment' as there "*was categorically no mention made of any risks related to the use of these blood products*".[161]

69. Another Inquiry witness received treatment at the Coventry and Warwickshire Hospital under the care of Professor Shinton until he was 18 years old.[162] He was treated with a wide range of blood products including cryoprecipitate, Lister FVIII, Factorate, Kryobulin (Immuno), BPL Elstree, Profilate (Abbott), Koate (Cutter), Oxford FVIII, and BPL's 8SM.[163] He states that his "*parents were never made aware of the risks associated with using blood products. HBV, HCV, HIV or AIDS were never mentioned*".[164] As a result of being treated with blood products, he was infected with hepatitis B, hepatitis C and HIV.[165]

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[156] WITN0503001 para 13
[157] WITN0503001 para 13
[158] WITN0503001 paras 9-10
[159] WITN0503001 paras 9 and 12
[160] WITN0503001 para 14
[161] WITN0503001 para 30
[162] WITN1369001 para 10. The witness' mother has also provided a written statement WITN2969001.
[163] WITN1369001 paras 5-7
[164] WITN1369001 para 13 and 46
[165] WITN1369001 paras 15-16

70. An Inquiry witness' father died after being infected with HIV, HCV and HBV through contaminated factor VIII concentrate.[166] He was treated by Dr Shinton at Coventry Hospital and even invited Dr Shinton to his wedding.[167] The witness gave oral evidence to the Inquiry on 11 June 2021.[168]

71. The witness' father had haemophilia A and received treatment from Coventry and Warwickshire Hospital and Oxford Haemophilia Centre.[169] According to his medical records, he started home treatment in 1976 and it appears that he was first given factor VIII concentrate in 1977.[170] He was treated with various factor products including BPL products, Hemofil by Baxter and Armour Factor VIII.[171]

72. An Inquiry witness attended Hereward College in Coventry and received treatment at Coventry & Warwickshire Hospital and Walsgrave Hospital under the care of Dr Strevens.[172] He gave oral evidence to the Inquiry on 18 June 2019.[173] In his written statement, he stated that during 1979 to 1983, he was administered with contaminated factor VIII.[174] He was given "*absolutely no advice in terms of the risk of Factor 8*".[175]

73. Another Inquiry witness described how her late husband was infected with HIV and HCV as a result of receiving contaminated blood products.[176] He attended the Haemophilia Centres in Coventry, Exeter and Oxford, and the Lord Mayor Treloar School.[177] She gave oral evidence to the Inquiry on 2 May 2019.[178] She explained how she sought advice from Coventry Hospital regarding having children:[179]

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[166] WITN1210001 para 2
[167] INQY1000127 p. 5
[168] INQY1000127
[169] INQY1000127 p. 3
[170] INQY1000127 p. 4
[171] INQY1000127 p. 3
[172] WITN1577001 para 4. The witness' wife has also provided a written statement WITN3571001.
[173] INQY1000021
[174] WITN1577001 para 5
[175] WITN1577001 para 9
[176] WITN1589001 para 2
[177] WITN1589001 para 4
[178] INQY1000003
[179] WITN1589001 paras 35-36

"35... We sought advice from Coventry Hospital in 1986 and told the doctors that we would like to have children. We were told by Dr Shinton at the Haemophilia Centre that "it is not a good idea but if you want to go ahead, we will monitor you". At the time, I had not realised that testing me for HIV and "monitoring" might not be in my interests. I believe that they were waiting for me to become HIV positive.

36. We were offered no advice – we were just "monitored" – looking back, and with the other evidence unfolding, it makes me shudder. We went to doctors because we needed help and support. As we went ahead they tested me for HIV every month, there was nothing regarding reducing risk of infection, ovulation or pregnancy."

74. An anonymous witness's late husband also received treatment for haemophilia at the Walsgrave Hospital in Coventry.[180] She stated that "*We were never given any information or advice about the severity of H's condition and we were left to get on with managing his condition ourselves*".[181] Her late husband had a severe reaction to factor VIII but was told that this was just her imagination.[182] As a result of her late husband's reaction to factor VIII, she did not feel comfortable giving him factor VIII at home.[183] He was later given medication to counteract the side effects and, despite his allergic reaction, was able to have factor VIII at home.[184] The anonymous witness and her husband were later diagnosed with HCV although she was not told about it at the time by the staff at Coventry Hospital.[185]

75. Any changes (or proposed changes) in treatment policies at a regional level in response to the risk of HCV/HIV, such as those discussed at the West Midlands RHA Working Party meetings, are covered below.

