SMALLER HAEMOPHILIA CENTRES PRESENTATION
CHARING CROSS HOSPITAL, FULHAM

Directors, facilities and staffing

1. The Directors of the Haemophilia Centre at Charing Cross Hospital during the 1970s-80s included Dr T R Mitchell and Dr Catherine Haworth. Dr E Ranasinghe was named as Director of the Centre in the 1981 annual returns,[1] and Dr J R Kendra was named as Director of the Centre in the 1982 annual returns.[2]

2. Although not a Director of the Centre, from 1983 to 1998, Dr Samson was a Senior Lecturer in Haematology at Charing Cross and Westminster Medical School.[3] She has provided a written statement to the Inquiry dated 10 December 2020.[4] Her responsibilities at Charing Cross Hospital included sharing in responsibility for the clinical and diagnostic work of the department. She had particular responsibility for the care of patients with haematological malignancies.[5] Dr Samson worked at Charing Cross Hospital from the autumn of 1983 until she moved to Hammersmith Hospital around the end of 1995.[6]

3. Charing Cross Hospital was one of three hospitals under the umbrella of Charing Cross and Westminster Medical School (University of London). The other two hospitals were Westminster Hospital and Queen Mary's Hospital. The Head of the Department of Haematology at Charing Cross and Westminster Medical School was Professor A J Barrett (who was Director of the Haemophilia Centre at Westminster Hospital from around 1979 to 1988).

4. According to the written statement of Dr Samson:

> *"The following were my senior colleagues at different times and may have been*

[1] HCDO0001506
[2] HCDO0001608
[3] WITN4673001 para 6
[4] WITN4673001
[5] WITN4673001 para 6
[6] WITN4673001 para 19

involved in caring for patients with haemophilia and allied disorders.
Head of Dept Prof AJ Barrett, until 1989, replaced by Prof Brian Durie, until 1992, then post vacant until merger with RPMS in 1994 when Prof John Goldman became Head of Department.
Senior Lecturer Dr Minou Foadi
Senior Lecturer Dr Catherine Haworth, until 1993, subsequently Dr Donald McCarthy and then Dr Edward Kanfer
Later joined by Associate Specialists Dr Diana Hagger and Dr Faiza Nadir, I do not remember the date they took up this role."[7]

5. Other personnel at Hammersmith Hospital included:

    a. Dr M Desai, who represented Dr Haworth at a UKHCDO meeting on17 October 1983.[8]

    b. Professor (then Dr) Christine Lee, who spent part of her time working at the Charing Cross Hospital from 1984.[9]

    c. Dr Paul Giangrande, Lecturer (Hon. Senior Registrar) in Haematology at Westminster and Charing Cross Medical School on rotation to Westminster Hospital, Charing Cross Hospital and Queen Mary's Hospital, Roehampton between December 1984 and November 1987.[10]

6. Dr Samson described limited facilities at Charing Cross Hospital:[11]

    "*Charing Cross was a very small centre treating only a few patients. There was no physical entity designated "Haemophilia Centre". We did not have a dedicated specific treatment area or any dedicated staff.*"

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[7] WITN4673001 para 26
[8] PRSE0004440
[9] WITN4673001 para 24. See oral evidence of Professor Christine Lee on 20 October 2020
[10] WITN3311003 para 2.7
[11] WITN4673001 para 22

7. The Inquiry has received evidence from a witness, Mrs C, who had sons diagnosed with haemophilia.[12] The witness described her experience of the facilities at Charing Cross:[13]

> "*Charing Cross hospital kept... beds for haemophiliac children.... We seemed to be going to Charing Cross a lot with my... boys. They didn't have a haemophilia ward at Charing Cross so you would have to wait until they sent the Cryoprecipitate treatment down to the ward. The Cryoprecpitate would only last 2 hours before it was no good to use.*"

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

8. The Haemophilia Centre at Charing Cross Hospital was based in Fulham at Fulham Palace Road, London W6 8RF. It was designated as a new Associate Centre late in 1976.[14]

9. At a meeting of Directors of Haemophilia Centres/Associate Haemophilia Centres (Regions 04, 05 and 06) and Blood Transfusion Centres on 15 December 1976 (attended by Dr Mitchell on behalf of Charing Cross Hospital),[15] it was noted that the number of Haemophilia Centres in Region 05 (and 04) was out of proportion to the number of patients and that some of these appeared to be unnecessarily close, that some designated Haemophilia Centres had fewer patients than the Associate Centres; and that Dr Mitchell of Charing Cross Hospital "*had asked if they could become an Associate Centre although they were only 2 miles from Hammersmith, as some of the consultants who looked after haemophiliacs attending Charing Cross were anxious to continue to look after them*".[16] After discussion, it was agreed to maintain the status quo and to recommend that Charing Cross Hospital should be added to the list of Associate Centres.[17] It appears from a list of those present at the meeting that Charing Cross was part of the North West Thames Region (05). The relevant regional distributor of blood

[12] WITN2687001. Mrs C gave oral evidence to the Inquiry on 8 May 2019 [INQY1000006]
[13] WITN2687001 para 14
[14] OXUH0000863_002
[15] CBLA0000533
[16] CBLA0000533
[17] CBLA0000533

products for Charing Cross Hospital was the North London Blood Transfusion Centre, in Edgware.

