SMALLER HAEMOPHILIA CENTRES PRESENTATION

LINCOLN

Directors, Facilities and Staffing

1. The Lincoln Haemophilia Centre was established in 1981.[1] From 1982, Dr M I Adelman and Dr D R Prangnell were joint Directors of the Centre.[2] Dr Prangnell has provided a written statement to the Inquiry dated 18 August 2021.[3]

2. Dr Prangnell joined Lincoln County Hospital and Grantham Hospital as a full time Consultant Haematologist in 1978.[4] He retired in 2008 save for some part time employment.[5] He fully retired in 2014.[6] He was a member of the British Society for Haematology from 1971 to 2014.[7]

3. Dr Prangnell and Dr Adelman authored an article in the Haemophilia Society Bulletin which described the facilities and personnel at the Lincoln Haemophilia Centre in 1983:[8]

> "*THE LINCOLN HAEMOPHILIA CENTRE*
>
> *Before 1981 a huge area of eastern England, comprising the counties of Lincolnshire and South Humberside, had no Haemophilia Centre of its own. Patients frequently travelled over 60 miles to Sheffield, Nottingham or Derby for treatment. It was not unknown for local hospitals to commit grave errors in managing haemophiliac bleeding due to unfamiliarity with the disease and ignorance of the service provided by Haematologists in distant hospitals.*
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> *Since 1981 the situation has improved greatly with the opening of Lincolnshire's own Haemophilia Centre, based at The County Hospital, Lincoln. The Centre serves over 60 haemophiliacs, about half in the 'severely'*

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[1] WITN5591001 para 5.1
[2] WITN5591001 para 5.1
[3] WITN5591001
[4] WITN5591001 para 2.5.1
[5] WITN5591001 para 2.6.1
[6] WITN5591001 para 2.7.1
[7] WITN5591001 para 3.3
[8] PRSE0000411 p. 9

and 'moderately severely' affected category. Housed in Victorian buildings the Centre has the great advantage of being just inside the front door of the hospital. Patients can be driven to within a few feet of the treatment area and porters are on hand to assist with chairs and advise on car parking etc. a major disadvantage is that we share a treatment area with patients attending for blood sampling and treatment of other blood diseases.

The Centre provides a round-the-clock service with two Consultant Haematologists available to supervise treatment and give advice to outlying hospitals. Sister Brenda Brown, our Haemophilia Nurse, is responsible for administering therapeutic material, training patients for home treatment, issuing supplies of anti-haemophilic factor and home treatment pacts. She has also become an expert Agony-Aunt specialising in social problems of a delicate nature.

The interests of all members of the team overlap in particular with our Social Worker, Mary Dundon. Mary has become a member of the British Association of Social Workers Special Interest Group (on Haemophilia) and has represented Lincoln at their conference in London. She has become particularly expert in educational matters and arranging financial assistance for haemophiliacs who have become unemployed as a result of their condition.

By no means the least of our blessings is an active local branch of the Haemophilia Society with Mr Leslie Mumby as chairman and Mrs Sue Cooke, secretary. The group is usually well attended, meeting on the last Sunday of every month in the Nurses' Home. Recently it has concentrated on three main areas: providing a forum to discuss developments in the treatment of Haemophilia; fund raising for the National Society and encouraging and assisting needy families in our own area. Recently it gave financial help towards a holiday on the coast and also purchased vital equipment for the laboratory. This year six year old ***[GRO-A]*** *won the Brendan Foster award for his swimming as a result of encouragement from the local group.*

As a new Centre we are trying to incorporate all the best features of larger, well established Centres. This we will continue to do after we move to new premises in the District General Hospital, due to open in 1985, with the aid of our enthusiastic staff, loyal patients and the generosity and support of our local branch of The Haemophilia Society."

4. According to the Haemophilia Society Treatment Survey in 1986:[9]

    a. Nurses played a major role in treatment at 19 centres including Lincoln;[10]
    b. More than 25% of severely affected patients had seen an orthopaedic surgeon or rheumatologist at 15 hospitals including Lincoln;[11]
    c. More than 75% of severely affected patients were on home therapy at 20 centres including Lincoln.[12]

5. Other personnel at Lincoln County Hospital included Dr B B Scott, gastroenterologist and hepatologist.[13] Dr Scott was a member of the Trent Regional Hepatitis C Virus Study Group.[14]

Status of Haemophilia Centre, Relationship with other Haemophilia Centres, Relationship with Regional Transfusion Centre

6. The Haemophilia Centre at Lincoln was based at Lincoln County Hospital, Sewell Road, Lincoln, LN2 52Y.[15] The designated Haemophilia Centre Number was 051.[16]

