Witness Name: Sarah Bowman
Statement No.: WITN0636001
Exhibits: None
Dated: 10 . 11 2020

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF SARAH BOWMAN

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 27 August 2019.

I, Sarah Bowman, will say as follows: -

Section 1: Introduction

1. My name is Sarah Bowman. My home address is known to the Inquiry. My date of birth is GRO:C 1969. My professional qualifications are: General Nursing (Level 1), English National Board for Nursing, Midwifery and Health Visiting (ENB) 1991 and Diploma in Social Work, Central Council for Education And Training In Social Work (CCETSW) 1996.

2. My work history is:

   a. Registered General Nurse, Monsall Infectious Diseases Hospital, Manchester. Employer: North Manchester General Hospital, 1991-1992. D Grade Staff Nurse providing care as specified in Contract. Patient Cohort: People diagnosed with HIV;

b. Registered General Nurse, Ruchill Infectious Diseases Hospital, Glasgow. Employer: Stobhill General Hospital, 1992-1995. D Grade Staff Nurse (Bank) providing care as specified in Contract. Patient Cohort: People diagnosed with HIV;

c. Social Worker, Level 1, Morecambe Adult Community Team, Lancashire City Council. 1996-1998;

d. Social Worker, Level 1, Children's Social Work Service, Ryegate Children's Assessment Centre, Sheffield City Council, 2000-2003;

e. Social Worker, Level 2, Northern General Hospital, Adult Discharge Team, Sheffield City Council, 2003-2006;

f. Social Worker, Level 2, Northern General Hospital, AICS Team, Sheffield City Council, 2006-2009;

g. Social Worker, Level 2, Royal Hallamshire Hospital, Specialist Haemophilia Social Worker, Sheffield City Council. 2009-present day.

3. I have not been a member past or present of any committees or groups relevant to the Inquiry's Terms of Reference.

4. I have not provided any evidence or been involved in any other inquiries, investigations, criminal or civil litigation in relation to Human Immunodeficiency Virus ("HIV") and/or hepatitis B Virus ("HBV") and/or Hepatitis C virus ("HCV") infections in blood and blood products.

Section 2: Role as a Haemophilia Social Worker

5. I currently work 18.5 hrs a week as a Haemophilia Social Worker in a Regional Haemophilia Comprehensive Care Centre based in a hospital. This is primarily an Adult Service with a link to the Children's Hospital via Transition Services and to Obstetric Services when required.

6. The post is paid for by NHS but my contract lies with the Local Authority ('LA").

7. I cover approximately 1,378 people with genetic bleeding disorders over a wide geographical area. My post crosses health and LA boundaries requiring skills in negotiation, communication and effective planning. I provide a therapeutic approach to care using the Social Model of Care. I have built up an in-depth knowledge of Haemophilia, awareness of the cultural assumptions, differing beliefs and approaches and understand the physical and psychological impact of having a bleeding disorder and in particular blood borne viruses as well as thorough knowledge of the history and situation in regard to the (NHS) Contaminated Blood Issue. My remit is to provide a specialist, more enhanced service to people who may not be eligible for Local Authority Services, particularly those individuals and families who have been affected by the contaminated blood situation, especially those who contracted HIV and/or HCV as a result or have experienced bereavement.

8. I work as a core member of the Centre's multi-disciplinary team. My tasks include case management, crisis intervention, duty, safeguarding, management and support of vulnerable adults. There is an emphasis on providing emotional support using initial counselling approaches such as Solution Focused Therapy.

9. My goal is to maximise engagement with our service by addressing barriers to this that people may experience due to issues such as anxiety, depression, substance misuse, domestic violence and so on. I provide specialist advocacy for individuals through liaison, education and other support across multi agency teams such as housing, community health, education, employments, courts, police etc, providing professional reports, documentation and attending meetings as representative of the Haemophilia Centre for an individual and/or family.

10. I work closely with social service colleagues and teams such as Mental Health, Children and Young People and Transition to ensure a whole family approach. Part of my role is to assess and identify appropriate resources that may be of assistance to individuals, their families and carers and to assist them in accessing support.

11. As ongoing service development, I provide (and review) Transition Services to encourage lifelong engagement with the Centre prioritising physical and mental health, following lifelong transition not just in adolescence.

12. An increasing amount of my work has been accessing benefits, grants and government payment, especially for people who contracted HIV and HCV via

contaminated NHS blood products. This has resulted in individuals and their families requiring ongoing counselling and support as well as advocacy on their behalf to Government and Health Departments and educating fellow health colleagues regarding psychological effects of trauma and stigma.

13. My role as Specialist Worker means I also undertake training for other professionals in health, social care, education etc which includes speaking at professional conferences, at study days, 'patient' and Charity events.