10. Dr Mitchell sent his apologies to a further meeting of Directors of Haemophilia Centres/Associate Haemophilia Centres (Regions 04, 05 and 06) and Blood Transfusion Centres on 23 September 1977,[18] but attended a meeting on 1 September 1978.[19]

11. Patients who were infected with HIV were referred from Charing Cross to St Thomas's Hospital Haemophilia Reference Centre. Dr Samson gave evidence that:[20]

> "*By 1985 – 86 when the problem of HIV and potential other infectious agents was clear, several patients, including newly diagnosed patients were transferred to the care of the Haemophilia Centre at St Thomas' Hospital, because it was felt they required more expert care and support than we could give at Charing Cross.*"

12. As well as links with St Thomas' Hospital, there were also ties with the Royal Free Hospital as a Haemophilia Reference Centre and Professor Christine Lee for general advice. According to the evidence of Dr Samson:[21]

> "*Management would have been decided on an individual basis and would have been guided by current knowledge and expertise as transmitted to us via the UKHCDO meetings and by reading the literature. We would also have sought advice from colleagues at the Royal Free Hospital Haemophilia Centre which was our Reference centre. Dr Lee who worked at the Royal Free also spent 1 day a week at Charing Cross from 1984 and though I do not remember exactly what her role was she would have been able to give advice.*"

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[18] CBLA0000657
[19] CBLA0000838
[20] WITN4673001 para 23
[21] WITN4673001 para 24

Number of patients treated and/or registered at the Centre

13. In the following years, the numbers of patients registered and/or treated at Charing Cross from the available evidence were as follows:

    a. 1976: A note of a phone call from Dr Mitchell in 1977 suggests that 1 patient with haemophilia was treated with 63 units of cryoprecipitate, and 1 patient with von Willebrand's disease (who was a visitor from Saudi Arabia) was treated with 9 units of cryoprecipitate.[22]

    b. 1977: The Annual Returns for 1977, signed by Dr T R Mitchell, indicate that 2 patients with haemophilia A, 1 carrier of haemophilia A, and 1 patient with Christmas disease were treated at the Centre.[23]

    c. 1978: The Annual Returns for 1978, signed by Dr T R Mitchell, show that 5 patients with haemophilia A, and 1 patient with Christmas disease, were treated at the Centre.[25]

    d. 1979: The Annual Returns for 1979, signed by Dr T R Mitchell, indicate that 6 patients with haemophilia A were treated during the year. No patients with Christmas disease were treated.[27] Of the 6 patients who were treated, 2 patients were overseas visitors and 1 patient was registered in Southampton.

    e. 1980: The Annual Returns for 1980 signed by Dr T R Mitchell show that 5 patients with haemophilia A were treated at the Centre.[28] It is noted in manuscript that 1 patient was registered with the Hammersmith Hospital and he usually attends that hospital but on this occasion he was admitted to Charing Cross after an accident. There were 9 registered patients with haemophilia A, 2

[22] HCDO0000039_001
[23] HCDO0001148
[25] HCDO0001243
[27] HCDO0001312
[28] HCDO0001408

registered patients with haemophilia B, 1 registered carrier of haemophilia A, and 1 registered patient with von Willebrand's disease at the Centre.[29]

f. 1981: The Annual Returns signed by Dr E Ranasinghe reported that 7 patients with haemophilia A were treated at the Centre.[30] Of the 7 patients treated, 2 patients were registered with the Haemophilia Centre at Birmingham Queen Elizabeth Hospital and 1 patient was registered with Manchester Royal Infirmary. There were 11 registered patients with haemophilia A, 2 registered patients with haemophilia B, 1 registered carrier with haemophilia A, and 1 registered patient with von Willebrand's disease at Charing Cross.

g. 1982: The Annual Returns for 1982, signed by Dr J R Kendra, indicate that the Centre treated 4 patients with haemophilia A.[31] There were 16 registered patients with haemophilia A, 2 registered patients with haemophilia B, 1 registered carrier of haemophilia A, and 3 registered patients with von Willebrand's disease.

h. 1983: The Annual Returns for 1983, signed by Dr Haworth, indicate that the Centre treated 4 patients with haemophilia A.[32] There were 16 registered patients with haemophilia A, 2 registered patients with haemophilia B, 1 registered carrier of haemophilia A, and 3 registered patients with von Willebrand's disease.

i. 1984: The Annual Returns for 1984, signed by Dr Howarth, report that the Centre treated 4 patients with haemophilia A.[33] There were 15 registered patients with haemophilia A, 2 registered patients with haemophilia B, 1 registered carrier of haemophilia A, and 3 registered patients with von Willebrand's disease.[34]