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[180] WITN3549001
[181] WITN3549001 para 5
[182] WITN3549001 para 11
[183] WITN3549001 para 11
[184] WITN3549001 paras 12-13
[185] WITN3549001 paras 20-21

Knowledge of risk of hepatitis and response to risk

76. Dr Shinton and/or Dr Strevens regularly attended UKHCDO meetings including on 13 January 1977,[186] 24 October 1977,[187] 13 November 1978,[188] 20-21 November 1979, [189] 9 October 1981,[190] 13 September 1982,[191]17 October 1983,[192] 27 September 1984, [193] 21 October 1985,[194] 17 March 1986,[195] 9 October 1986,[196] 25 September 1987,[197] 29 September 1988,[198] 16 June 1989,[199] 9 October 1989,[200] 11 September 1989,[201] 21 September 1990,[202] 7 October 1991,[203] and 18 September 1992,[204] and can therefore be taken to have had knowledge of matters discussed at those meetings.

77. In addition, as noted above, Dr Shinton and/or Dr Strevens regularly attended meetings of the West Midlands RHA Working Party on the Treatment of Haemophiliacs.

78. Dr Shinton also attended a meeting with other Haemophilia Centre Directors and Immuno at London Airport on 24 January 1983.[205]

79. Dr Strevens explained his understanding of the risk of hepatitis as follows:[206]

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[186] PRSE0002268
[187] PRSE0001002
[188] HSOC0010549
[189] CBLA0001028
[190] DHSC0001312
[191] CBLA0001619
[192] PRSE0004440
[193] PRSE0003659
[194] PRSE0001638
[195] PRSE0001688
[196] PRSE0004317
[197] HCDO0000485
[198] BART0002329
[199] PRSE0002656
[200] HCDO0000015_035
[201] HCDO0000436
[202] HCDO0000015_021
[203] HCDO0000491_001
[204] HCDO0000248_013
[205] PRSE0002647
[206] WITN3808005 paras 22.1-22.2

"*22.1. When I started in Coventry in 1979, Hepatitis B was a clearly defined viral infection and donors and donations were screened for infection. Nevertheless Hepatitis B infection could still infect blood recipients and so all haemophiliacs were routinely immunised as soon as vaccines became available and preferably before they started regular treatment. My understanding of NANB hepatitis was that it was ill-defined and could be due to a number of different viruses or something else completely. It was generally regarded as less severe than Hep B but without a test for the virus(es) little could be said about the nature of the infection. With regards patients receiving concentrates it was recognised that soon after commencing treatment patients experienced what was often a mild illness with minor disturbance of liver function which sometimes settled but could also result in a persistent mild disturbance of liver function. Whether this was due to persistent infection or something else to do with the treatment was not clear. Most doctors did not regard it as a serious problem. However Dr Eric Preston (later Professor) in Sheffield where I trained became increasingly concerned and eventually took liver biopsies from some affected patients. I remember the results being presented at a UKHCDO meeting. The results showed that some had serious, advanced liver disease. HIV infection was the major concern at the time and effective heat treated concentrate was subsequently introduced. When NANB hepatitis was identified as being due to Hepatitis C it was also found that the heat treatment for HIV also inactivated the Hep C virus.*

22.2. From my appointment in 1979 to Professor Shinton's retirement in 1991 he was in charge of the haemophilia outpatient clinic and it was Professor Shinton together with the Haemophilia sister who organised the testing and follow up for both HIV and HCV in the Coventry haemophilia patients. My knowledge of Hepatitis C came via communications from the UKHCDO, publications in the medical press and from colleagues."

80. In response to the knowledge of risk of hepatitis, Dr Strevens added:[207]

[207] WITN3808005 paras 23.1

> "*23.1. Re questions 23 and 24: Once there was a test to demonstrate HCV infection, all patients who had received factor concentrates were tested for the virus and the significance explained to them together with information about the prevention of spread to others. All this was organised by my colleague Prof. Shinton who ran the haemophilia clinic. The further use of concentrates was not an issue since it had been demonstrated that the heat treatment introduced to inactivate HIV was also highly effective in inactivating HCV.*"

81. It does not appear that Dr Shinton or Dr Strevens contributed to the Glasgow Symposium on "*Unresolved problems in Haemophilia*" in 1980,[208] or the Manchester Symposium on "*Current Topics in Haemophilia*" in 1982.[209]

Knowledge of risk of AIDS and response to risk

82. As stated above, Dr Shinton and/or Dr Strevens regularly attended UKHCDO meetings and meetings of the West Midlands RHA Working Party on the Treatment of Haemophiliacs, and can therefore be taken to have had knowledge of the discussions which took place at these meetings.