14. In 2017 I founded and was Chair of the Haemophilia Social Work Association (UK) until October 2019.

15. Since 2017, I have been the national Social Work representative of the UKHCDO Peer Review Working Party for UK Haemophilia Centres and undertaken Peer Review.

Numbers and role of Haemophilia Social Workers across UK and development over time

16. To my knowledge there are currently seven Haemophilia Social Workers in the UK and there are an additional two Haematology Social Workers who have some dedicated hours for Haemophilia, this is broken down as:

    - Sheffield: 18.5 hours Adult Regional Service
    - London: 18.5 hours Adult Service (shared Sickle Cell)
    - Cardiff: 18.5 hours Adult and 18.5 Paediatric Regional Service
    - Belfast: 18.5 hours Paediatrics, 18.5 hours Adult (x1 Worker) Regional Service
    - Newcastle: 20 hours Adult and Paediatric Regional Service
    - Leeds: 18.5 hours Paediatric Regional Service
    - Leeds: 10 hours Adults (Haematology Social Worker) Regional Service
    - Manchester: Full time, shared Malignant Haematology, Regional Service
    - Birmingham: has funding available for full time Social Worker but has been an 'empty' post for some years.
    - Glasgow: had funding for a Social Worker but this funding stream has ended.

17. Nationally, the role and remit of the Haemophilia Social Workers broadly mirrors my own. Those workers who have other responsibilities in addition to Haemophilia are

required to balance their duties with the demands of other Haematology service users allocated to them and prioritise accordingly.

18. I am unclear as to how many Haemophilia posts there were in the past but my understanding is that the number of posts have reduced over the years.

19. The Haemophilia Social Work Association (UK) was formed in 2017. It is only since this time that I have been able to collate information about the work we undertake. There is no formal job plan nationally for Haemophilia Social Worker.

20. The Haemophilia Social Work role has developed over the years due to increasing legal requirements, government policy and the needs of the local councils, hospital trusts and Haemophilia Centres. There have been changes and developments in legislation, for example The Care Act, Mental Capacity Act, Safeguarding requirements and working with Vulnerable Adults, this has resulted in a significant increase in statutory work having an impact on any additional work we can take on.

21. There have been changes in Benefit legislation which have had a direct impact on Service Users. The change from Disability Living Allowance (lifetime awards) to Personal Independent Payments and the frequent reviews of eligibility. The change from Incapacity Allowance to Employment and Support Allowance then Universal Credit and the changes in associated payment has had an impact on our workload, this coincided with a reduction in the availability of workers able to assist in the community (ie Citizens Advice Bureau, access to Legal Aid). I would say this is now the predominant work we undertake.

22. My belief is that there has been a significant increase in demand for Mental Health Services which has not been reflected in increased provision in the Community or in access to specialist services. Again, we have found ourselves picking up high level, long term cases that would have been managed differently when alternative provision was available.

23. My view is that the reduction in services in the community setting overall has meant we are providing more generic services to support people to manage at home which may not be directly connected to a bleeding disorder and because our cohort of people are lifelong we are not able to refer on as we would have in the past. In effect, we are often now the main resource rather than part of a multi-agency team.

24. There has been a very welcome rise in life expectancy in the Haemophilia community. We now have an ageing population which we didn't have when I first started in this area. This has affected workloads due to managing additional disability and co-morbidities. It has required an increase in co-working and co-ordination of services locally and across regions with more input needed for older people. Again, we are often the sole resource.

25. There has been an increase in acknowledgement of the specific needs of women who bleed and the services they require with the need for development, support and advocacy locally and regionally.

26. An increase in people coming to live in the UK from a wide range of countries has meant there are more interventions with asylum seekers, refugees, people whose first language is not English. For example, people with severe disability caused by previous non-availability of treatment, people who have experienced high levels of trauma, with additional mental health issues and people who are isolated and unsupported. This has meant a growing change and increase in people using the Haemophilia Service and it brings an increased requirement for intervention that we need to prioritise within our working hours.

27. My sense is that there been an increase in prescription and non-prescription drug use and substance misuse generally. This has brought additional issues such as non-engagement and this has a direct impact on our workload, especially working with young people in transition, locally and regionally.

28. All these issues impact on Haemophilia Social Worker's caseloads and our ability to offer services, particularly counselling and long-term emotional support, to people infected and affected by the infected blood issue.

29. I understand from colleagues nationally in Haemophilia Services that, in the past, the Haemophilia Social workers were predominantly in post to assist and support those people who were infected and affected by the Infected Blood situation, this was the main remit. This is especially pertinent when these infected and affected people require additional services as they are ageing, living with the viruses long term and having increasing psychological and physical needs.