7. Lincoln was part of Trent Regional Health Authority[17] and fell within the Sheffield Supraregion,[18] with Sheffield as the regional Haemophilia Reference Centre. Other Haemophilia Centres within Trent Regional Health Authority included Sheffield, Sheffield Children's, Derby, Leicester and Nottingham.[19]

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[9] HCDO0000276_032

[10] Para 6.5

[11] Para 6.9

[12] Para 6.10

[13] WITN5591001 para 5.6

[14] DHSC0002546_042

[15] BPLL0010509 as at 8 August 1984 and DHSC0002263_005 as at 15 February 1985

[16] HCDO0000119_138 and HCDO0000602

[17] HSOC0017344

[18] OXUH0000863_002

[19] HSOC0017344

8. It is understood that Lincoln was supplied by the Trent Regional Transfusion Centre in Sheffield.[20] Dr Prangnell described having a "*very good relationship with the transfusion centre. We had no difficulty with supply of cryoprecipitate or British untreated concentrate in the early 1980s*".[21] In November 1994, Dr Adelman wrote to Dr James at the Regional Transfusion Centre enquiring as to the "*official BTS line*" for partners of haemophiliacs who wished to donate blood.[22] The donor was married to a haemophiliac who was HIV positive but the donor herself tested negative. Dr James responded to Dr Adelman by letter dated 8 December 1994 acknowledging that "*[w]e do have problems about accepting the sexual partners of haemophiliacs. The issue has not yet been resolved; at the moment we do not wish such people to donate blood. The situation is even more difficult in the case of sexual partners of haemophiliacs known to have been HIV positive who have died with AIDS. There is a feeling that we still do not know quite enough about the HIV virus…*"[23]

Number of Patients Registered and/or Treated at the Centre

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

10. 1981: The Annual Returns for 1981 are somewhat faint and difficult to read.[24] It is unclear how many patients were treated during 1981.

11. 1982: The Annual Returns for 1982, signed by Dr Adelman / Dr Prangnell, show that the Centre treated 19 patients with haemophilia A, 0 patients with von Willebrand's disease, and 2 patients with haemophilia B.[25]

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[20] NHBT0015832_001 p. 3 and WITN5591001 para 35.1
[21] WITN5591001 para 11.1
[22] JPAC0000025_298
[23] JPAC0000025_297
[24] HCDO0001540
[25] HCDO0001638

12. 1983: The Annual Returns for 1983, signed by Dr Adelman / Dr Prangnell, show that the Centre treated 22 patients with haemophilia A, 0 patients with von Willebrand's disease, and 3 patients with haemophilia B.[26]

13. 1984: The Annual Returns for 1984, signed by Dr Adelman / Dr Prangnell, show that the Centre treated 24 patients with haemophilia A, 0 patients with von Willebrand's disease, and 6 patients with haemophilia B.[27]

14. 1985: The Annual Returns for 1985, signed by Dr Prangnell / Dr Adelman, show that the Centre treated 19 patients with haemophilia A, 3 patients with von Willebrand's disease, and 4 patients with haemophilia B.[28]

15. 1986: The Annual Returns for 1986, signed by Dr Prangnell / Dr Adelman, show that the Centre treated 19 patients with haemophilia A, 3 patients with von Willebrand's disease, and 5 patients with haemophilia B.[29]

16. A list of centres with patients under 19 years of age includes Lincoln County Hospital which suggests that children were treated there.[30]

Treatment policies and blood product usage

17. According to data contained in the Annual Returns, Lincoln used the following blood products:

18. 1981: To treat haemophilia A patients, the Centre used cryoprecipitate in hospital but not for home treatment. The Centre also used NHS factor VIII in hospital and for home treatment; Armour Factor VIII (Factorate) in hospital; and Immuno Factor VIII

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[26] HCDO0001737
[27] HCDO0001830
[28] HCDO0001924
[29] HCDO0002020. The Annual Returns for 1987 are at HCDO0002108, 1988 at HCDO0002201, 1989 at HCDO0002293, 1990 at HCDO0002384,
[30] HCDO0000013_269

(Kryobulin) in hospital and for home treatment.[31] To treat haemophilia B patients, the Centre used NHS factor IX concentrate in hospital and for home treatment.[32]

19. 1982: To treat 19 patients with haemophilia A, the Centre used:[33]

    a. 28,080 units of cryoprecipitate in hospital (no cryoprecipitate for home treatment);
    b. 688 bottles of NHS factor VIII in hospital and 311 bottles of NHS factor VIII for home treatment;
    c. 175 bottles of Cutters Factor VIII (Koate) in hospital and 60 bottles of Koate for home treatment;
    d. 20 bottles of Immuno Factor VIII (Kryobulin) in hospital and 20 bottles of Kryobulin for home treatment.