83. Dr Strevens stated:[210]

> "*15.3. The 'risk' of infection from concentrates was an emerging issue. The Inquiry has provided a letter from the UKHCDO dated 24th June 1983 following a meeting of the Reference Centre Directors. The fourth paragraph states that "there is as yet insufficient evidence to warrant restriction of the use of imported concentrates in other patients in view of the immense benefits of therapy but the situation will be constantly reviewed."*

[208] RLIT0001242
[209] DHSC0002221_003
[210] WITN3808005 paras 15.3-15.4

15.4. In much of the practice of interventional medicine there is always a balance between risk and benefit. For example if a patient required a hip replacement and wanted to know the risk of dying, the risk of serious life changing infection etc. the surgeon can provide advice as there is data available. In 1983 there was very little data available about the size of the risks from concentrates confounded by the absence of tests to predict problems and so treatment was provided in this context."

84. Dr Strevens further explained:[211]

"*18.2. When the high risk of HIV infection became clearly apparent in 1985 following the introduction of testing for HIV, the production of heat treated products quickly followed although it took a little time to optimise the heat treatment process. As far as I can remember there was no change in home treatment policy at that time.*

18.3. There was emerging evidence of a link between HIV infection and the use of factor concentrates throughout the early 80s. How this would translate into policy was always going to be difficult. Fortunately we had within the UKHCDO national /international experts who met to discuss these issues and offer guidance to Haemophilia directors like myself. Document HCDO 000270_004 is a good example of the guidance we were being given. We were of course free to take or reject the advice. It is always important to address the consequences of extreme actions like stopping all concentrate usage. As an 'older' haematologist I have vivid recollections of the consequences of inadequately treated haemophilia - something that is too easy to forget. As far as I can remember there was no significant change to home treatment policy."

85. Dr Strevens explained his understanding of the risk of HIV/AIDS as follows:[212]

[211] WITN3808005 paras 18.2-18.3
[212] WITN3808005 paras 26.1-26.4

"*26.1. Cases of unusual immunodeficiency were first described in the USA in the early 1980s. One sign of a possible new problem was the increased demand for Pentamidine - a treatment for PCP pneumonia - an unusual exotic form of pneumonia. There was also an increase in an unusual cancer - Kaposi sarcoma. These conditions were found to be associated with immune deficiency and seemed to be occurring in gay men and IV drug abusers. There were early concerns that it could represent a blood borne infection and this suspicion was enforced when similar problems started to be seen in patients with haemophilia who were using recently introduced factor concentrates.*

26.2. There was always concern in the UK about the use of American concentrates. The concern was of a non-specific nature - that is blood should be taken from healthy unpaid volunteers rather than paid donors some from dubious backgrounds and in poor health. The first potential case of immunodeficiency in a UK haemophilia patient was featured in a letter from the UKHCDO in 1983 to all Haemophilia centre directors and included advice about the use of concentrates (HCDO0000270_004).

26.3. From memory I thought the advice was balanced - the issue being the dramatic effect on haemophilia care if all concentrates were withdrawn at that stage.

26.4. It was only when the HIV virus was identified and testing was introduced, that the extent of infection in blood products and the transmission of infection to haemophilia patients became apparent."

86. He stated that he first became aware that there might be an association between AIDS and the use of blood products in around 1982:[213]

"*27.1. From around 1982 there was concern that the syndrome of AIDs might be blood borne and that Haemophilia patients were being affected, at first in*

[213] WITN3808005 para 27.1

the US and then in UK, provoking the letter from the UKHCDO in 1983 to all Haemophilia directors."

87. In response to the risk of HIV/AIDS, Dr Strevens stated that all haemophilia patients were tested for HIV as soon as a test became available (and that Professor Shinton was in charge of this).[214] The Centre continued to administer factor VIII concentrates as it was impossible to judge the extent of the risk without a test. Dr Strevens stated: [215]

> "*30.1. The UKHCDO letter from 1983 alerted us to the issue and in accordance with the advice given, patients continued to receive concentrates. It was in 1985 that the extent of the problem became clear.*
>
> *30.2. In 1983 without a test it was impossible to judge what the extent of the risk was, although I believe at that time CD4 monitoring was being introduced. What was clear was that to withdraw concentrate and to terminate home treatment programmes would have a profound effect on the day to day lives of severe haemophiliacs taking us back to a time when severe disability was common and life expectancy was significantly shortened.*"

88. In response to the letter from Professor Bloom and Dr Rizza to the UKHCDO dated 24 June 1983,[216] the treatment policies at Coventry Hospital did not change and the Centre did not revert to using cryoprecipitate. According to Dr Strevens:[217]

> "*32.1. From the early days of concentrate usage there were some concerns about the use of American concentrates. The concern was not about known risks but the as yet unknown risks of the US policies of plasma donation. The difference of approach to blood donation in the UK v USA was emphasised to me during my six-month training at the Sheffield Blood Centre. Each year at*

[214] WITN3808005 para 28.1
[215] WITN3808005 paras 30.1-30.2
[216] HCDO0000270_004
[217] WITN3808005 paras 32.1-32.2

the regular UKHCDO meetings we were presented with graphs of concentrate usage rising but the availability of UK concentrate increasingly failing to keep up.