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[29] HCDO0001408
[30] HCDO0001506
[31] HCDO0001608
[32] HCDO0001705
[33] HCDO0001800
[34] HCDO0001800

a. 1985: The Annual Returns for 1985, signed by Dr Howarth, report that the Centre treated 3 patients with haemophilia A.[35] There were 15 registered patients with haemophilia A, 2 registered patients with haemophilia B, 1 registered carrier of haemophilia A, and 4 registered patients with von Willebrand's disease.

j. 1986: The Annual Returns for 1986 signed by Dr Haworth show that 3 patients with haemophilia A were treated at the Centre.[36] 1 patient with acquired haemophilia A was treated but no blood products were used.[37] There were 15 registered patients with haemophilia A, 2 registered patients with haemophilia B, 1 registered carrier of haemophilia A, and 6 registered patients with von Willebrand's disease.[38]

14. Dr Samson recalled that the number of patients at Charing Cross Hospital decreased after 1985-6 when the Centre began referring patients to St Thomas' Hospital.[39]

15. Dr Samson referred to children being treated at Charing Cross.[40] This is supported by the documentary evidence,[41] and the evidence of Mrs C.[42] A letter dated 5 February 1985 from Dr Haworth to Dr Snape of BPL sets out the requirement for heat-treated Factor VIII at Charing Cross Hospital for 3 children.[43]

16. Data from Charing Cross Hospital was contributed by Dr Mitchell to published studies including: "*Treatment of haemophilia and related disorders in Britain and Northern Ireland during 1976-80*" by C R Rizza and Rosemary J D Spooner.[44]

Treatment policies and blood product usage

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[35] HCDO0001892
[36] HCDO0001988
[37] HCDO0001988
[38] HCDO0001988
[39] WITN4673001 para 28
[40] WITN4673001 para 37
[41] CBLA0002018
[42] WITN2687001
[43] CBLA0002018
[44] HCDO0000586

17. Mrs C described the experience of her son (S), who had severe haemophilia A, being treated at Charing Cross Hospital.[45] Her witness statement explains the treatment provided:

> "*15. S used to be treated with Cryoprecipitate. S medication was then changed to Factor VIII. In 1983 Factor VIII came in and they started training me to give it to S by injection around this time. I was first trained on an Orange, then, one brave doctor at Charing Cross hospital let me do it to him. If he wanted a blood test done he would let me put it into the tubes and that's how I first learnt*
>
> *16. S had been going to hospital on a regular basis. When this new drug came in I was told it would be easier for us as they wouldn't need to come into hospital so often as they had to with cryoprecipitate treatment. So as soon as they had a bleed I could give the treatment, which we kept in our fridge.*
>
> *17. There was no warning around Factor VIII. It seemed like a brilliant thing because you could give it to them straight away so there were no bad bleeds. We were not told where Factor VIII came from. Cryoprecipitate was fresh and didn't last long so Factor VIII was better because it was kept it in the fridge and could be administered when needed. It was easier because we didn't have to run to the hospital and when S used to have the Cryoprecipitate it was a bit of a struggle because he didn't like it when he was about 4 or 5 because so we had to roll him up in a sheet and lots of us hold him, which made it so much worse. S was a very nice child but he didn't like that treatment.*"

18. In her oral evidence to the Inquiry on 8 May 2019,[46] Mrs C added:

> "*Q. Were you given any warnings about the Factor VIII products?*
> *A No, I was just told it was an amazing thing and, in my head, it did seem that way because when we used to go to the hospital and it was cryo, you would go and you'd wait to see the doctor, then the doctor would bring the stuff down,*

[45] WITN2687001
[46] INQY1000006

then you had to wait again and the cryo used to take quite a long time to go in as well, so this was a lot better.

Q. Was there ever any discussion with you about the particular Factor VIII products that were being used or any differences between different kinds of Factor VIII products?

A. No."

19. From the available evidence, it appears that the Centre used the following blood products in the following years:

    k. 1976: A note of a phone call from Dr Mitchell in 1977 suggests that 1 patient with haemophilia was treated with 63 units of cryoprecipitate, and 1 patient with von Willebrand's disease (who was a visitor from Saudi Arabia) was treated with 9 units of cryoprecipitate.[50]

    l. 1977: To treat 2 patients with haemophilia A, the Centre used 148 bottles / around 8,400 units of cryoprecpitate.[51] To treat 1 carrier of haemophilia A, the Centre used 9 bottles of cryoprecipitate / around 550 units of cryoprecipitate.[52] To treat 1 patient with Christmas disease, the Centre used 5 bottles / around 2,800 units of NHS factor IX concentrate (Oxford).[53] No commercial concentrates were used.

    m. 1978: To treat 5 patients with haemophilia A, the Centre used 893 bottles / 62,510 units of cryoprecipitate, and 3 bottles / 1,440 units of Hyland Factor VIII (Hemofil).[54] To treat 1 patient with Christmas disease, who was not on regular home therapy, the Centre used 35 bottles / 20,960 units of NHS factor IX concentrate.[55]