Adequate Counselling/psychological support available to infected and affected people past and present

30. I am not able to comment on the adequacy of services provided in the UK prior to 2017. I am aware that some Haemophilia Comprehensive Care Centre have access to or employ directly Clinical Psychology. I cannot give numbers. The Cardiff and Newcastle Centres have access to Haemophilia Psychologists and Psychology is available in Edinburgh which also has some cover in Glasgow.

31. Separate to Psychology provided by some Centres, my view is people infected or affected currently or in the past 10 years did not have access to consistent, dedicated and specialist counselling in regard to the issue of Infected Blood. I am aware that funding could be accessed via the Skipton Fund or Macfarlane trust to access counselling services.

32. In Sheffield, those infected with HIV have had access to the general HIV Psychologist (ie not particular to contaminated blood issue). Family members do not have access. We have a Haematology Psychologist available for some hours weekly covering all Haematology services and we very have limited access to this service.

33. As far as I am aware, Haemophilia Nurses, particularly those working at the height of the diagnosis of people who had received infected blood undertook the bulk of the counselling in addition to their duties, for example the Haemophilia Nurse in Sheffield was sent on a Counselling Course to help her manage the counselling requirements.

34. It has been part of the national role of Haemophilia focussed Social Work to offer some limited counselling. This is dependent on qualification and competency. A Social Worker role is not the same role as Counsellor. For specific or long-term counselling we have usually approached the Trusts and Schemes for funding assistance to access private services (again not specialist to their infected status) or referred to GP service to request further referral to Psychology or Community Mental Health Services.

35. The present position is as above. My view is that Community Mental Health Services are sometimes difficult to access and the GP Improving Access to Psychological Therapies (IAPT) is not specific to the specialist counselling required in this cohort. It

can be difficult to identify counselling for this service group and they have traditionally been reluctant to access formal counselling when offered.

Section 3: Haemophilia Social Work Association (UK)

36. My role at HSWA (UK) was Chairperson from 2017 until 2019 when the role of chair 'rotated' to Karen Gray.

37. I am still part of this organisation; HSWA (UK) was set up in 2017.

38. HSWA (UK) was set up as I had come to realise there was very little Haemophilia Social Work support in the UK (not in Scotland) and that this was not standardised. We were working in isolation with no peer support, ongoing education, development or links and I did not feel this was an effective way to work with or advocate for our Service Users nationally.

39. The aim was to bring the national Haemophilia Social Workers together, to look at what service we each provided then formulate national standards and a defined role for Haemophilia Social Work so we could ensure Haemophilia Centres knew the service existed, what we did and that they could then try and petition their Trusts to invest in these services to support service users.

40. We had identified that the Social Work role had been written out of the standards for Core Group Multi-Disciplinary Teams as a requirement for optimal functioning of Centres, we requested participation in the UKHCDO Peer Review Working Party to address this, we felt this was vital in order to start to address service users holistic needs in an environment that was predominantly concerned with the Medical Model of care.

41. The original and primary function is to try to address the national inequality of service provision for people with Haemophilia by highlighting what we can offer and how we can contribute to achieving optimal physical and mental health outcomes and advocate for Service Users. We have attempted to do this in a variety of ways, speaking at conference, undertaking Haemophilia Centre reviews, ensuring the role is written back into core MDT participation, advocating for service users nationally i.e.

with EIBSS, DWP as a group and locally within our local services, taking best practice from our group and trying to develop our learning and support structures.

Section 4: Impact on people infected and affected

42. My knowledge of the impact on people infected and affected by infection comes in particular from undertaking the England Infected Blood Support Scheme ("EIBSS") applications from October 2017, the past 10 years in my work, speaking to service users and through discussion with Haemophilia Social Work colleagues in the Haemophilia Social Work Association UK.

43. A consistent experience while undertaking EIBSS applications for those infected was that they described their quality of life as being poor though most people felt 'lucky to be alive'.

44. They felt that they may be observed by others to be leading 'normal' lives but that this was 'superficial' and that due to the level of secrecy around their infection and their functioning it meant many felt they lived 'half' lives They felt 'hidden away' and 'living in secret' and, as such, they weren't able to function or engage like other people in society and this affected their quality of life.

45. Most people said that they had been told they had 'cleared' the Hepatitis C virus but they didn't associate this with being 'cured'. Many were anxious that the virus would re-occur, or was still affecting them in a way that was not yet known. They didn't trust the medical diagnosis given and this impacted negatively on their day to day quality of life.

46. People spoke in detail during the EIBSS process about private relationships and family life.

47. People Infected felt they put loved ones 'at risk'. They were a' burden' and felt 'guilty' about speaking to partners/parents about their feelings, especially over the decades. They felt they couldn't 'open up' about their worries as they didn't want to worry loved ones. Most people interviewed had never discussed their feelings since diagnosis and the EIBSS process was the first time many infected people had spoken about what had happened to them, how they felt and how they had managed.