20. To treat 2 patients with haemophilia B, the Centre used 73,660 units of NHS factor IX in hospital and 18,035 units of NHS factor IX for home treatment.[34]

21. 1983: To treat 22 patients with haemophilia A, the Centre used:[35]

    a. 153 bags / 10,710 units of cryoprecipitate in hospital (no cryoprecipitate for home treatment);
    b. 157,881 units of NHS factor VIII in hospital and 156,270 units of NHS factor VIII for home treatment; and
    c. 46,164 units of Cutters Factor VIII (Koate) in hospital and 7,100 units of Koate for home treatment.

22. To treat 3 patients with haemophilia B, the Centre used 30,370 units of NHS factor IX in hospital and 14,269 units of NHS factor IX for home treatment.[36]

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[31] HCDO0001540
[32] HCDO0001540
[33] HCDO0001638
[34] HCDO0001638
[35] HCDO0001737
[36] HCDO0001737

23. 1984: To treat 24 patients with haemophilia A, the Centre used:[37]

    a. 8,750 units of cryoprecipitate in hospital (no cryoprecipitate for home treatment);
    b. 175,920 units of NHS factor VIII in hospital and 202,220 units of NHS factor VIII for home treatment; and
    c. 1,540 units of Cutters Factor VIII (Koate) in hospital and 1,920 units of Koate for home treatment.

24. To treat 6 patients with haemophilia B, the Centre used 38,450 units of NHS factor IX in hospital and 45,150 units of NHS factor IX for home treatment.[38]

25. 1985: To treat 19 patients with haemophilia A, the Centre used:[39]

    a. 85 bags / 5,950 units of cryoprecipitate in hospital (no cryoprecipitate for home treatment); and
    b. 42,970 units of NHS factor VIII in hospital and 227,180 units of NHS factor VIII for home treatment.

26. It appears that no commercial concentrates were used in 1985. To treat 3 patients with von Willebrand's disease, the Centre used 175 units of cryoprecipitate in hospital and 1,000 units of NHS factor VIII in hospital.[40] To treat 4 patients with haemophilia B, the Centre used 5,860 units of NHS factor IX in hospital and 49,560 units of NHS factor IX for home treatment.[41]

27. 1986: To treat 19 patients with haemophilia A, the Centre used:[42]

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[37] HCDO0001830
[38] HCDO0001830
[39] HCDO0001924
[40] HCDO0001924
[41] HCDO0001924
[42] HCDO0002020

a. 83 bags of cryoprecipitate in hospital (no cryoprecipitate for home treatment);
b. 293,185 units of NHS factor VIII in hospital and 267,640 units of NHS factor VIII for home treatment; and
c. 31,758 units of Alpha Factor VIII (Profilate) in hospital and 15,800 units of Profilate for home treatment.

28. To treat 3 patients with von Willebrand's disease, the Centre used 60 bags of cryoprecipitate, 860 units of NHS factor VIII, and 760 units of Profilate in hospital.[43] To treat 5 patients with haemophilia B, the Centre used 9,020 units of NHS factor IX in hospital and 29,380 units of NHS factor IX for home treatment.[44]

29. Dr Prangnell stated that from 1982, he jointly made decisions with Dr Adelman regarding the selection, purchase and use of blood products on the basis of availability and national and regional opinion.[45] He stated that it was their policy to keep patients on the same treatment preparation whenever possible.[46] The reasons or considerations that led to the choice of one product over another included "*availability, safety, price in that order*".[47]

30. In March 1985, Dr Adelman wrote to Dr Snape at BPL regarding the choice of product for a severely affected haemophiliac patient.[48] Dr Prangnell stated that the letter "*indicates there were limited supplies of British heat treated concentrate available to us*".[49] The letter stated:[50]

> "*This severely affected haemophiliac (Factor VIII less than 1%) has been treated exclusively with BPL Factor VIII Concentrate (unheated). Recent testing has shown him to be HTLV III antibody negative.*

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[43] HCDO0002020
[44] HCDO0002020
[45] WITN5591001 para 8.1
[46] WITN5591001 para 8.1
[47] WITN5591001 para 8.3
[48] CBLA0002106
[49] WITN5591001 para 26.6
[50] CBLA0002106

> *He has been referred by his local dentist… It is proposed to extract his teeth under cover of heated BPL Factor VIII Concentrate, provided by the Sheffield Centre.*
>
> *I can foresee problems when we have to supply him with his usual allocation of Factor VIII Concentrate, as it would seem unreasonable for him to be treated with an unheated product, once his parents know that a safer preparation is available at another Centre. Would you think it reasonable to provide a supply of the newly heat treated BPL Factor VIII Concentrate…? His annual Factor VIII Consumption is approximately 3200 units."*

