Witness Name: Nicholas Fish
Statement No.: WITN4466002
Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF NICHOLAS FISH

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 23 November 2020.

I, Nicholas Fish, will say as follows:

Section 1: Introduction

1. **Please set out your employment history prior to your appointment at the Macfarlane Trust (MFT), Skipton Fund (SF) and Caxton Foundation (CF).**

    1.1. Prior to starting work with the Skipton Fund through a temping agency I worked for Aviva Life and Pensions Department after graduating from university.

2. **Please describe how you were appointed to your roles at MFT, SF and CF.**

    2.1. I was appointed to the Skipton Fund initially as a temporary member of staff before becoming a full-time employee a few months later. Whilst employed with the Skipton Fund my role was adapted to provide administrative assistance to the Macfarlane Trust and later to the Caxton Foundation to a lesser extent.

3. **Please confirm the time period for which you worked at the MFT, SF and CF. Please explain whether your roles were full or part time and how your time was**

split between the various organisations. You may find [SKIP0000030_013] of assistance.

3.1. I started with the Skipton Fund in November 2004 as a full-time temp before becoming a full-time employee a few months later. My time was primarily allocated to the Skipton Fund with the % shares with the Macfarlane Trust, and later the Caxton Foundation, fluctuating over time depending on the workload at the Skipton Fund. I cannot recall the exact splits at the exact times but the copy of the minutes you provided from February 2011 showing an 80:20 split in favour of the Skipton Fund provides a good approximation. Again I cannot recall exactly when I started splitting some of my working hours with the Macfarlane Trust but it was relatively soon after I started with the Skipton Fund, and with the Caxton Foundation it was probably as soon as the charity was set up as I was the Assistant to the Chief Executive of the Macfarlane Trust at the time, who became the first Chief Executive of the Caxton Foundation.

4. Please describe your role, responsibilities and any training or supervision you were given when you began your position at the SF.

4.1. When I started with the Skipton Fund my role was to assist the Scheme Administrator with basic administrative duties such as answering telephone calls from applicants, writing letters to applicants and doctors and responding to emails. I was given training by another temporary member of staff who had been there from the outset and explained how the application process worked, how to use the database, where to find template letters etc. Both of us were provided support and guidance by the then Scheme Administrator. Not long into my time with the Skipton Fund we were given a presentation on hepatitis C by Professor Christine Lee at the Royal Free Hospital.

5. Please describe your role, responsibilities and any training or supervision you were given when you began your position at the MFT.

5.1. My role when I first started with the Macfarlane Trust was to assist the Finance Manager with research and basic admin duties. I was provided training and guidance by the then Finance Manager.

6. **Please describe your role, responsibilities and any training or supervision you were given when you began your position at the CF.**

6.1. My role with the Caxton Foundation was the assistant to the Chief Executive, by which time I had been with the Alliance House Organisations for many years and didn't require any specific training. Supervision for this role was provided by the then Chief Executive. My responsibilities were minute taking and helping to analyse the cost of potential discretionary payment policies as well as providing general assistance to the Chief Executive as and when required. After the initial Chief Executive left, my working involvement with the Caxton Foundation was minimal.

7. **Was there an application process and was any further training offered to you when you began the additional role with MFT? How was your employment contract and salary charge altered to reflect this change of role?**

7.1. There was no application process when I began working with the Macfarlane Trust as the role was very basic and I was either still employed via the temping agency or very soon after becoming full time with the Skipton Fund. Further training was offered by the Finance Manager each time I was given a new task. There was no change in salary but I cannot recall if there was any change to my employment contract, although I believe as I began doing work for the Macfarlane Trust whilst temping my initial full-time contract did reflect the percentage split between the 2 organisations.