48. They felt they 'limited the lives' of their partners as they were physically unable to do things due to exhaustion/illness like dancing, rambling, socialising etc.

49. They felt they were 'mentally draining' due to being depressed, having feelings of 'isolation' they felt they isolated their partners too, they often didn't want to mix or socialise with others, they didn't feel comfortable due to feeling 'different' or felt that people would know there was something wrong. Many people had been left by partners or were afraid of being left or 'rejected' again. Some people had chosen not to embark on relationships since diagnosis due to negative experiences from people they had loved.

50. Anxiety about children was a huge issue for those infected. Many had decided not to tell their children or had decided not to have children. They described feeling 'disconnected' and that sometimes this had been done purposefully in case they died. Those infected were often extremely anxious about infection and passing virus onto their children. This was also an issue for infected grandparents as well as parents.

51. People described having been 'emotionally shutdown', as parents, that they hadn't been the 'dad they should have been' or that they hadn't done the physical, emotional or financial things they should have done and were left feeling guilty and regretful about this.

52. Relationships with parents were often difficult. There were many who had been told by parents of their status, told to keep it secret and it was never discussed again. There were other parents who very much restricted the infected children and their contacts within and outside the family and as adults/adolescents many people infected did not feel able to speak openly to parents about their infection as they didn't want to worry them, they also didn't feel able to talk about their feelings in regard to having boyfriends/girlfriends as they were frightened of parents' reactions.

53. Infected children tended to lead very sheltered lives. They didn't join regular activities such as clubs, scouts, and youth clubs as they didn't want to draw attention to themselves. This limited their friendships and opportunities. They did not engage with peers, embark on relationships, they reported feeling frightened of being found out and the consequences of this.

54. In relation to the siblings of those infected there was discussion around the perceived resentments that siblings felt towards them, that they were treated differently, either more favourably, then siblings felt jealous or negatively then they felt rejected and unloved, they felt less valued and this often was often again because their infected status was secret. These difficult relationships often carried into adulthood in their relationships with family, partners, children and peers.

55. There were also particular issues for those who had infected siblings, cousins, other immediate family, especially for those who had had loved ones who had died, this was not uncommon and, again, negatively impacted on well-being with feelings of guilt, survivors' guilt and feelings of loss being common.

56. People infected described how, while growing up, they were treated within nuclear and extended families. Many described feeling 'dirty' or 'unclean'. They felt 'isolated' within their families, often due to secrecy but also, on a practical level, having separate crockery, cutlery, towels, bedding etc. This was also replicated in school and damaged relationships with peers, reducing confidence and causing a lack of self-esteem and self-worth. This often carried on into adulthood and could be replicated at university or in the workplace.

57. Partners of infected people often spoke about the anger they felt about how their infected partners had been treated when asked at the EIBSS appointments. In particular how they'd been told of their status and lack of information. The lack of support and financial hardships, as well as the effects on their relationships, physical and psychological wellbeing, were a particular grievance.

58. In my experience, the partners who'd stayed during and following diagnosis were the individuals with less anger directed outwards because they had seen the whole process from the start.

59. Anger was often directed at practices in the more general hospitals in the 1980s where staff were less well informed about virus and cross contamination and, as a result, sometimes made infected people feel 'degraded'. GP and Dentist attitudes made people very wary in local community settings. There were issues about broken confidentiality and being made to feel 'dirty' was a common feeling caused by professionals' attitudes to them.

60. There had been very little if any counselling given to affected people at that time. Generally, partners were very protective and supportive and became part of the secrecy around infected status.

61. During the EIBSS process I observed how much was emotionally repressed regarding diagnosis. This unfortunately had sometimes resulted in prescription and non-prescription drug and/or alcohol misuse as a way of 'self-prescribing' and blocking out emotions that people couldn't face dealing with alone.

Access to Education, work etc

62. On diagnosis, people described feeling as if they had been given a 'death sentence' and many didn't see the point in continuing or advancing in education or employment. Some gave up on work or education due to mental health issues, exhaustion or other health problems. Many, in my experience, retired early.

63. Some people lost jobs due to the association in employers and colleagues minds between Haemophilia and infected blood even though most kept their diagnosis secret. The issue was often in the news. People described anxiety, paranoia, stress and secrecy associated with work.

64. Many people's ability to work or achieve in education was affected by the awful treatments for HCV and the physical and psychological side effects caused by the drugs available. This was in addition to the difficulties caused by Haemophilia itself necessitating time off work to manage bleeds, treatment etc. Many felt they let work and colleagues down and, as a result, sometimes went to work while ill thus making things worse.