32.2. In Coventry therefore patients would not be given concentrate if their condition could be adequately managed with cryoprecipitate but this was not the case for patients with severe haemophilia. Our treatment policies therefore did not change as a result of the 1983 advice. However our policies were constantly policed by blood bank staff and on-call haematologists (consultant or senior registrar)"

89. Dr Shinton chaired an extraordinary meeting of the West Midlands RHA Working Party on 17 December 1984,[218] "*to discuss the implication of AIDS on the provision of concentrate for the treatment of Haemophiliacs*." It was decided that non-heat treated Factor VIII should no longer be used if possible:[219]

> "*The committee accepted that the use of Factor VIII concentrate was associated with a risk of transfusing the AIDS virus. Dr. Stewart, Regional Scientific Officer accepted the scientific evidence presented by various members of the committee linking the use of Factor concentrate with the sero-conversion of HTLV III antibody positivity and the risk of developing AIDS. Dr. Hill informed the committee that the statistics regarding the incidence of AIDS in HTLV III positive patients had risen to I in 50. It was considered imperative that heat treated Factor VIII should, given the available scientific evidence, be made available to haemophiliacs as a matter of urgency. Unfortunately, the Chairman informed the committee that this was unlikely to occur with N.H.S. Factor VIII until 1st April, 1985, but that Armour heat treated material would be available in January 1985. Following discussion, a treatment policy to cover the interim period was agreed upon:-*

[218] SHIN0000026_002
[219] SHIN0000026_002

1. Mildly affected patients – Haemophilia A, and von Willebrand's disease to be treated with DDAVP or cryoprecipitate.

2. Newly diagnosed severe haemophiliacs to be managed wholly on cryoprecipitate.

3. a) Patients with no previous exposure to commercial Factor VIII should continue on NHS Factor VIII.

b) Patients with previous exposure to commercial Factor VIII should continue on NHS factor VIII if available and heat treated commercial Factor VIII when not."

90. At a second extraordinary meeting of the West Midlands RHA Working Party on 15 February 1985,[220] chaired by Dr Shinton, the committee agreed that NHS untreated material should no longer be used and the treatment policy was as follows:

"*The document outlining the views of the Reference Centre Directors on the effects of AIDS on the treatment of haemophiliacs was received. It was given full support. The treatment policy as advocated in the Minutes of the Extraordinary Meeting of 17th December was at variance with that from the Reference Centre Directors. It was agreed that N.H.S. untreated material should no longer be used. The new treatment strategy now recommended is:-*

a) Use DDAVP in mild Haemophilia A and vWd if possible.

b) For Haemophilia A needing blood products

i. "Virgin" patients those not previously exposed to concentrate, and children, use cryo or heated N.H.S. Factor VIII (if possible).

ii. Severe and moderate haemophiliacs previously treated with Factor VIII, use heat treated N.H.S. Factor VIII, if available or heat treated U.S. commercial.

c) For Haemophilia B

i. Mild Christmas. Fresh frozen plasma if possible (otherwise N.H.S. Factor IX.

ii. "Virgin" patients and those not previously exposed to concentrate use fresh frozen plasma (or N.H.S. Factor IX concentrate if essential).

[220] SHIN0000025

iii. Severe and moderate Christmas disease previously exposed to Factor IX concentrate continue to use N.H.S. Factor IX."

91. Dr Shinton also chaired a meeting of the West Midlands RHA Working Party on 29 July 1985,[221] at which the treatment policy was reviewed. It was recorded that:

> "*In view of the shortfall in supplies and that Prof A Bloom, Chairman of the haemophilia Centre Directors, in a letter to the British Medical Journal, proposed a policy whereby cryoprecipitate should not be used until HTLV III screening of donors was established, the committee agreed to review the treatment guidelines…*
>
> *a) Use DDAVP in mild haemophilia and von Willebrand's disease if possible.*
>
> *b) For haemophilia A requiring blood products*
>
> *i. Use NHS product 8Y in*
>
> *1. Virgin patients i.e. those not previously treated with Factor VIII concentrate*
>
> *2. Patients minimally treated and showing no evidence of Hepatitis…*
>
> *ii. Severe or moderate haemophiliacs previously treated regularly with Factor VIII or showing evidence of Hepatitis, use commercial heat treated Factor VIII or NHS 8Y if the latter is available.*
>
> *c) For von Willebrand's disease, it was agreed that cryoprecipitate screened by the BTS in their pilot studies of Wellcome HTLV III kits would be made available to treat severe and type II von Willebrand's disease.*
>
> d) *For haemophilia B – as heat treated Factor IX – 9A – is not available until October 1985, no change in policy is envisaged.*"

92. In relation to the treatment of AIDS, the Regional Haemophilia Policy was set out as follows:[222]

> "*It was agreed that haemophiliacs with HTLV III antibodies or AIDS related disorders should be followed up at the discretion of the Haemophilia Centre*

[221] SHIN0000023
[222] SHIN0000023 p. 2

Directors. All haemophiliacs should be screened. Spouses and immediate family should be offered screening for HTLV III antibody. Any haemophiliacs opting out of knowing his status should be advised to behave as though he were HTLV III positive. It was considered appropriate to inform the GP but not the Clinical Medical Officer in the case of children…

It was thought appropriate to review the HTLV III status in haemophiliacs and spouses every twelve months.

The committee were unanimous in the opinion that haemophiliacs and spouses, when HTLV III positivity had been identified should be advised against pregnancy."

93. Dr Shinton chaired a further meeting of the West Midlands RHA Working Party on 2 December 1985.[223] It was noted that from 14th October, official testing for HTLVIII antibodies commenced and all blood donations since that date have been screened, and that "*all therapeutic material was now either HTLV III screened or heat treated*".[224]

94. Dr Shinton thereafter chaired a meeting of the West Midlands RHA Working Party on 24 March 1986.[225] It was noted that "*HTLV III antibody positive Haemophiliacs could be screened every three months, subject to local considerations, to investigate antibody status and haematological abnormalities*".[226]

95. Dr Shinton also chaired a meeting of the West Midlands RHA Working Party on 14 July 1986.[227] It was noted that:[228]

[223] SHIN0000022
[224] SHIN0000022 p. 2
[225] SHIN0000021_001
[226] SHIN0000021_001
[227] SHIN0000020
[228] SHIN0000020 p. 2

"*the Committee viewed with disquiet the seeming underfunding of plasma procurement set against a willingness to buy commercial Factor VIII concentrate... a switch in funding would allow an increase in pro rata supplies of Factor VIII concentrate commensurate with increased plasma procurement. This would further enable the West Midlands to be self sufficient in NHS Factor VIII which was undoubtedly the safest product.*"

Testing patients for HTLVIII and informing them of diagnosis

96. Dr Strevens explained:[229]

> "*31.1. Prof. Shinton together with the Haemophilia sister organised the testing of patients for HIV and HCV infection. They would have been responsible for counselling patients.*
>
> *31.2. As the infected patients entered a programme of regular monitoring with blood tests it would be surprising if they had not been aware of why they were being monitored. The one exception could have been children where parents may have kept the details from their children.*"

97. Dr Strevens did not have information about the process of testing for HIV including pre-test and post-test counselling as Professor Shinton arranged the testing.[230]

98. An Inquiry witness and her family were not aware that her brother had been infected with HIV until they heard a television news story which reported the fact that haemophiliacs had been given contaminated blood products.[231] They contacted the hospital and he was given an appointment to undergo a blood test.[232] After the blood test was taken, the witness attended the hospital with him for his results.[233] She

[229] WITN3808005 para 31.1-31.2
[230] WITN3808005 para 43.1-44.1
[231] WITN0503001 para 15
[232] WITN0503001 para 15
[233] WITN0503001 para 16

recalled that, despite the gravity of the situation, they were kept waiting in a corridor for several hours.[234] She explained:[235]

> "*18. Finally we were called in to see Dr Strevens who asked us why we were there?Having told him that we had come to see if [the patient] had been infected with HIV, his response was, "of course he has been infected, all haemophiliacs have been infected." We were then invited to leave.*
>
> *19. We received no explanations, no advice or guidance, and nothing 'in writing.' Our invitation to leave was worded as, "... was there anything else?" We felt that we had been wasting the doctors time, as a result of our ignorance and a failure to grasp the situation placed before us. We were embarrassed by the manner in which we were dismissed, and left having been given no opportunity of discussing the infections my brother had, and their consequences for him, his life, his family and friends.*"