8. **The Inquiry understands that you did some work from time to time for other Alliance House organisations (AHOs). Please explain:**
   a. **What if any other tasks you performed and for which AHOs.**
   b. **How such ad hoc arrangements came about.**
   c. **Whether you and/or the SF/MFT received payment for this work.**

8.1. I may have done a small amount of work for the Eileen Trust but, if I did, I cannot now recall what it would have been after such a long time. This would likely have been to analyse the potential cost of new grant payment policies from the existing pot of money. There was a separate Fund within the Macfarlane Trust called the Honeycombe Fund, I believe, which was funded by a relatively small legacy left by a deceased beneficiary and was ring-fenced specifically for bereaved partners

to apply for grants to assist them in getting back into employment. For a short period of time I was asked to consider any grant applications that came through from this pot but applications were few and far between; in fact I don't remember receiving any grant applications during the short time that this was my responsibility.

8.2. Any work I did for any of the AHOs (other than the Skipton Fund) would have come through the then Chief Executive of the Macfarlane Trust, or the Finance Manager in the very early days.

8.3. Neither I nor the Skipton Fund received additional payment for any work that I may have done.

9. Please explain the extent to which the AHOs shared premises, staff and resources. What impact did this have on data sharing and confidentiality and how were such issues managed? How were documents and information stored by the relevant AHO? Was information shared across the AHOs? If so, were registrants aware of this?

9.1. The Skipton Fund, Macfarlane Trust and later the Caxton Foundation shared the same office in Caxton Street. I am not sure about the Eileen Trust but they didn't have a full time member of staff in Alliance House. Some roles were separate and some roles were split between organisations using a percentage salary share. Some resources were shared, such as the photocopier, and some resources were ordered separately by each organisation, such as stationery. Roles that were specific to one organisation would not have had access to data from the other organisations, roles that were shared had access to the necessary data from each organisation to fulfil their role. However, data could not be shared between organisations without the beneficiary/applicant's consent, i.e. if an applicant contacted the Skipton Fund to provide a new address they could either give their consent for us to share this with the Macfarlane Trust or would have had to notify them separately, if applicable. Each organisation had its own filing area for storing documents and information relating to that company/charity and a separate password protected area of the database.

10. Please confirm what committees, working groups or sub-committees you were a member of at the MFT and SF and how you came to be appointed onto these.

10.1. I wasn't a member of any committees or sub-committees nor any working groups as far as I recall. The Skipton Fund did not have any such committees or groups.

11. Please set out your membership, past or present, of any other committees, associations, parties, societies or groups relevant to the Inquiry's Terms of Reference, including the dates of your membership and the nature of your involvement.

11.1. I'm not, and never have been, a member of any committees, associations, parties, societies or groups relevant to the Inquiry's Terms of Reference.

12. Please confirm whether you have provided evidence to, or have been involved in, any other inquiries, investigations or criminal or civil litigation in relation to human immunodeficiency virus ("HIV") and/or hepatitis B virus ("HBV") and/or hepatitis C virus ("HCV") infections and/or variant Creutzfeldt-Jakob disease ("vCJD") in blood and/or blood products. Please provide details of your involvement and copies of any statements or reports which you provided.

12.1. I provided limited evidence to the Archer Inquiry but cannot recall the specific nature of this, I believe it was to confirm the number of ex gratia payments that had been made up to that date by the Skipton Fund. Any information I did provide would have been stored on the Skipton Fund's server, although can probably be found in the Archer Inquiry report.

<u>Section 2: Functioning of the Skipton Fund</u>

13. Please identify the other positions at the SF and how these changed over time

13.1. I became the Scheme Administrator and Company Secretary of the Skipton Fund in 2006. I was responsible for administering the scheme as set out by the DHSC which included liaising with applicants and doctors regarding their applications, making decisions on applications jointly with one of the directors, managing scheme assistants, providing feedback, statistics and forecasts to the DHSC as

well as general admin duties associated with administering a scheme, such as keeping the application form and guidance notes up to date (I was not involved in the initial design) as well as the content of the website. The company secretary duties were those of a typical company secretary of a company limited by guarantee – meeting filing deadlines, ensuring director details were kept up to date with Companies House etc. I also became the secretariat to the independent Appeals Panel after this had been established by the DHSC which involved arranging their meetings and preparing case files, although I did not attend the meetings and was not involved in their decision making.

14. What did you understand the aims and objectives of the SF to be? What principles or philosophy underpinned its establishment and working?