[50] HCDO0000039_001
[51] HCDO0001148
[52] HCDO0001148
[53] HCDO0001148
[54] HCDO0001243
[55] HCDO0001243

n. 1979: To treat 6 patients with haemophilia A, the Centre used 584 bottles / 40,880 units of cryoprecipitate, 3 bottles / approximately 750 units of Abbott Factor VIII (Profilate), and 123 bottles / 34,770 units of Hyland Factor VIII (Hemofil).[56]

o. 1980: To treat 5 patients with haemophilia A, the Centre used 265 packs of cryoprecipitate, 83,414 units of Hyland Factor VIII (Hemofil), and 4,760 units of Immuno Factor VIII (Kryobulin) in hospital. No material was used for home treatment.[57]

p. 1981: To treat 7 patients with haemophilia A in hospital, the Centre used 465 units of cryoprecipitate, 2,600 units of NHS factor VIII concentrate, 1,634 units of Armour Factor VIII (Factorate), 15,875 units of Hyland Factor VIII (Hemofil), 2,968 units of Immuno Factor VIII (Kryobulin). For home treatment, the Centre used 5,200 units of NHS factor VIII concentrate, 3,276 units of Armour Factor VIII (Factorate), and 4,480 units of Hyland Factor VIII (Hemofil).[58]

q. 1982: To treat 4 patients with haemophilia A in hospital, the Centre used 464 units of cryoprecipitate, 26,774 units of NHS factor VIII concentrate, 72,625 units of Armour Factor VIII (Factorate), 700 units of Hyland Factor VIII (Hemofil), and 3,262 units of Immuno Factor VIII (Kryobulin). No material was used for home treatment.[59]

r. 1983: To treat 4 patients with haemophilia A in hospital, the Centre used 7,7895 units of NHS factor VIII, and 94,982 units of Armour Factor VIII (Factorate). For home treatment, the Centre used 25,530 units of NHS factor VIII concentrate, and 50,600 units of Armour Factor VIII (Factorate).[60] This roughly

[56] HCDO0001312
[57] HCDO0001408
[58] HCDO0001506
[59] HCDO0001608
[60] HCDO0001705

corresponds with the amounts recorded in a handwritten note as used by Charing Cross Hospital in the N W Thames region in 1983.[61]

s. 1984: To treat haemophilia A patients in hospital, the Centre used 6,120 units of NHS factor VIII concentrate and 3,370 units of Armour Factor VIII (Factorate). For home treatment, the Centre used 45,200 units of NHS factor VIII concentrate and 120,400 units of Armour Factor VIII (Factorate).[62]

b. 1985: To treat haemophilia A patients in hospital, the Centre used 44 bottles / 71,000 units of cryoprecipitate and 7 bottles / 1,750 units of Armour Factor VIII (Factorate). For home treatment, the Centre only used commercial concentrate, namely, 591 bottles / 147,750 units of Armour Factor VIII (Factorate).[63] A list of haemophiliacs treated within NWT RHA with NHS heat-treated factor concentrate in April 1985 shows three patients under the care of Dr Haworth at Charing Cross Hospital.[64]

t. 1986: To treat 3 haemophilia A patients in hospital, the Centre used 4,240 units of NHS factor VIII, 740 units of Alpha Factor VIII (Profilate), and 18,610 units of Armour Factor VIII (Factorate). For home treatment, the Centre used 20,470 units of NHS factor VIII concentrate, 16,280 units of Alpha Factor VIII (Profilate), and 72,660 units of Armour Factor VIII (Factorate).[65] It appears that the Centre used 49 packs of cryoprecipitate in hospital for von Willebrand's patients.[66]

20. Dr Samson could not recall how, and on what basis, decisions were made about the selection and purchase of blood products.[67] According to her evidence, the reasons or considerations for the choice of product "*would have included severity of bleeding disorder, practical considerations e.g. home therapy and patient choice*".[68] She did not

[61] HCDO0000152_003
[62] HCDO0001800
[63] HCDO0001892
[64] BPLL0010517_002
[65] HCDO0001988
[66] HCDO0001988
[67] WITN4673001 para 31
[68] WITN4673001 para 32

think there would have been any financial considerations in play given the small number of patients involved.[69] She did not recall having any involvement in making decisions about blood products.[70]

21. In relation to treatment, Dr Samson stated:

> "*At Charing Cross Hospital from 1983 onwards I know both cryoprecipitate and Factor VIII concentrate were used because I remember they were used in one specific patient, but I do not know how much and for what type of patient, as no Annual Returns are available. I am aware of at least 2 patients who were on home treatment with concentrate prior to my arrival at Charing Cross and I imaging, but cannot be sure, that as they were children they would have received NHS concentrate. I do not know if commercial concentrate was ever used.*"[71]

22. In relation to decisions as to which products to use to treat individual patients, Dr Samson said that:[72]

> "*Management would have been decided on an individual basis and would have been guided by current knowledge and expertise as transmitted to us via the UKHCDO meetings and by reading the literature. I cannot remember being personally involved in such a decision in any individual patient.*"

23. In relation to alternative treatments, Dr Samson stated that "*Both DDAVP and cryoprecipitate were available*".[73] However, DDAVP "*was only suitable for mildly affected patients with haemophilia A or those with von Willebrands disease. Cryoprecipitate was not really suitable for home treatment*".[74] From her recollection of one individual patient at Charing Cross Hospital, Dr Samson stated that "*after the problem of HIV became apparent in around 1984, DDAVP would be used in preference*