65. Some individuals actively put off HCV treatment due to side effects as they couldn't afford time off work, even when liver cirrhosis started. This was particularly problematic if people were self-employed or were carers. They had no extra money to cover their absence due to sickness.

66. Schooling presented a number of problems for those diagnosed while of school age. Behaviours from home were mirrored at school with separate crockery and cutlery being common. In addition to this, hypervigilance of teachers and other staff effectively marked infected people out thus having a knock-on effect on making

friends which was already difficult due to the levels of secrecy around non-disclosure of an infected status. Many of the children themselves felt stressed about infecting others at school.

67. In addition to their infection diagnosis, children also had to manage their haemophilia, bleeds and treatments for this together with the HCV virus. This could negatively affect educational achievement and was mirrored for others at university.

68. Over the years I have sometimes given advice to people with Haemophilia who want to apply for mortgages. Attitudes have improved over the years but infected people find it very stressful to have to discuss their status with other people. There are real fears about disclosing information and confidentiality, often to people who live in their own communities.

Any difficulties encountered by people who were infected and affected to obtain financial support from the Trusts and Schemes, EIBSS, and the welfare benefits system

69. I am only able to comment on areas that are covered by a Haemophilia Social Work service nationally and/or seen at the Sheffield Haemophilia Centre.

70. Infected people seem to be aware of the schemes and trusts though access can be dependent on their confidence and the level of support they receive while applying. The repeated complaint is that people feel they are made to beg for assistance and any extras they may need. They find this degrading and this causes anger about the systems.

71. Most infected people who 'spontaneously' cleared HCV did not qualify for the Stage 1 Skipton Fund payment and, as a result, have not benefited from any payments. They are now not eligible for the Special Category Mechanism through EIBSS. Nationally, this is felt to be particularly unjust and has caused a lot of anger and resentment among people who received contaminated blood and those affected many of whom have experienced years of psychological distress as a result of their experiences.

72. Individuals have found the Welfare Benefits system to be increasingly challenging to successfully navigate over the past ten years. My experience is that this causes severe levels of ongoing stress, anxiety and depression.

73. Historically, Disability Living Allowance was the main benefit people infected with virus were in receipt of and they were often given 'Lifetime' awards. With a change in system to Personal Independence Payment (PIP) benefit this changed and everyone was then reassessed, having to re-prove their level of disability, difficulties managing day to day living and their mental health issues.

74. This is especially challenging for infected people used to keeping their status secret. In the Sheffield Haemophilia centre we complete the application together and I gather evidence to forward with a written report of my own. We are always allocated a medical assessment to attend. Assessors tend not to have had chance to read any of the documentation and they then ask all the same questions again. My sense is that this simply seems to be an attempt to catch people out.

75. This is extremely distressing for a cohort of people trying to maintain their confidentiality. It feels to them that they are begging for support, that they are not believed and they fear losing the support which is crucial to their quality of life. In my experience, on many occasions, PIP has been downgraded or stopped and we have had to appeal this thus prolonging the process of application and reassessment. This is perceived as oppressive and unjust.

76. Incapacity Benefit used to be the benefit given to those unable to work. This was then changed to Employment and Support Allowance (ESA) and has now changed again to Universal Credit. It has changed from a lifetime award and thus, again, everyone was reassessed and had to go through exactly the same process for PIP.

77. Both of these benefits are frequently reassessed. Initially PIP and ESA were reassessed yearly. Only recently are awards set for longer periods. Frequently, individuals would successfully navigate the appeal process only to be called for reassessment a few months later. The process has therefore caused high levels of stress, anxiety and, in my view, a major increase in mental health issues for people infected and affected with contaminated blood. Especially detrimental is that infected people have had to describe in detail their status and the effect this has had on them only to be then refused or downgraded. It has felt to many that they are not believed and are perceived as 'scroungers'.

78. Infected people are only supported in applying for these benefits in areas where there is Haemophilia Social Work support. My view is the majority of infected and affected people have little or no support with any of these complex processes.

Section 5: Trusts and Schemes

79. In both my own experience and the experience of Haemophilia Social Work colleagues in HSWA (UK), there was a lack of drive by Government to advertise trusts or schemes. I was never contacted directly by anyone to disseminate information or encourage uptake. No links were made through me and any information that I have received has usually been via politically active patients or when Haemophilia colleagues have heard of changes informally and passed these on.

80. I was not aware of steps made by trusts and schemes to advertise their existence. Any knowledge I gained historically came via an experienced Social Worker who had been in post in Birmingham for a number of years. I was advised about newer schemes by politically active patients and Haemophilia colleagues who had informally heard information.