14.1. The aims and objectives of the Skipton Fund were to administer the terms of the scheme as set out by the DHSC. The scheme was set up some months before I joined, so I was not involved in its establishment, but the reason the Government set it up was to provide financial recognition to people who had been infected with, and affected by, hepatitis C through treatment with infected NHS blood or blood products through NHS treatment. I gather this was as a result of pressure from campaign groups. The principles that underpinned its workings from my point of view as the scheme administrator and those of the board of directors were to administer it in as efficient and empathetic way as possible whilst keeping within the fairly rigid rules and guidelines as determined by the DHSC.

SF's relationship with DHSC

15. What did you understand the role of DHSC to be in the workings of the SF?

15.1. The DHSC designed and set up the scheme and they determined exactly what level of payments could be made under what qualifying circumstances. However, the decision making on individual applications was left to the responsibility of the Skipton Fund board and staff. Any alterations to the scheme in terms of level of payment or how people could qualify for these was solely the responsibility of the DHSC.

16. **The agency agreement for the SF noted that the SF was an agent of the DHSC. In a [draft] letter to beneficiaries from Peter Stevens he states that the SF could only alert the DHSC to operational issues and could not make proposals to amend government policy. [SKIP0000031_003] Did the agency agreement impact the SFs ability to achieve its aims? Did the agency agreement impact on the SF communication with the DHSC?**

16.1. As the Skipton Fund's aims were to administer the scheme as set out by the DHSC this did not limit the Fund's ability to achieve those aims. However, there was sometimes some crossover between operational issues and government policy, so occasionally alerting the DHSC to operational issues may have inadvertently led them to review government policy. An example of this was the limited window they provided to bereaved families to apply for an ex gratia payment when they widened the terms of the scheme. We alerted them to the fact that many people were coming forward to apply for a payment after the window had closed as they had only just learned of the change to the scheme. In turn this led the DHSC to relax the window provided the applicant had a good reason for not having applied before the window closed.

17. **In the Directors meeting on 17 February 2011 it is noted that you and Mr Stevens had met with the DHSC on a number of occasions and raised various concerns with them about the SF [SKIP0000030_013]:**

a. **How frequently did meetings take place between the DHSC and SF? Were they regular meetings, or were they requested by one or other of the organisations?**
b. **Who attended these meetings?**
c. **What typically was discussed?**
d. **Were formal minutes taken of these meetings? If so, by whom? Did you see these minutes afterwards?**
e. **Was it common for the SF to raise concerns about the terms of the Scheme at such meetings?**
f. **What issues did SF bring to these meetings? [SKIP0000030_013] makes it clear that the cut-off dates by which time applications needed to be made was one such issue, were there others?**

17.1. Meetings were ad hoc depending on whether alterations to the scheme were under consideration by the DHSC or one or both parties had an issue they wanted to discuss, but there would be at least one meeting per year.

17.2. The attendees would be different each time but tended to be me, Martin Harvey (Skipton Fund director) and Peter Stevens (Skipton Fund chairman) from the Skipton Fund. From the DHSC it would be the relevant civil servants at the time which changed numerous times during the period I worked for the Skipton Fund.

17.3. There would be an annual meeting where Skipton Fund payment numbers were discussed as well as future forecasts and any operational issues that needed to be discussed. During periods where more regular meetings occurred this would be because the DHSC were considering changes to the scheme, so the discussion would focus on these potential changes and the logistics of making these changes from the Skipton Fund's point of view.

17.4. There were no formal minutes taken of these meetings but usually each side would produce a brief set of notes (or possibly we would take it in turns, I can't recall) and agree upon a final version following the meeting.

17.5. For the majority of the time I was at the Skipton Fund the terms of the Scheme remained unchanged, during which times new concerns would be rare, but if there were they would be discussed if necessary. However, we could use the meetings to raise any concerns surrounding potential changes to the scheme and/or concerns following changes to the scheme, but this could also be done by email or telephone and was not limited to physical meetings.