[69] WITN4673001 para 32
[70] WITN4673001 para 34
[71] WITN4673001 para 37
[72] WITN4673001 para 40
[73] WITN4673001 para 41
[74] WITN4673001 para 42

to any blood product for untreated patients with mild – moderate Haemophilia A and von Willebrands disease and then if necessary cryoprecipitate".[75] Dr Samson could not recall any specific policy regarding the use of cryoprecipitate for the treatment of patients with bleeding disorders.[76] However, "*after 1983-4 every effort would be made not to use any blood product at all if bleeding could be controlled by DDAVP*".[77] According to Dr Samson, the policy "*would have been informed by discussions with, and guidance received from UKHCDO*".[78]

24. Dr Samson could not recall any specific policy regarding home treatment. However, there were two, or possibly more, patients at Charing Cross Hospital who were already on home treatment when she started working there.[79] There may have been more patients on home treatment at Charing Cross but Dr Samson did not remember.[80]

25. Dr Samson could not recall any policies in relation to prophylactic treatment, or the use of factor concentrates for children.[81] She could not recall the extent to which people with mild or moderate bleeding disorders were treated with factor concentrates.[82]

26. Dr Samson remember one 'previously untreated patient' (PUP) "*at Charing Cross Hospital, who had severe von Willebrand's disease, and who was treated with DDAVP and cryoprecipitate*".[83] This patient (and subsequently other new patients) were referred to St Thomas' Hospital Haemophilia Centre for further management.[84]

27. Attached to a memo dated 19 April 1991, from J K Smith to Mrs G Fryers, was a list of users of products formerly issued from PFL "*mostly without charge on the*

[75] WITN4673001 para 42
[76] WITN4673001 para 43
[77] WITN4673001 para 44
[78] WITN4673001 para 45
[79] WITN4673001 para 46
[80] WITN4673001 para 46
[81] WITN4673001 para 47-48
[82] WITN4673001 para 49
[83] WITN4673001 para 113
[84] WITN4673001 para 113

understanding that clinical data would be provided".[85] Dr Samson appears on the list of users. Dr Samson explained that:[86]

> "*This memo concerns practical arrangements for obtaining so-called "minor blood products", that is, products which were not often used but which were previously manufactured by the PFL and would in future be manufactured by BPL. These could be requested by telephoning the PFL. I note that the memo is circulated to haematologists who had used antithrombin III (ATIII), Factor VII concentrate, and Factor XI concentrate.*"

28. Dr Samson could not recall how much product was provided to Charing Cross,[87] and confirmed that the product was provided free of charge.[88] She believed she used Factor VII concentrate for one patient while at Charing Cross.[89] She could not recall specifically whether patient consent was obtained for the sharing of data but stated that this would have been her normal practice.[90]

Knowledge of risk of hepatitis/HIV and response to risk

29. As Director of the Haemophilia Centre at Charing Cross, Dr Mitchell attended several meetings of UKHCDO, including on 13 November 1978,[91] and 20-21 November 1979,[92] and can therefore be taken to have knowledge of matters discussed at those meetings. He sent his apologies for the UKHCDO meeting on 24 October 1977.[93] On 9 October 1981, Dr Rarasinghe attended the UKHCDO meeting in place of Dr Mitchell on behalf of Charing Cross.[94] Dr Clarke attended on behalf of Dr Ransinghe for Charing Cross Hospital on 13 September 1982.[95]

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[85] BPLL0005964
[86] WITN4673001 para 120
[87] WITN4673001 para 121
[88] WITN4673001 para 122
[89] WITN4673001 para 123
[90] WITN4673001 para 125
[91] HSOC0010549
[92] CBLA0001028
[93] PRSE0001002
[94] CBLA0001464
[95] CBLA0001619

30. Prior to moving to Charing Cross, Dr Samson regularly attended UKHCDO meetings on behalf of Northwick Park Hospital, including on 24 October 1977,[96] 13 November 1978,[97] 21 November 1979,[98] 9 October 1981,[99] 13 September 1982,[100] and 27 September 1984.[101] She can therefore be taken to have knowledge of the matters discussed at those meetings. Dr Samson acknowledged that the minutes of the UKHCDO meeting in 1984 show that she attended the meeting,[102] but did not indicate whether she attended as Director or in place or someone else.[103] Dr Samson did not recall the decision at the meeting on 27 September 1984 but knew that some patients at Charing Cross were subsequently tested for HIV.[104]

31. In respect of the UKHCDO meeting in October 1985,[105] Dr Samson pointed out the minutes show that Dr Haworth again attended the meeting but did not state that Dr Samson gave her apologies or that Dr Haworth was attending in Dr Samson's place suggesting that Dr Haworth was attending as Director.[106]

32. It is recorded in the minutes that Dr Haworth attended UKHCDO meetings on 21 October 1985,[107] and 17 March 1986.[108] Dr Desai attended on behalf of Dr Haworth for Charing Cross Hospital on 17 October 1983.[109]