81. Our experience at our Haemophilia Centre in relation to schemes previous to the EIBSS scheme, access to Trusts and Schemes was infrequent. There was little information and infected and affected people felt that they did not want to be 'reduced to begging'. There was a lot of anger reported nationally by Haemophilia Social Work colleagues who felt the support was unfair and inaccessible.

82. When the Sheffield Haemophilia Centre found out about the EIBSS process, a decision was made that the team would proactively support and encourage people infected to access the scheme. The Nurses took responsibility for contacting all those registered as having been infected and, as a result, we have had a big uptake of the EIBSS scheme, mostly around the Special Category Mechanism.

83. I believe that many nurses, consultants and Haemophilia social workers in the Haemophilia Centres around the UK tried their hardest to support applications where they were able to do so. I believe the level of support available greatly affected the success rates of applicants.

84. In relation to the Skipton Fund, I believe that more should have been done to encourage application. In the Sheffield centre we identified that some people had not 'migrated' over from the Skipton Fund to EIBSS. We therefore proactively advised them that they had not been notified in order that they could apply for additional funds.

85. I am sure that more could have been done to reach infected and affected people particularly in relation to EIBSS. Centres were not notified in advance of any changes to systems, letters were sent out directly to people and there were strict time limits. The reality is that only people who were proactive would contact the Centres to find out what was going on and seek support. Many people were not proactive due to a number of reasons. For example, not understanding the contents of the letter and implications, not accessing services due to mental health issues, substance misuse, PTSD, learning difficulty etc, being worried about 'bothering' the Centres, being worried about implications of the money, especially on other benefits.

86. Ideally the Centres should have been informed/given advance notification that letters were to be sent out so that all staff were able to plan and prepare for the big influx of time limited work which would ensue. This would have enabled us to have reassured and advised people appropriately in the initial stages. We could also have contacted people in a sensitive and supportive manner reducing anxiety and stress for infected and affected individuals.

87. The criteria for EIBSS was and is publicly accessible and available. I feel it is clear and user friendly. I do not believe the current EIBSS system requires unnecessary repeat applications.

88. Historically, previous to EIBSS, Senior Nurses in our Centre applied to Trusts and Schemes. I am unsure what happened in other Centres. With hindsight I do not feel this was sufficient. This was in addition to their Nursing roles and tasks and often had to be done in their own time in order to support their patients. They were generally not given training, advice or support in undertaking these tasks.

89. Where Social Work support is available, we are able to give practical and emotional support, assistance and advocacy to people to make applications. However as previously noted, haemophilia social work provision is sparse in the UK and this task

would not be undertaken in wider social work teams due to haemophilia service users generally not meeting most local authority's criteria for social work intervention. I understand that at many other Haemophilia Centres Nurses and Consultants give assistance where they are able to do so.

90. The EIBSS system was rolled out with no prior warning to all infected and affected people who had been migrated from Skipton Fund. A time limited application window was given which covered the Christmas period. No sufficient practical support or assistance was offered by EIBSS to enable applicants to make applications and their first call was predominantly to the Haemophilia Centres who knew nothing about it.

91. The extra workload over the Christmas period in 2017 was phenomenal for all staff nationally. There seemed to have been limited consideration given to the timing or to the actual application process which, for most people, involved talking and going through issues that had not been spoken about for decades. The whole process was very emotional and challenging for the infected and affected people and for staff dealing with the fallout from this. No psychological support at all was available unless applied for specifically to EIBSS by service users and this was via financial assessment.

92. We (at the HSWA UK) were so concerned that as the Chairperson I wrote to the EIBSS to complain about the situation. This was also followed by Haemophilia Nurses Association (HNA) and the Haemophilia Consultants (UKHCDO). I did not receive any follow up from this though the deadline date was extended by a month or so.

93. Many applicants felt they had had to bring up issues that were extremely traumatic over the festive period in an attempt to apply for money. For those individuals, this again felt like begging for support. They had limited support for this and, due to workload capacity, we were only able to offer limited appointments and follow up support after the whole process was finished.

94. As the Haemophilia Comprehensive Care Centres are regional, infected and affected people were having to travel up to 4 hours, often on motorways, during busy periods in winter weather to hospitals to then discuss traumatic events most had not spoken about since diagnosis with little planned emotional support before or after. They then had to travel home, manage Christmas and hope for a few months afterwards that

they had had a successful application. No money was available for travel, parking, loss of earnings etc. Nevertheless, if people wanted to access support then there was very little choice.

Fairness and accuracy of application and decision making:

95. I am personally only able to comment on EIBSS.

96. I do not feel that eligibility requirements were fair and appropriate because those infected with HCV who then 'spontaneously' cleared the virus were not allowed to apply for Special Category Mechanism because they had not initially been eligible for Stage 1 of the Skipton Fund payments. This was in spite of the fact that many of those people had been affected emotionally to a significant degree by this experience.