17.6. After such a long time I cannot recall what issues we raised with the DHSC at these meetings but the cut-off date for bereaved families to apply for a payment after the scheme had been extended to cover people who died before the original scheme was announced in parliament is a good example. We were finding that many families had not applied during the short window as they had been unaware that changes to the scheme had been made, for example because they no longer needed to attend a haemophilia centre following the death of their family member. We would have informed the DHSC that there were many reasons why family members had been unable to register prior to the cut-off date and it was agreed that provided the applicant provided a good reason for late registration in writing we could still consider their application. Another issue I recall is the lack of medical records available to confirm whether or not a deceased person had developed cirrhosis so many years after they passed away when medical records were usually no longer available. These are examples of operational issues we

would raise with the DHSC, but due to the Agency Agreement we were not permitted to make recommendations about changes to the scheme (e.g. suggest the removal of the registration cut-off date).

18. **Regarding the concerns raised by the SF at the meeting of the Board of Directors held on 17 February 2011 [SKIP0000030_013] about the cut-off date of 31 March 2011:**
    a. **Why, in so far as you are aware, did the DHSC include this cut-off date?**
    b. **What were the SF's concerns in relation to this deadline?**
    c. **What was the response to these concerns from the DHSC?**
    d. **The Inquiry notes that in the minutes of the Directors Meeting of 11 March 2013 you noted that provided the estate of somebody who died before 20 August 2003 had a good reason for not registering until after the March 2011 deadline, the application would still be considered [SKIP0000030_085]. See also [SKIP0000031_055]. Was this DHSC policy or SF policy? Was the deadline formally amended so potential beneficiaries would continue to apply? If not, why not?**

18.1. I cannot recall the reason the DHSC included this cut-off date but it is likely that it was for budgeting reasons so that they knew the total cost of these payments. However, they would need to confirm as I could be wrong.

18.2. Our concerns were that there were people coming forward with legitimate claims whose applications we would potentially be unable to consider because they did not apply within the short window. We felt this was unfair, especially as this was almost always because the applicant had not been aware of the change to the scheme.

18.3. The DHSC agreed that we could consider such applications if the applicant provided a good reason why they had not registered before the cut-off date.

18.4. This was DHSC policy which they introduced following our feedback that there were still people making applications who had only just learned of the change to the scheme. The deadline was not formally amended which would have been a DHSC decision rather than a Skipton Fund one. However, practically speaking I don't recall ever having to reject an application from an estate simply because they did not register in time as they always had a good reason for not registering

beforehand (i.e. they had only learned of the change after the deadline had passed).

19. In August 2014, the DHSC requested that the SF contact those beneficiaries who had received a 'Stage One' payment, though with whom there had since been no further contact [CAXT0000110_134]. Prior to this request, had the SF sought to contact those beneficiaries, who had received a Stage One payment, though with whom there had since been no further contact?

19.1. No, the Skipton Fund was set up by the DHSC to administer one-off ex-gratia payments to people who successfully applied to the scheme. Once an applicant had received a stage 1 payment they were sent a remittance advice and further details of the stage 2 payment for if they had developed, or went on to develop, one of the qualifying conditions.

Relationship between the SF directors and senior management

20. Please describe the working relationship between the directors of the SF, and the senior management team including yourself. In particular:

a. Were you aware of any difficulties?

b. If so, what were they and how did they impact on the running of the SF?

c. How were they resolved?

d. Were there any trustees that you worked particularly closely with? If so, who were they and why?

20.1. There was a good working relationship between the Skipton Fund board of directors and senior management with no difficulties.

20.2. N/A

20.3. N/A

20.4. I naturally liaised more with the chairman, Peter Stevens, but any decisions would have been considered by the whole board.

21. At a Board meeting held on 17 February 2011 [SKIP0000030_013], there was a discussion regarding the appointment of directors based on relevant skills and merit. How, and to what extent, was senior management involved in the appointment of new directors and to what extent was this a matter for the DHSC? What criteria was used to assess applications?