33. It does not appear that Dr Mitchell, Dr Samson or Dr Haworth contributed to the Glasgow Symposium on Unresolved problems in Haemophilia in 1980,[110] or the Manchester Symposium on Current Topics in Haemophilia in 1982.[111]

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[96] PRSE0001002
[97] HSOC0010549
[98] CBLA0001028
[99] CBLA0001464
[100] CBLA0001619
[101] PRSE0003659
[102] PRSE0003659
[103] WITN4673001 para 21
[104] WITN4673001 para 82
[105] PRSE0001638
[106] WITN4673001 para 21
[107] PRSE0001638
[108] PRSE0001688
[109] PRSE0004440
[110] RLIT0001242
[111] DHSC0002221_003

34. By letter dated 7 January 1985 from Peter Kernoff, of the Royal Free Hospital, Dr Samson was invited on behalf of Charing Cross Hospital to a meeting of Directors of Haemophilia Centres supplied by NBTS Edgware arranged for 18 January 1985 to discuss the problems related to AIDS/HTLVIII in Haemophiliacs.[112] Dr Samson did not have a copy of the minutes of the meeting. She did not know if she attended the meeting and did not recall the discussion.[113]

35. In relation to the knowledge of risk of infection associated with blood and/or blood products, Dr Samson described:[114]

> "*This all changed after I moved to Charing Cross Hospital when in 1984 it became evident that HIV could be transmitted by blood products, particularly products prepared from pooled plasma, and subsequently that commercial products were associated with a higher risk than NHS products. The sources of my knowledge were information received from UKHCDO meetings, together with published articles in journals such as the BMJ, the Lancet, and the New England Journal of Medicine. Of course the internet did not exist and communication was slow. I believe that the UKHCDO meeting in 1984 (PRSE0003659) was the first meeting at which the role of HTLV3 in AIDS in haemophiliacs was discussed, and I think I would not have known about it before that meeting.*"

36. Dr Samson noted that it "*was known by 1980 that the risk of hepatitis B was greater with commercial concentrate than with NHS blood product*", and that they therefore would "*have suspected that the risk of other infections would be greater with commercial concentrate*". It was Dr Samson's memory that "*the risk of HIV was demonstrated to be greater in commercially supplied products around the end of 1984 after serological testing became available*".[115] Dr Samson stated that she "*did not know in 1983 that HIV could be transmitted by blood and blood products*" but that she

[112] CBLA0001975. The Directors of the following Haemophilia Centres supplied by NBTS Edgware were invited to the meeting: GOSH, UCH, Luton & Dunstable, Ashford, Bedford, Edgware, Middlesex, Hillingdon, Lister (Stevenage), and Charing Cross.
[113] WITN4673001 para 78
[114] WITN4673001 para 55
[115] WITN4673001 para 57-58

"*became aware of this sometime during 1984*".[116] In particular, "*certainly it was discussed at the UKHCDO meeting in 1984*".[117]

37. In relation to the risk of hepatitis C, Dr Samson stated:[118]

> "*…when I began working at Charing Cross, it was known that both hepatitis B and non-A non-B hepatitis could be transmitted by blood products. UK blood donors were already screened for hepatitis B, and at that time it was not appreciated that non-A non-B hepatitis could lead to chronic liver disease. Knowledge regarding the risks of non-A non-B hepatitis grew slowly during the 1980s and I cannot say with any certainty when I became aware that there was a significant risk of serious liver disease.*"

38. In response to the risk of hepatitis C, Dr Samson stated that:[119]

> "*As I remember, we would, wherever possible*
>
> - *avoid the use of blood products*
> - *use cryoprecipitate in preference to concentrate*
> - *use heat treated concentrate (after this became available)*
> - *choose NHS over commercial concentrate*"

Testing patients for HTLVIII and informing them of diagnosis

39. Dr Samson gave evidence that:[120]

> "*No patients were tested without consent as far as I am aware. It was hospital policy at Charing Cross that no patient whatever the diagnosis should be tested for HIV without giving their consent. However, I do not remember how consent was obtained and recorded.*"

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[116] WITN4673001 para 63
[117] WITN4673001 para 64
[118] WITN4673001 para 59
[119] WITN4673001 para 61
[120] WITN4673001 para 111

40. A different account was given in the evidence of Mrs C:[121]

> *"45. I never gave my consent for S to be tested for HIV or HCV and I didn't know they were going to test S for HIV. I only found out that he had been infected from his dentist at Charing Cross hospital when he needed a tooth extracted when I asked why the dentist was gowned up in a head to toe suit."*