31. In an undated letter regarding a patient with severe haemophilia, Dr Adelman stated "*We have been using only British (BPL) unheated Factor VIII Concentrate and do not wish… to receive unheated commercial material*".[51]

32. Dr Prangnell met with a Senior Sales Representative from Cutter[52] and representative from Immuno[53] but he had no recollection of the details of these meetings.[54] In general terms, he stated that there "*was strong competition between these companies and these meetings were essentially negotiations about price. Safety will have been discussed but we did not rely on the safety claims made by the companies*".[55] An internal Cutter memo dated 2 October 1985 refers to a visit to Lincoln which "*also re-affirmed the thinking of SHEFFIELD*".[56] It was noted that:

> "*LINCOLN remains self-sufficient in Factor VIII and IX concentrate. However, it is without doubt that should they require any commercial material, they will choose Cutter's.*"

33. Regarding the decisions as to which products to use for individual patients, Dr Prangnell stated:[57]

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[51] ULHT0000006
[52] BAYP0000008_369
[53] BAYP0000025_088
[54] WITN5591001 para 8.5
[55] WITN5591001 para 8.5
[56] BAYP0000007_113
[57] WITN5591001 para 12.1

> "*Most of our patients were already on treatment when we took over their management and we continued on the same treatment. Patients who were starting home therapy were often transferred from cryoprecipitate to concentrate. Also some patients were offered or requested to change from cryoprecipitate to concentrate. When we had to transfer patients from NHS to commercial concentrate we did not offer them a choice of manufacturer.*"

34. It appears from letters dated 3 November 1986,[58] and 7 December 1987,[59] that Dr Adelman also met with representatives from Cutter to discuss Koate HT. He was told in the 3 November 1986 letter that "*Koate HT is effective in eliminating HTLV III and also results in a significant reduction in the incidence of Non-A, Non-B Hepatitis in haemophiliac recipients*",[60] and in the 7 December 1987 letter that "*Koate HT has a reduced risk of transmission of Non A Non B Hepatitis as shown by the Allain study*".[61]

35. The Inquiry has received evidence from a witness with mild haemophilia A who was treated at Lincoln Haemophilia Centre from 1980 to 1996 under the care of Dr Adelman and occasionally Dr Prangnell.[62] In relation to his treatment, the witness stated:[63]

> "*As soon as I started attending appointments alone, I recall being told by Dr Adelman, in a very blasé way that all of the blood products came from Scotland and therefore there was no risk of infection. I feel knowledge of my infection was very evident, certainly during the early 1980's. All blood laboratory work had risk of infection stamped on it. Also within my records I found a medical circular that stated young haemophiliacs that hadn't been given Factor viii or were mild should be given DDAVP or Cryo. This never happened and a very interesting file on 18.11.1992 stating I have never had*

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[58] BAYP0000009_050
[59] BAYP0000010_179
[60] BAYP0000009_050
[61] BAYP0000010_179
[62] WITN0274001 para 7
[63] WITN0274001 para 9

> *DDAVP treatment and when I was tested I was around 35%. Good enough for mild bleeds which I commonly had*."

36. The witness later learned that he had contracted hepatitis C.[64]

37. Another witness was first treated with factor VIII when he had his wisdom teeth extracted at Lincoln County Hospital in the early 1980s.[65] Prior to this, the witness had been given cryoprecipitate for his bleeds.[66] From the early 1980s, up until the late 1990s, the witness was given factor VIII at hospitals as and when he had a bleed. After this, the doctor at Lincoln County Hospital trained him to start administering factor VIII to himself at home whenever he had a bleed.[67] He does not believe his parents were provided with any information or advice about the risk of being exposed to hepatitis C or any infections from using factor VIII blood products,[68] and he himself was not aware that there was a risk of infection from factor VIII blood products.[69] The witness was infected with hepatitis C and believes this occurred when he received factor VIII for this tooth extraction in January 1983.[70]

38. Regarding the information provided to patients about the risk of infection, Dr Prangnell stated:[71]

> "*I cannot recall specifically what information was given to patients at different times. Nearly all of our patients were already on therapy when the Centre opened. Fortunately we did not have to use unheated concentrate from America so we considered the risks of the treatment we were using to be small. The nature of Non A Non B hepatitis was not fully appreciated*".