21.1. Senior management was not involved in the appointment of new directors, this had to be a decision reached by the full board of the time. I did, however, meet Professor Dusheiko at a Department of Health meeting where I had presented payment statistics, and during our chat after the meeting he expressed an interest in possibly joining the Board. I made this suggestion to the Board who agreed it would be beneficial to have somebody with his expertise involved. I believe the initial Board was appointed by the DHSC

22. Prior to the appointment of Professor Thomas in March 2013 [SKIP0000030_085] was there anyone at the SF (either Director or senior management) with medical knowledge?

22.1. One of the directors, Elizabeth Boyd, had worked at the Royal Free Hospital, although in what exact capacity I am not sure. Another director, GRO-A, suffered from haemophilia and was therefore knowledgeable surrounding this condition. The DHSC appointed no qualified medical practitioners on the initial board or senior management, presumably because they had designed the scheme so that it could be administered by lay people with the medical input coming from the applicant's own doctor.

23. Did you consider that the number of directors was adequate in order for the SF to operate effectively?

23.1. Yes I felt that the number of directors was adequate to operate effectively.

24. At a Board meeting held on 15th March 2007 [SKIP0000030_139], a discussion was raised regarding remuneration of directors. Who decided how directors were remunerated and to what extent did senior management have a role in this? How were directors remunerated?

24.1. The hourly rate of director remuneration was decided by the DHSC, senior management had no involvement in this process. Directors were able to claim for any hours they spent on Skipton Fund business, although not all directors chose to do so.

Eligibility for the Skipton Fund

25. Who set the substantive eligibility requirements an applicant needed to satisfy before (i) being accepted as eligible as a beneficiary for a stage one payment from the SF and (ii) for a stage 2 payment? In particular what role did the DHSC have in this and what role did the SF have?

25.1. The eligibility requirements were set by the DHSC for both stage 1 and 2 payments.

26. What were the substantive eligibility requirements an applicant needed to satisfy before being accepted as eligible as a beneficiary for the SF? Did they change over time and, if so, how? In particular did the SF, in so far as you are aware, have any input into the decision to impose a cut-off date for eligibility for payments from the SF of infection prior to September 1991? If so, please set out the reasons why this date was chosen.

26.1. The Skipton Fund had to be satisfied that, on the balance of probabilities, the information provided by the applicant and their doctor showed that it was probable that the applicant was chronically infected with hepatitis C through treatment with NHS blood or blood products prior to September 1991 for a stage 1 payment and that it was probable, i.e that it was more likely than not, that they had developed a stage 2 qualifying condition for a stage 2 payment to be made. To be eligible for a stage 1 payment the doctor completing the application form had to confirm that they had seen evidence that the applicant had been chronically infected with hepatitis C, that they had seen evidence that the applicant had received treatment with NHS blood or blood products prior to

September 1991 and that there were no known greater risk factors, so in their opinion the infection was more likely than not to have been due to the aforementioned treatment. After a review of the scheme by the NHS Counter Fraud and Security Management Service (CFSMS) in 2006 it became necessary for the completing medical practitioner to provide a photocopy of the evidence that they had seen. The inclusion of the cut-off date of September 1991, before which an applicant had to have received treatment with NHS blood or blood products, was a DHSC decision. This, the DHSC informed us, is that date when all NHS blood and blood products would have been screened for hepatitis C.

27. Were these substantive eligibility requirements written down and available to applicants? If so, where were they available and how could they be accessed by applicants? If not, why not?

27.1. The questions in the application form and information in the supporting guidance notes were clear that in order to qualify for a payment the applicant and their doctor had to confirm/provide evidence of chronic hepatitis C infection, confirm/provide evidence that the applicant received qualifying treatment and that there were no greater risk factors for transmission. The final question on the form that the doctor had to complete asked if, in their opinion, treatment with NHS blood or blood products was the probable source of the applicant's chronic hepatitis C infection. The application forms were available in hard copy on request and were readily available to view on the Skipton Fund website.

28. Please describe any role haemophilia centres/haemophilia centre directors had in identifying whether individuals met the eligibility criteria for the Skipton Fund.