97. I believe that it was unfair that they did not qualify for the initial Stage 1 Skipton Fund Payment and I cannot understand the reasoning behind this. It has caused widespread anger and resentment among infected people.

98. I do not feel that the requirement for proof of exposure to blood and /or blood products was fair or appropriate. In many cases, it is very difficult to find exact proof for a number of reasons. Many people have moved area and between hospitals with records covering many decades. In some instances records have been destroyed thus finding evidence in these circumstances is often impossible. The passage of time has covered a period that saw notes go from written to digital and my experience is that sometimes papers go missing.

99. The requirement for supporting evidence was not, in my opinion fair or appropriate. Most people infected with HCV/HIV received the majority (if not all) of their care from Haemophilia Centres. The priority at the Centres is to treat Haemophilia, managing joint/target bleeds and maximising potential through prophylaxis etc.

100. The request was for evidence that people had struggled with mental health/psychological issues, depression, anxiety etc. The majority of our patients rarely if ever discussed these issues with their consultant hence there was no documented 'evidence' in the medical notes. The patients were rarely if ever asked about emotional well-being as traditionally a Medical Model of health care was

predominant so again no documentation. The focus of the then medical care was not on psychological issues.

101. Historically, haemophilia patients were seen at the Haemophilia Centres as a 'one stop shop'. They rarely visited their GP for access to care and support. Since GP Surgeries are usually located in their local communities with other members of staff (i.e. reception, cleaners) also being local, there was a very real fear of GP Practices finding out individuals were infected or affected by contaminated blood. Thus people desperate for their diagnosis of contaminated blood to remain confidential would not discuss this with GPs and many asked for their GPs not to be informed. In my experience this has meant that very little 'evidence' was recorded by GPs to forward for claimants.

102. In answer to specific questions put:

a. As far as I am aware current decisions are made fairly in line with published guidelines (EIBSS);

b. As far as I am aware current medical judgements to inform decisions are made fairly (EIBSS);

c. I have no knowledge of any practice of securing loans against properties (EIBSS);

d. I have little direct knowledge of this as applications in Sheffield were historically made by Senior Nurses;

e. As far as I am aware the current decisions are made in an efficient and timely manner (EIBSS);

f. As far as I am aware applications are currently decided in a consistent way (EIBSS);

g. I am not aware of any current refusals (EIBSS).

103. Haemophilia Social Work colleagues advise that the infected and affected people they worked with were angry about the way the Macfarlane Trust was

managed and gave examples of the unsympathetic attitude of the staff. They felt that the application process was bureaucratic and complicated with long time frames to hear whether the grant would be awarded. People likened it to feeling like they were 'begging for money'.

104. As far as I'm aware, applications made by the Senior Haemophilia Nurses were usually successful if forwarded with supporting Nursing information. Under the current system all applications that I am aware of have been dealt with through Haemophilia Centres.

105. For example, all those under EIBSS Special Category Mechanism (SCM) required a written statement from a haematology consultant and to be signed off. I believe that, in some areas, the haematology consultants did not sign the SCM applications off and these were then refused even if they also came with the support of the Haemophilia Social Worker.

106. All the SCM applications (infected people) in Sheffield went through the Haemophilia Centre, involving myself, the Clinical Nurse Specialist and Haematology Consultant. They were all successful. I do not know the percentage of applications which were successful in other areas without this support. We have had no time to undertake any scoping exercise.

107. Recently I have made application for EIBSS stage 1. This again required the Haematology Consultant to sign off, this application was successful but would not have been without this. I have made applications for EIBSS 'Discretionary Support Scheme'. These have been successful but have had to be accompanied by quotes on services which I've had to obtain and details of approaching other services for assistance first, people have again complained of feeling they need to 'beg' for assistance.

108. I have been advised by Haemophilia Social Work colleagues in Wales that the Wales Infected Blood Support Scheme (WIBSS) provide a welfare rights service and are generally thought by infected people and Haemophilia workers to be much more approachable and reactive to requests

109. In Wales, it is reported that the Haemophilia Social workers, Nurses, Centres and infected and affected individuals have generally good relationships with WIBSS

welfare rights workers who have worked with them to find evidence in medical records to support applications made by relatives on behalf of a family member who died in late 1980s, early 1990s. As far as I am aware, this has not been available in England. I do not know why there is a disparity.

110. In reality, during the initial stages of EIBSS in England, it was not felt that staff working at EIBSS were particularly helpful or supportive when contacted for advice and information.