Knowledge of risk of hepatitis and response to risk

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[64] WITN0274001 para 10
[65] WITN1099001 para 7
[66] WITN1099001 para 7
[67] WITN1099001 para 8
[68] WITN1099001 para 17
[69] WITN1099001 para 23
[70] WITN1099001 para 12
[71] WITN5591001 para 40.1

39. Dr Prangnell stated that he was "*not able to recall the detailed chronology nor the detail of the sources*" of his understanding of the knowledge of risk, nor what he knew at any particular time.[72]

40. Dr Prangnell confirmed that either he or Dr Adelman attended most UKHCDO annual general meetings.[73] The minutes of UKHCDO minutes show that either Dr Prangnell or Dr Adelman attended on dates including 13 September 1982,[74] 17 October 1983,[75] 17 March 1986,[76] 9 October 1986,[77] 25 September 1987,[78] 29 September 1988,[79] 21 September 1990,[80] 18 September 1992,[81] 1 October 1993,[82] 30 September 1994,[83] 3 October 1996,[84] 12 September 1997,[85] 1 October 1998,[86] and 30 September 1999.[87]

41. In response to the risk of hepatitis, Dr Prangnell stated:[88]

> "*The perceived priority at the time was to reduce the long term complications of severe bleeding disorders – particularly joint damage. To this end we were motivated to give early treatment at adequate dosage to this group of patients. We used the products that we considered had the lowest risk. We avoided the use of preparations from paid donors. In the early 1980s the complications and risks of hepatitis were poorly understood.*"

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[72] WITN5591001 para 18.1
[73] WITN5591001 para 89.1
[74] CBLA0001619
[75] PRSE0004440
[76] PRSE0001688
[77] PRSE0004317
[78] HCDO0000485
[79] BART0002329
[80] BART0002382
[81] HCDO0000248_013
[82] HCDO0000493
[83] HCDO0000494
[84] HCDO0000015_003
[85] HCDO0000497
[86] BART0000947
[87] HCDO0000499
[88] WITN5591001 para 23.1

42. Dr Prangnell made clear that "*it was thought that converting to the use of cryoprecipitate was not a viable alternative. Patients were not offered the choice of discontinuing treatment with concentrate and transferring to cryoprecipitate*".[89]

Knowledge of risk of AIDS and response to risk

43. In addition to the UKHCDO meetings referred to above, Dr Adelman also participated in a Symposium on Pathology of AIDS at the Royal College of Physicians on 25 November 1985.[90]

44. By letter dated 27 February 1985, Dr Adelman wrote to Dr Snape at BPL raising concerns about the risk of transmitting AIDS to patients with Christmas disease using factor IX concentrate and the use of factor VIII concentrate.[91] The letter stated:

> "*Dr Dennis Prangnell and myself as Co-Directors of the Lincoln Haemophilia Centre have been giving some thought to the use of Factor IX Concentrate and the risk of transmitting AIDS to patients with Christmas disease.*
>
> *I understand that some of the Centres in our Region are proposing to use heat-treated commercial Factor IX Concentrate in preference to the BPL product. As we are uncertain about the safety of this little-tried material we would prefer to continue to use BPL Factor IX Concentrate, to restrict our Christmas disease patients, but to issue only those batches to which our individual patients have been previously exposed.*
>
> *I am in the process of screening our patients for HTLV III antibody. So far the results indicate that our severely affected Christmas disease patients have not apparently developed antibodies to the AIDS virus.*
>
> *We, therefore, feel uncertain about exposing them to new untried batches…*

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[89] WITN5591001 para 41.1
[90] BPLL0002766
[91] BPLL0010606

> *We would also be interested in your reaction to issuing specified batches of unheated Factor VIII Concentrate to HTLV III antibody negative haemophiliacs previously exposed to this material. We would prefer this arrangement to using the commercial heat treated Factor VIII Concentrate, until the BPL and heat-treated anti-haemophilic globulin becomes available*."

45. By letter dated 22 March 1985, Dr Adelman wrote to Dr Snape at BPL stating:[92]

> "*We are in the process of testing all our patients who have received Factor VIII concentrate for HTLV3 antibodies. I would like to think that those not already tested might be eligible for the heat treated product. We are at present treating our patients with Cryoprecipitate and unheated BPL Factor VIII concentrate. We are not proposing to purchase heated commercial concentrate in anticipation of the availability of the BPL heated product.*"

46. Dr Prangnell commented that:[93]

> "*Un-heated BPL concentrate was considered much safer than commercial unheated concentrate. The treated commercial concentrate was known to contain plasma from unpaid donors and from infected donors. There was anxiety that the treatment of these products did not render them safe.*"

47. Dr Prangnell further explained that the Centre did not maintain its position of not purchasing commercial concentrate due to limited supply of British concentrate:[94]

> "*We eventually had to buy commercial concentrate because of the limited supply of British concentrate. I cannot recall the details, but confidence in commercial concentrates improved as the manufacture of products improved*."