99. Dr Strevens responded to the witness' written statement ,[236] stating that all criticisms related to an outpatient attendance when the patient was given information that he was infected with HIV. At that time, Dr Strevens had no responsibilities in that clinic and had no recollection of the consultation described.[237] Dr Strevens believed that he located a record of the consultation in the patient's medical records and that the handwriting was of Professor Shinton.[238] The record included the word "*counsel*" and listed further blood tests including a repeat HIV (HLTVIII) test.[239]

100. The patient was also advised that he had been infected with hepatitis as a result of having been given contaminated blood product.[240] The witness did not know when

[234] WITN0503001 para 16
[235] WITN0503001 paras 18-19
[236] WITN3808001
[237] WITN3808001 para 4
[238] WITN3808001 para 5
[239] WITN3808001 para 5
[240] WITN0503001 para 26

this happened other than that they were told of the diagnosis between 1985 and 1991 when her brother died.[241]

101. An Inquiry witness recalled being tested for HIV in January 1985:[242]

> *"15. I was first tested for HIV (HTLV III) in January 1985. However, my parents received a letter from DR M. D. Williams, Registrar in Haematology, Coventry and Warwickshire Hospital which today may seem a little anachronistic, since it was dated 2nd June 1983. It stated: "I am sure you are aware of the recent publicity about Acquired Immune Deficiency Syndrome (AIDS) and the possible risk of this occurring in haemophiliacs using Factor VIII concentrate. We would like to monitor all our haemophiliacs because of this and would therefore be grateful if you could attend the Blood Bank, Walsgrave on June 30th for a blood test". A copy of this letter is now shown to me marked WITN1369002.*
>
> *16. This request predates even the AIDS test by nearly two years, so I can only assume that this was some sort of serum collection exercise or perhaps they intended to use some sort of surrogate testing, such as looking at T-lymphocyte abnormalities? That letter was contemporaneous with the dreadful publicity on the TV and the receipt of it at that time had the effect of notifying our family that I was not only at risk, but reading between the lines, it was more likely than not that I had been infected. I believe that when they first knew something was wrong they collected samples for a library so they would be able to test retrospectively when a test was developed (as they no doubt knew it would be).*"

102. The witness stated that his parents and his GP were not informed by Professor Shinton at the Haemophilia Centre of the HTLV III result of 3 January 1985 (which was positive) until some 8 months later.[243]

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[241] WITN0503001 para 26
[242] WITN1369001 para 14
[243] WITN1369001 paras 18 and 44-45

103. Another Inquiry witness received a letter from Dr Williams at Coventry and Warwickshire Hospital dated 2 June 1983 inviting him to attend the blood bank for a blood test.[244] He was invited to return on 19 July for his test result but he was due to be away at university so spoke to the nurse over the phone. He described that:[245]

> "*13…a nurse just told me over the phone that the test was positive. There was no advice given during the phone call except to get my affairs in order because I only had three to six months.*
>
> *14. The blood test results were shared in a very informal way. I trusted them because they felt like family but when something major like this happens they should not treat it so informally. Even within families there is a certain protocol depending on the nature of the shared information.*
>
> *15. I was not given adequate information to help me understand and manage the infection, in fact I was given no information what so ever. They thought giving us information would be a waste of time because I did not have enough time to live. They considered the HIV as a death sentence and they were not trained to deal with someone on death row. They were not ready for this kind of bombshell.*
>
> *16. I feel I should have been provided more support at the time of the diagnosis instead of just being told over the telephone. I was left numb, lost and absolutely shell-shocked. Normally, when you become ill you are meant to have a social worker and a team to help you, everyone knows what their job is but there was nothing like this for me. It would have taken two or three months to get the social worker into place but by then they thought I would be gone. They considered us too far gone to provide value for money.*

[244] WITN1577001 para 13
[245] WITN1577001 paras 13-17

17. The way I was told lacked compassion. I was told on the telephone, alone, at university and at the start of the academic year I had no real friends to call upon. They said to go home, say goodbye to my family and get my paperwork in order due to my imminent death."