41. Mrs C explained how she found out that her son, then aged 7, had been infected with HIV:[122]

> *"18. In 1984-95 when S was 7 years old, he had a loose milk tooth, which was causing him problems because it wouldn't come out due to a haematoma swelling caused by his haemophilia. One of the doctors, (I cannot recall her name), from the haematology department (there was no haemophilia unit at Charing Cross hospital then) said she would call the dentist to take a look. So I took S to Charing Cross Hospital to see the specialist dentist there.*
>
> *19. The dentist kept trying to give reasons not to come down and said the tooth would come out eventually. Where it was so wobbly he couldn't eat properly and because the gum was so swollen it wouldn't allow the tooth to come out.*
>
> *20. I was frightened and concerned because the dentist came in wearing something that I can only describe as 'space suit' she looked like she was going into outer space. She came covered up in a mask and a suit and it frightened me because I didn't know what was going on. When I tried to show her his tooth I got the impression she backed away and she wouldn't go near S or look into his mouth. I felt scared when she did this and I knew something was not right. S was a little 7 year old boy, he must have wondered what was going on, seeing her dressed like that. The doctor told the dentist to take the tooth out so she took S tooth out accompanied by a nurse and it came out in a matter of sections.*

[121] WITN2687001
[122] WITN2687001

21. I asked the doctor what was going on and she took me into a room and told me that both my boys had been tested positive for HIV. I was given a blue plastic bottle and plastic gloves. She just said that in future, when using the Factor VIII that I should use the bottle and the gloves and put any needles in the bottle. She told me to wear gloves. I didn't really know what this meant.

22. I did not even know what HIV was. I didn't know what the diagnosis meant and how it might affect S in the long term. I told the nurse had a baby at home, my daughter was… years old at the time and I asked her for advice on what I should do, but her only response was that she didn't know. She left me to go home on my own.

23. I wasn't aware that they were being tested. I had no knowledge of them testing my boys before then and I didn't know who had authorised the tests. She said the tests had come back positive. They didn't tell us when or why they were done. I asked her what she meant. When the doctor was telling me what the problem was I was thinking about all my other children and I asked the doctor what it meant and what I should do. Her response was that she didn't know.

24. I was not given any advice by the hospital at all and I was not given any other advice about what I should do next. I was never given any leaflets and I never received anything in writing from the hospital to confirm the HIV diagnosis. I do not feel that adequate information was ever given to me about HIV and no attempt was made to help me to understand and manage the infection. I was never given any advice about risk to my family. I was given no advice whatsoever other than the bottle and using gloves when injecting Factor VIII."

42. Mrs C recounted these events in her oral evidence to the Inquiry on 8 May 2019:[123]

[123] INQY1000006

"*She said that it would fall out eventually. So I said to her it wouldn't because this had been going on for a couple of weeks. I said his gums is too -- I was trying to show it to her but she didn't want to come close and she certainly didn't want to put her hands by his mouth, so then the doctor said to her that they needed to take it out. It wouldn't take -- because it was so loose so that she took him away, and I said to the doctor what is going on because I didn't understand and she took me in a room. That is when she give me blue plastic bottle and a box of gloves and she told me that the boys had been tested for HIV. I didn't know what she was talking about and she said that they'd tested positive and in future when I give them their Factor VIII I had to wear gloves and use the blue plastic bottle to put them in.*

I said to her, because I'd seen how the dentist was reacting, "but what about my other children", and she just said to me she didn't know and then sent me home and that's how it was."

"*Q. Did the doctor tell you what HIV was?*

A. No.

Q. Did the doctor tell you anything about the connection between HIV and AIDS?

A. No, she didn't but then later on in them days there was a lot coming on on the news but then they were saying it was drug takers, gay people that were getting it, and it was horrible actually at that time. It was really horrible. But to be honest, I don't know, I think I shut it out of my mind. I just didn't -- these two little boys, I just didn't accept what they were saying."

"*Q. And you weren't I think given any information about what the longer term prognosis would be for either of them?*

A. No.

Q. You were particularly concerned for a whole range of reasons but you had a baby at home.

A. Yes.

Q. And you asked about the risks of infection and what you should do in relation to any of your other children and the only answer you got was that --

A. That she didn't know.

Q. Did you know that your boys were going to be tested for HIV?

A. No.

Q. Did you ever receive anything in writing about the diagnosis of HIV from the hospital after that?

A. No.

Q. So it was a bottle, gloves and "I don't know".

A. Yes..."

43. Mrs C further explained what happened in the aftermath of being told that her sons had been infected with HIV:[124]

"*26. A few days later my GP showed up at my front door with a lady (I am not sure who she was). She said that they had been told by Charing Cross Hospital that they had to inform S school that S had contracted HIV. I didn't understand why they needed to inform the school but I never noticed the school treat either myself, or S any differently after this, the school never said anything to me about it. I didn't notice any change by my GP in their treatment of us either but we generally always went to the hospital because of the specialist haemophilia department there if there was a problem.*

27. Even though they told us about the HIV we didn't realise how bad it was. In 1984-95 a lot of horrible things were going on in the news and HIV was reported as a gay disease. A week later my sister rang me about a newspaper article her neighbour had had seen, (I think in the Daily Star) about 3 haemophiliac children with AIDS who were dying in Charing Cross hospital. I knew of only 3 haemophiliac children in Charing Cross hospital, my 2 sons and another boy. I told the doctor at Charing Cross about the newspaper article and she said it wasn't AIDS it was HIV and when they found out who had told the press that person would be in trouble. I was never told of the outcome of this or who had informed the papers. I would think a copy of this article would still be available.