111. Currently many infected people state that they feel angry that surplus funds were transferred to the Terrance Higgins Trust (THT) when the Macfarlane Trust was wound up. They are of the view that there was minimal consultation with the beneficiaries. People would have liked the surplus funds to be equally distributed to all the beneficiaries or the opportunity to be fully consulted on how the funds would be used in the future. My understanding is that the THT are going to use the money to fund support workers/schemes for people with IBD but won't be giving financial support to individuals. Infected people feel this is another example of things being 'done to them' rather than 'with them'. No discussion was had with our National group concerning this change.

112. The applications I have made under EIBSS have been processed in a very timely manner with evidence given accepted.

Section 6: Role as a HIV Nurse

113. I worked with people infected with 'HIV' and predominantly those who had developed 'AIDS' between 1989-1995 initially as a Student Nurse on placement, then as a basic grade staff nurse full time in Manchester then part time as a 'Bank Nurse' (i.e. without permanent contract) in Glasgow. I was based in the Infectious Diseases Hospitals which were physically separate to the main General Hospitals.

114. During this time, the main cohort of patients were gay men and then increasingly people who had been or were using intravenous drugs. I only encountered two patients over those years who had Haemophilia infected via blood product.

115. The patients in the HIV Units were cared for by staff who had received training in the various aspects of 'HIV' and 'AIDS' i.e. developing treatments, counselling, testing, end of life, legal issues etc. There were strong ties with voluntary organisations such as Body Positive and Terrance Higgins Trust who provided a lot of staff training and support.

116. Both Units were refurbished and had well-staffed, multidisciplinary teams. Specialist Nurses, Doctors, allied health professionals, (such as Social Workers) and volunteers were able to give peer support and supervision as well as supporting families, friends and partners, especially during and after patient death. Due to limited treatments being available, deaths were frequent and patients were generally young.

117. Many of the patients, staff and voluntary groups involved in 'HIV' services at that time were political and vocal, linking into other groups and networking to demand developing drug therapy, services and legal changes in regard to 'HIV' and within the gay community. The other main cohort in the 'HIV' units were those who had been/were injecting drug users and they generally did not engage with the other patients.

118. Unfortunately, because the 'HIV' patient cohort was often viewed different to the 'norm', there were frequent moral judgements made outside the HIV Units in society about the 'deserving' and 'undeserving' infected. From discussion with Haemophilia service users, this was a commonly held view within their own patient cohort at that time. There was a real effort to distance themselves from others diagnosed with 'HIV'. i.e the 'undeserving'. Many people with Haemophilia now regret this widespread attitude and, with hindsight, recognise that everyone suffered and was due care and dignity. However, at that time, to be associated with those other infected patients meant being stigmatised and potentially rejected by family, friends, employers etc so they kept apart and tried not to draw attention to themselves. They felt that, in wider society it didn't matter whether you had 'HIV or 'Hep C'. You were still infected and therefore the same.

119. My impression of that time is that the Haemophilia Community did not have strong political engagement. They were not vocal as a community. Rather, they 'hid' on purpose to try and protect themselves and their families. Infected people have

said they didn't want to receive care in the Infectious Diseases Hospitals/'HIV' units due to the stigma attached there. They were frightened that others would find out about them. Consequently, those infected and affected people were isolated. They were disengaged from voluntary support groups and systems and the ongoing specialist counselling and services. They were unable to be open up about their situation and I feel this level of secrecy, along with lack of services, has caused long term psychological damage for many people infected and affected in the Haemophilia community.

Section 7: Other Issues

120. In addition to information given, I would like to highlight a number of issues that were raised nationally by infected people with Haemophilia while undertaking the EIBSS applications and with discussions with Social Work colleagues.

121. People have often been angry when discussing their diagnosis/infected status. This was a UK wide issue discussed with all Haemophilia Social Workers at various times. Often they could not recall having been asked for consent to test in regard to their infected status. Many recalled being given information regarding their status once only with no follow up or repeated discussion to check their understanding of the nature of infection and its consequences. Many people stated there had been significant time lapse between being unknowingly tested and being told of their infection status. This was sometimes years later and that they felt they had put others at risk by not knowing.

122. Nationally there was also widespread discussion about whether they (patients) had been told clearly about the risks of receiving treatment during the height of the crisis and questioning whether they had been treated unnecessarily and the implications that this had.

123. Nationally infected and affected people advised that they felt that their mental wellbeing had not been sufficiently addressed at the time of diagnosis or

subsequently over the decades and as a result they had been left to cope on their own psychologically. They generally agreed that their Haemophilia condition had been well managed and they often described 'gold standard care' being given from the Haemophilia Centres but that their infected status had been largely 'ignored'.

Statement of Truth

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

Signed GRO:C

Dated 10. 11. 2020