104. Another Inquiry witness recalled being tested for HIV at Coventry Hospital:[246]

"*I attended Coventry Hospital in or about June 1987 for a HIV test and was later told "it looks as it might be positive" and that I had probably sero-converted but I had to wait for a second test to confirm the results. I went numb and floated through the next few weeks in a strangely numb state. The hospital told [witness' husband] that my second test had come back HIV positive when he attended his own appointment but they did not tell me directly.*"

105. Following her positive test for HIV, the witness described her treatment at Coventry Hospital:[247]

"*When I was confirmed to be infected with HIV I continued to be a patient at the Coventry Haemophilia unit until the 1990 legal case. The solicitor we were using at the time, Peter Jones, consulted Dr Rizza at Oxford Haemophilia Centre about the treatment both [the witness' husband] and I had received at Coventry. Dr Rizza told him that he would have dealt with my case differently than Coventry had, so after that we moved to Oxford Haemophilia Centre. However, when Peter Jones asked Dr Rizza to make a formal statement about the problems with my treatment under Coventry Dr Rizza initially refused. Dr Geoff Savage, from St Thomas's Haemophilia Centre wrote a report condemning Coventry's treatment of me under Dr Shinton.*"

[246] WITN1589001 para 10
[247] WITN1589001 para 21

106. The witness described a "*breakdown in trust in Dr Shinton and Coventry Unit*".[248] She and her husband later received treatment at the Oxford Haemophilia Centre.

107. Another Inquiry witness described how her husband was tested for HIV and informed of his diagnosis:[249]

> "*11. In the Spring of 1985, Dr Shinton invited us into his office for a chat. He shuffled through [the patient's] medical notes when he casually said 'your test results are positive'. We were extremely confused and asked "what test results?". He then said [the patient]had been diagnosed with HIV. He also told us that there was no cure. We asked when [the patient]would die but Dr Shinton said he didn't know.*
>
> *12. He told us that we were not to have sex or kiss, and we shouldn't share toothbrushes. He said that as we were married, I would also have to be tested.*
>
> *13. We asked when [the patient]had been tested and he said it was some time ago. [The patient's] notes show that he first tested positive in November 1984. This means that Dr Shinton likely knew about [the patient's] test results for months but he still neglected to tell [the patient]the results of the test. I cannot believe how dangerous this was, and I am very fortunate to have tested negative*
>
> *14. We were absolutely gobsmacked. We walked in to that office a happy, having only married a year previously, and came out with the knowledge that our lives had changed forever.*
>
> *15. They said I would have to be tested every 3 months. It wasn't [the patient's] fault but this put a lot of stress on our relationship and [the patient]struggled with the thought that he may have infected me.*"

[248] WITN1589001 para 45
[249] INQY1000127 p. 5 and WITN1678001 paras 11-15

108. The patient's medical records show that he was first tested for HIV in November 1984.[250] The witness stated that it was "*disgraceful that Dr Shinton kept this result from him particularly when he knew we were newly married*".[251]

109. The witness stated that they were never told anything about HCV and the patient never knew that he had also been infected with HCV.[252] The patient had no knowledge that he had been tested for HIV or hepatitis and therefore could not have consented to these tests.[253]

Numbers infected with HIV

110. According to provisional data received by the Inquiry from UKHCDO, it appears that 16 patients were infected with HIV at Coventry Hospital: 5 patients in 1984, 10 patients in 1985, and 1 patient in 1986.[254]

111. At a meeting of the West Midlands RHA Working Party on 6 April 1987,[255] "*Professor Shinton reported one late sero conversion at Coventry. This was considered to be related to the previous use of heat treated Armour.*" At the meeting on 16 May 1988,[256] there was reference to "*one AIDS case in Coventry*".

Testing for HCV

112. Dr Strevens did not know how many patients at the Centre were infected with HCV.[257] Professor Shinton would have organised the testing of HCV and Dr Strevens had no information about the extent of the testing programme.[258]

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[250] WITN1678001 para 21
[251] WITN1678001 para 21
[252] WITN1678001 para 17
[253] WITN1678001 para 19
[254] INQY0000250
[255] SHIN0000015_001
[256] SHIN0000011_002
[257] WITN3808005 para 49.1
[258] WITN3808005 para 49.1-52.1

113. An Inquiry witness stated that he was "*secretly tested for Hepatitis C on 21st January 1991*" at Coventry and Warwickshire Hospital.[259] It was only after his transfer to the Royal Free Hospital in October 1992 that he first became aware of his infection with HCV. The consultant, Dr Wood, was surprised that the witness was not aware of his HCV positive status as Coventry and Warwickshire Hospital was aware of it and it was written in his transfer letter dated 14 September 1992. The witness was not aware of this letter until 2003 when he acquired his medical notes.[260] The witnessbelieves that he was tested for HCV without his consent or knowledge and without his parents' consent or knowledge.[261] The positive test result was not made known to him for at least 21 months.[262]

114. Another Inquiry witness believed he was tested for hepatitis in January 1980 and that he was suspected of having non-A non-B hepatitis although this was not communicated to him at the time.[263] He was not told of his infection with HCV until 1993 although he was being treated for cirrhosis resulting from HCV without being told he had HCV.[264]