[124] WITN2687001

28. Also, a man who... worked with in... told him that his father had been at Charing Cross hospital and also heard about the 3 boys and that 2 of them were brothers with AIDS.... Said that he must have been talking about our 2 boys and the other boy at Charing Cross. We hadn't put AIDS and HIV together until then. My husband and I didn't really associate HIV with AIDS, so it came as a shock. We thought what is it? It was a pretty traumatic time.

29. Although the hospital was telling me these things I didn't seriously feel anything was going to happen. There were things in the papers about AIDS but I didn't think it had anything to do with haemophilia. I though it was to do with gay people. S HIV infection developed into AIDS but we didn't realise.

30. S continued to attend his usual check ups. S was transferred to St Thomas Hospital in 1986 as the hospital had a specialist unit for haemophilia and it was felt that he could be better looked after there…"

44. In her oral evidence to the Inquiry on 8 May 2019,[125] Mrs C was shown a copy of a newspaper article from the Gazette from around the time referred to.[126] By reference to the newspaper article, Mrs C elaborated on what information was provided to her at the time:

"*Q... So it talks about three boys with a deadly virus in hospital. It says the children do not necessarily have the killer disease AIDS but experts say that about 1 in 10 people found with the virus later develop the disease and that because of their low resistance to infections haemophiliacs stand a higher than average chance of catching the disease.*
Had you been told any of that by the hospital?
A. No.
Q. The higher chance of HIV turning to AIDS because of --
A. I've only just -- when they sent me this paper, I think it was last week, I only saw it then. So

[125] INQY1000006
[126] WITN2687006

I wasn't aware of it, no.

Q. The hospital hadn't told you that?

A. No.

Q. Then if we just read on down it says:

"The parents of the children know of the risks to their children."

Had the risks ever been explained to you?

A. No.

Q. Then a spokesman for the Northwest Thames Regional Health Authority says:

"They have been informed about the positive tests. They are being counselled by senior doctors and the three boys are being monitored very closely."

Were you counselled by senior doctors?

A. No, I was not.

Q. Do you recall whether the boys were being closely monitored at the hospital?

A. Well, we used to go to -- we actually did go to the hospital a lot because we used to go and have their treatment done there so we was at the hospital a lot, but I don't know if they was being monitored closely for this."

Testing for HCV

45. Dr Samson did not recall when testing began and whether any haemophilia patients were tested for HCV.[127] She stated that those at greatest risk had already been referred elsewhere.[128] She was not aware of anyone who was tested during the time they were treated at Charing Cross.[129]

46. Mrs C later found out, after S died, that he had also been infected with hepatitis C as well as HIV.[130] S was tested for hepatitis without Mrs C's knowledge although this appears to have been at St Thomas' Hospital after he was referred by Charing Cross. Mrs C was not told of his diagnosis whilst S was alive nor that he was tested for it.[131]

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[127] WITN4673001 para 101
[128] WITN4673001 para 101
[129] WITN4673001 para 104
[130] WITN2687001
[131] WITN2687001 paras 44, 46

Numbers infected with hepatitis C / HIV

47. The Inquiry does not have information currently as to the precise numbers of patients infected with HIV or hepatitis C in consequence of their treatment for their haemophilia care at Charing Cross Hospital. The provisional UKHCDO data received by the Inquiry does not contain information regarding Charing Cross Hospital.[132]

48. Dr Samson specifically recalled 2 children who were infected with HIV:[133]

> "*I remember that at Charing Cross Hospital there were two children on home treatment who were treated and found to be HIV positive. I was not personally involved in their care. I do not remember if any other patients were tested, but I am not aware of any other patients who were HIV positive.*"

49. She believed this would have been in late 1984 or early 1985.[134] The two infected patients continued to be treated with factor concentrates:[135]

> "*I am aware that the 2 patients at Charing Cross Hospital who were already HIV-positive continued to receive concentrate. I do not know what type of concentrate and whether this changed. I do not recall whether there were any other patients receiving concentrate, and if so, what decision was taken in these patients*."

Treatment arrangements for HIV and HCV patients

50. Dr Samson reiterated that the two children infected with HIV were transferred to the Haemophilia Centre at St Thomas' Hospital. She did not remember any other patients with HIV but if there were any such patients, she believed "*they would also have been transferred to St Thomas' or possibly the Royal Free Hospital. This was so that they could benefit from the expertise and support available at a larger Centre.*"[136] Dr

[132] INQY0000250
[133] WITN4673001 para 65
[134] WITN4673001 para 88
[135] WITN4673001 para 69
[136] WITN4673001 para 129

Samson did not recall any patients with hepatitis B or hepatitis C but said they would have been referred to the consultant hepatologist for further management.[137]

51. This is consistent with the evidence of Mrs C whose son, S, was transferred to St Thomas' Hospital in 1986 after he tested positive for HIV.[138]

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June 2021

[137] WITN4673001 paras 134-135
[138] WITN2687001 para 30