48. In an internal BPL memorandum dated 2 May 1985, Dr Snape appeared to express surprise at the delay in providing heat treated factor VIII to Lincoln:[95]

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[92] CBLA0002102

[93] WITN5591001 para 27.2

[94] WITN5591001 para 28.1

[95] CBLA0002153

> "*I am a little surprised that Centres like the one at Lincoln are only now receiving their first consignment of heated F.VIII. Things must have moved pretty slowly in the provinces since the first batches of heated F.VIII left BPL.*"

49. Dr Prangnell stated:[96]

> "*…There was delay and the reasons were with the blood products laboratory and are admitted in CBLA0001998. I am not aware that it had any affect in terms of transmitting infection but clearly this was a risk. All our patients infected with HIV were infected before this time and probably also our patients with Hepatitis C.*"

50. In response to the risk of infection, Dr Prangnell stated that "*All patients were invited for annual review and these issues would have been discussed according to the knowledge at the time*".[97] Furthermore, that they maintained a "*preference for British products that were perceived to have lower risk*".[98] The Centre continued to use factor concentrates to treat patients after becoming aware of the possible risks of infection with HIV because they "*did not believe there was a viable alternative. There was no choice other than to leave patients untreated*".[99] Dr Prangnell noted that the "*UKHCDO view was not to revert to cryoprecipitate*".[100] He added that "*[a]ll patients on unheated concentrate were transferred to heat treated concentrate*" and they "*were instructed to return all unheated concentrate for reprocessing*".[101]

Testing patients for HTLVIII and informing them of diagnosis

51. Dr Prangnell stated that "*[m]ost patients who had received blood products were tested at annual review. Pre-test counselling became standard practice but it may not have been for the first few patients tested*".[102] Patients were told individually by Dr

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[96] WITN5591001 para 29.1
[97] WITN5591001 para 30.1
[98] WITN5591001 para 31.1
[99] WITN5591001 para 32.1
[100] WITN5591001 para 32.1 and PRSE0004440
[101] WITN5591001 para 33.1
[102] WITN5591001 para 45.1

Prangnell or his colleague that they had been, or might have been, infected with HIV in person.[103] He added that "*Patients were advised that the diagnosis was serious and had consequences for health and well-being (the risk of developing AIDS). They were not told to keep the diagnosis secret but they were alerted to the possible stigma associated with it.*"[104]

52. A letter dated 21 February 1985 from Dr Adelman to Dr Preston at Royal Hallamshire Hospital, Sheffield, shows that a specimen of a patient with moderate haemophilia A who was treated with factor VIII concentrate at Sheffield in August 1983 was sent for HTLVIII antibody testing.[105] The letter also refers to the results of specimens dispatched for testing on 21 January and 31 January.[106] Dr Preston responded by letter dated 18 March 1985.[107]

53. Further specimens of three patients were sent by Dr Adelman to Dr Preston for HTLVIII antibody testing under cover of letter dated 28 February 1985.[108] The patients comprised a mild haemophiliac who had received Cutter (Koate) from 22 March 1982 to 1 April 1982 but had received no factor VIII concentrate in the past 12 months; a mild haemophiliac who had received BPL concentrate 6 months previously but had no recorded exposure to commercial concentrate; and a mild haemophiliac who had previously been treated with cryoprecipitate, BPL concentrate in 1984 and Cutter (Koate) in 1982. Six further specimens were sent for HTLV III antibody testing under cover of letter dated 4 April 1985,[109] two further specimens were sent under cover of letter dated 25 April 1985,[110] and a batch of three further specimens were sent under cover of letter dated 23 July 1985.[111]

54. A further batch of six specimens were sent by Dr Adelman to Dr Preston for HTLV III antibody testing under cover of letter dated 12 August 1985.[112]

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[103] WITN5591001 para 46.1
[104] WITN5591001 para 47.1
[105] RHAL0000484_004
[106] RHAL0000484_029
[107] RHAL0000484_027
[108] RHAL0000484_005
[109] RHAL0000484_024
[110] RHAL0000484_018
[111] RHAL0000484_020
[112] RHAL0000484_013

Numbers infected with HIV

55. According to Dr Prangnell, as far as he could recall, there were 4 patients with severe haemophilia A at the Centre who were infected with HIV in consequence of treatment with blood products.[113]

56. In a letter dated 12 August 1985 from Dr Adelman to Dr Preston, Dr Adelman stated that "*So far, we have tested 27 of our severely affected patients with haemophilia and Christmas disease. Out of these [three patients] remain the only positives for HTLV III antibody*".[114]

57. Provisional data received by the Inquiry from UKHCDO records that 1 patient was identified as infected with HIV at Lincoln in 1985.[115]