Treatment arrangements for HIV and HCV patients

115. Dr Strevens stated:

> "*26.5. I took over the haemophilia clinic when Prof. Shinton retired in 1991. At that time patients infected with HIV were being treated with AZT which was the only drug available at that time. It was my impression that it was not very effective and patients were deteriorating. When HAART first became available in UK its use was restricted to certain specialist centres. In the West Midlands this was the infectious diseases unit at Heartland's Hospital in Birmingham. As HAART became more freely available I established a separate clinic for*

[259] WITN1369001 paras 20 and 24
[260] WITN1369001 paras 21-23
[261] WITN1369001 para 43
[262] WITN1369001 para 43
[263] WITN1577001 paras 11-12
[264] WITN1577001 paras 20

HIV patients in conjunction with a Genito-urinary medicine specialist for Haemophilia patients - they were very reluctant to attend the usual GUM clinics. It was gratifying to see the rapid progress these patients made. The GUM specialist was also delighted to be treating patients who without fail took the treatment regularly. Regimens were difficult at first but became less complex with time. Failure to take the drugs regularly as prescribed was known to cause drug resistance but because of their discipline in taking the drugs this was not a problem with the haemophilia patients."

116. Dr Strevens further explained what happened after the haemophilia outpatient clinic became his responsibility after Professor Shinton in 1991:[265]

"*When I took over many of the patients with HIV infection were taking AZT in response to falling CD4 counts. In spite of this it was clear that the disease was progressing until the mid 1990s when highly active antiretroviral therapy (HAART) became available. At first supplies were limited so the treatment was restricted to major centres. In the West Midlands this was the infectious disease unit at Heartlands Hospital. The unit developed a priority list and by then I had one or two patients desperately ill. I referred them and one was selected for immediate treatment. Not only was he given HAART therapy but they were able to identify and treat one of the exotic infections that patients with AIDS are susceptible to. He was treated for this and was also given immune boosting treatment. After two years of therapy he regained his weight and health was able to walk again. When HAART became more generally available in Coventry I established a joint clinic with a genito-urinary medicine specialist to treat the haemophilia patients who were extremely reluctant to attend the GU medicine clinic (mostly for patients with venerial diseases). It was gratifying to see the patients gradually respond to the treatment. At first the treatments were complex but with time they were simplified and became much easier for the patients to take. The GUM specialist was impressed with how haemophiliacs stuck to their treatment such*

[265] WITN3808005 para 64.2

that resistance was never a problem. As far as I am aware, after the introduction of HAART no haemophilia patient died with AIDS and even before HAART the numbers were very small."

117. Dr Strevens added that: "*I cannot remember the details but I believe that all patients were aware of the risks and benefits of the treatments they were being given. All patients were routinely monitored in the clinic*".[266]

118. Dr Strevens described the treatment for HCV patients as follows:[267]

"*65.1. Routine review was provided by the haemophilia sister at the patients' home with regular blood monitoring. Patients were seen in the clinic at the request of the patient / parent or the sister*

65.2. A) Patients were not routinely followed in a specialist clinic but would be if specific issues needed to be addressed.

65.3. B) Various forms of interferon were the only treatments available while I was in Coventry.

65.4. C) The main risks discussed were of unpleasant side effects and the significant risk of failure. The major benefit of course was the eradication of the infection and the hope that there would be no further deterioration in liver disease and the reduced risk of liver cancer.

65.5. D) As stated above the patients were kept under regular review."

119. As far as Dr Strevens was aware, there were no problems with funding of treatments for HIV or HCV.[268]

[266] WITN3808005 para 64.4
[267] WITN3808005 paras 65.1-65.5
[268] WITN3808005 para 68.1

Other issues

120. An Inquiry witness made a complaint to the Health Ombudsman regarding Coventry NHS Trust and their failure to provide information regarding his late father's medical notes.[269] The Ombudsman found maladministration.[270] As the witness explained in his oral evidence to the Inquiry,[271]

> "*…the Trust had told me for well over a year that not only did they not hold records for my father but that he was never a patient there. And they had told me this many times…*
>
> *In the run-up to BBC Panorama being aired, the producers sent a right of reply to the Trust saying basically that "[the witness] says he's tried to get the records for every year, you say you don't have them, just want to make sure this is the case."*
>
> *Within a day of that happening the Trust had gone back to the BBC saying, "Oh, we've just found three volumes of [the witness' father's] medical records*"."

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ANNABEL LEE

Inquiry Counsel Team

September 2021

[*Amended 8 October 2021*]

[269] WITN1210008 para 157
[270] INQY1000127 pp. 162-164
[271] INQY1000127 p. 161