Testing for HCV

58. In 1983, Dr Adelman wrote to Dr Preston at Royal Hallamshire Hospital, Sheffield, regarding three patients with hepatitis.[116] Dr Preston advised that liver biopsies should be performed on patients who have persistent abnormalities of liver enzymes.[117] This view was supported by Dr Triger.[118]

59. An anonymous witness was infected with hepatitis C through receiving contaminated blood products in England between 1984 and 1986.[119] He was treated at Lincoln General Hospital. He believed that neither he nor his parents were given any information in relation to the risks of infection from receiving factor IX blood products.[120] The witness recalled that:[121]

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[113] WITN5591001 para 51.1
[114] RHAL0000484_013
[115] INQY0000250
[116] ULHT0000002, ULHT0000003. The Inquiry does not have a copy of Dr Adelman's letter, only of the replies from Dr Preston and Dr Triger.
[117] ULHT0000002
[118] ULHT0000003
[119] WITN1422001
[120] WITN1422001 para 11
[121] WITN1422001 para 12

> "*…my mother and I were called in to Lincoln Haemophiliac Centre, to discuss the matter and the information given in relation to the infection was minimal. We were told that Hepatitis C was not as infectious as Hepatitis A or B and the doctor also attempted to explain some of the symptoms. The doctor also mentioned there were risks in having sexual partners and of having children. In the event of blood spillages, I was told to be as careful as possible*."

60. The witness did not think that they were given enough or adequate information in order to manage the infection.[122] He stated:[123]

> "*I believe that full and adequate information should have been provided to me as soon as it was found out that I had been infected. I should have been told about my infection as soon as possible. I am a very strong-minded person and try to overcome negative news and take it as well as I can. Nevertheless, my parents and I should have been fully informed.*
>
> *I was told at that time, there was no known cure or successful treatment which could be offered to me. Having Haemophilia B from birth, I was always given negative information about my health. Although it was difficult to digest sometimes, it became a big part of my life. The news about Hepatitis C was just another negative piece of news which I had to get on with.*"

61. Another witness recounted how he was told of his infection with hepatitis C following testing. He stated:[124]

> "*10. Dr Adelman did not tell me that I had contracted Hepatitis C until 1995. However he had full knowledge [in] January 1994 as more accurate testing had become available and this was carried out on stored bloods from 1990 (they had no permission to do this).*

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[122] WITN1422001 para 13
[123] WITN1422001 paras 14-15
[124] WITN0274001 paras 10-15

11. I comment briefly on the history that led to me being told about my Hepatitis C in 1995. I had been poorly for a number of years which involved in patient stays at the Lincoln County Hospital. I recall one such admission in 1990 when I weighed only 57 kilograms. I was unable to eat and had horrific back and abdominal pain. I actually looked anorexic. I was initially told that I had contracted Reiters Disease. I was then sent to the Genitourinary Medicine (GUM) Clinic as they suspected that I had contracted chlamydia. I certainly don't recall being told that I was being tested for Hepatitis C at this time and I don't think the GUM clinic tested me for this.

12. However, I recall that somewhere in my medical records (which are held by Malcolmson Law), there is a record about a Hepatitis C test being carried out in or around 1990 at the Lincoln County Hospital but I don't believe that this was taken when I was at the GUM clinic and was instead taken during a routine clinic appointment. This test was carried out without my knowledge or consent. Strangely this result was negative, although I am aware that tests do sometimes produce false negative results. I understand that the bloods taken from me at this time were then sent to Scotland and stored and retested in January 1994. This was also without my knowledge or consent.

13. In or around 1994, Dr Adelman then took further bloods from me, without my knowledge or consent, to test me for Hepatitis C. I understand that these test results were positive for Hepatitis C.

14. During the Christmas of 1994 I became very unwell. I therefore telephoned the Lincoln County Hospital on or about 27th/28th December 1994 and spoke to Dr Prangnell. I think I described how I was feeling at the time and I assumed that he was well aware, by this time, that I had Hepatitis C. He told me that it sounded like I may have Hepatitis C and he asked me to book an appointment to see either him or Dr Adelman.

15. This appointment took place in January 1995 when I was tested and still not notified of my infection. Finally in February 1995 I had a follow up appointment and was told about my infection by Dr Adelman. He did not give

> *me much information to allow me to either understand or manage my infection. He also told me that it was almost impossible to transmit the virus via sexual contact, about a 2% chance*."

62. The witness was critical of the information he received from Dr Adelman but explained that he received more information from the haemophilia nurse at Lincoln:[125]

> "*The Haemophilia Nurse, at Lincoln County Hospital actually told me a bit more about Hepatitis C. She was realistic and said that I would have to stop working and that there was no cure for this virus and that I would not recover from this. She said that I may require a liver transplant and that my diagnosis may not be good. She then told me to get out of Lincoln County Hospital and return to Sheffield Hospital. She told me that they were not treating me appropriately at Lincoln County Hospital and I note that she herself ended up leaving Lincoln County Hospital because she did not agree with how we were treated. I did not have a good working relationship with Dr Adelman. I found him patronising and condescending and I felt he thought I was beneath him*."

63. The witness had no doubt that he was tested for hepatitis B, hepatitis C and HIV without his knowledge or consent.[126]

64. Another witness with mild/moderate haemophilia A was told in 1988 that he was infected with non-A non-B hepatitis.[127] He could not recall if he was provided with any information at that time.[128] The witness was later shocked and horrified to discover a letter from Dr Adelman to Dr Chirodian dated 23 March 1983 in which the doctors knew in 1983 that the witness had non-A non-B hepatitis but they failed to tell him.[129] The witness also found out through his medical records that he contracted hepatitis B following factor VIII treatment in 1984. He was not told about this infection or given any information about how to manage the infection.[130]

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[125] WITN0274001 para 16
[126] WITN0274001 para 19
[127] WITN1099001 para 10
[128] WITN1099001 para 10
[129] WITN1099001 para 11, WITN1099002
[130] WITN1099001 para 15, WITN1099004

65. Dr Prangnell stated that patients were tested for hepatitis C at annual review when tests became available.[131] Patients were advised of the result by Dr Prangnell or his colleague in person.[132] Dr Prangnell could not recall that there were delays in informing patients of their diagnosis.[133] In relation to information given to patients infected with hepatitis C, Dr Prangnell stated:[134]

> "*The results of tests were not withheld from patients. The information given to patients changed over time as understanding of this condition improved and management options became available. I cannot recall the timescale or what was said at different times. Further tests became available that offered some prognostic information regarding response to therapy.*"

66. Dr Prangnell could not recall the precise number of patients at the Centre infected with hepatitis C but estimated that it was about 10.[135]

67. In relation to the taking of blood samples, Dr Prangnell stated:[136]

> "*Routine blood samples were taken at annual review as this was the only way to effectively review patients at the centre. Routine tests would include: factor levels; inhibitor screen; liver function; renal function, and; Hepatitis C and HIV when these tests became available. Blood samples would also be taken in order and to investigate specific problems encountered by patients. Blood samples would also be taken to manage specific treatment episodes. We explained what test we were going to do and why but we did not obtain written consent. We did not store samples except occasionally for a particular need such as for planned procedure and then only for a short period.*"

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[131] WITN5591001 para 56.1
[132] WITN5591001 para 56.1
[133] WITN5591001 para 60.1
[134] WITN5591001 para 57.1
[135] WITN5591001 para 59.1
[136] WITN5591001 para 64.1

68. Dr Prangnell stated that the Centre did not have a bank of stored samples.[137] Dr Prangnell also stated that "[*p]atients were not tested without consent*" and that "*[c]onsent was not recorded*".[138]

Treatment arrangements for HIV and HCV patients

69. Dr Prangnell stated:[139]

> "*We were initially responsible for managing patients with hepatitis and HIV. When treatment became available for hepatitis C our patients were managed by our local consultant gastroenterologist and hepatologist, Dr B. B. Scott. A new consultant was appointed to the genitourinary medicine department. He had experience of HIV management elsewhere and took over management of this aspect of care (I cannot recall his name).*"

70. In relation to his treatment for hepatitis C, an anonymous witness stated that "*Whilst undergoing my treatments, I had a good rapport with the nursing staff at the Haemophilia Centre who listened to my questions and advised me appropriately*".[140]

71. Another witness who contracted hepatitis C commenced a 7 month course of interferon treatment which was unsuccessful.[141] He became fed up with the care he had been given under Dr Adelman at Lincoln County Hospital and later transferred his care and treatment to Sheffield.[142]

72. Dr Adelman co-authored a paper published in 1991 by the American Society of Haematology on "*A Randomized Controlled Trial of Recombinant Interferon-a in Chronic Hepatitis C in Haemophiliacs*".[143] The paper was referred to in a letter dated

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[137] WITN5591001 para 65.1
[138] WITN5591001 para 67.1
[139] WITN5591001 para 5.6. See also paras 74, and 77-81.
[140] WITN1422001 para 26
[141] WITN0274001 para 24
[142] WITN0274001 para 25
[143] PRSE0004466

24 February 1992 from Dr Preston of Royal Hallamshire Hospital to all Haemophilia Centre Directors.[144]

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January 2023

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[144] HHFT0000945