28.1. The Skipton Fund was set up to consider applications that were received from applicant's doctors so it was down to haemophilia centres and the doctors diagnosing hepatitis C to identify patients who they believed would be eligible and to submit an application form on their behalf. The scheme was advertised by the DHSC to haemophilia centres and hospitals at the time it was established, but as I joined some months after the scheme had been operational I do not know the specific details of how they went about this.

29. Who set the procedural requirements an applicant needed to satisfy before being accepted as eligible for a stage 1 and/or a stage 2 payment from the SF?

29.1. As I started some months after the scheme was established I am not sure whether the procedural requirements were decided by the DHSC or whether they were left to the discretion of the Skipton Fund. When I started with the scheme in November 2004 the application process was explained to me by the staff of the time and I had no reason to question who decided this. After the application process was reviewed by the NHS CFSMS in 2006 the new procedural requirements were agreed between the Skipton Fund and DHSC.

30. To the extent that these procedural requirements were set by the SF, did the SF seek expert (medical or other) advice to inform the requirements? If so, what advice and from whom? [for example, SKIP0000031_068]. In particular:

a. Prior to the appointment of Professor Thomas as director on 11 March 2013, did the SF have access to any clinical assistance at all, when determining applications? The minutes of the meeting on 11 March 2013 suggests that Dr Mutimer had previously advised the SF on the evidence required to prove cirrhosis. Is that correct?

b. At the meeting of the Board of Directors of the SF held on 4 February 2014 [SKIP0000030_009], after considering appeal statistics the SF Board felt that it could benefit from greater medical expertise when considering applications. Was this in addition to the appointment of Professor Thomas? If so, why was additional medical expertise required?

30.1. As per my previous answer I cannot comment on the establishment of the initial procedural requirements but from time to time if a new scenario arose it might be necessary to seek advice from a medical expert with relevant expertise.

30.2. The majority of cases did not require the input of a medical expert as the scheme had been designed by the DHSC to be administered by lay people. However, one of the Fund's directors, Elizabeth Boyd, had contacts at the Royal Free Hospital who she would seek advice from when necessary. I believe it is correct that Professor Mutimer had assisted the Fund with the evidence required to show probable cirrhosis with the advancement of technology, such as the use of transient elastography scans that I don't believe were available when the scheme was first set up.

30.3. This was in addition to the appointment of Professor Thomas because by that time the majority of the more straightforward applications (from patients with haemophilia, patients who were identified by the NHS lookback scheme, patients who had definitive medical records etc.) had already been processed and more applications were being received from patients who either knew, or believed, they had received a blood transfusion prior to September 1991 but complete medical records weren't available, or if they were they may not have made reference to the use of blood or blood products as part of the treatment. Rather than reject an application where the medical records didn't explicitly mention the use of blood or blood products, it was felt that it would be fairer that a medical director within the Fund consider what medical evidence was available so that they could make an informed judgment of whether they believed treatment with blood or blood products was probable, i.e. more likely than not, and the application could proceed as such. It was felt that on occasion it would be beneficial for Professor Thomas to have another medical director to discuss such cases with as they were not always straightforward.

31. What were the procedural requirements for stage 1 and stage 2 payments from the Skipton Fund? Did they change over time and, if so, how? In answering this question please address the following:

a. Was there a burden of proof on the applicant and, if so, what was the standard and how did it operate?

b. What evidence or information did an applicant have to provide? In particular what medical evidence/evidence from their treating consultant had to be provided?

c. The Inquiry notes that at a meeting of the directors on 11 March 2013 [SKIP0000030_085] there was some discussion about the evidence required to prove cirrhosis (and so presumably eligibility for a stage 2 payment). There was also reference to a model being implemented for both mono-infected and co-infected to ascertain likely dates of progression of disease for those who had lost their medical records. Was this information disclosed to applicants/ If not, why not?

d. Who determined the applications that applied these requirements?

31.1. For stage 1 procedural requirements see the answer to question 26. Over time, as the availability and completeness of medical records became worse, the Fund, with the help of the medical directors, would more frequently consider

applications where there was no definite evidence of treatment with blood or blood products prior to September 1991 but there was some medical evidence available to be able to help determine if such treatment was probable. For a stage 2 payment the completing liver specialist had to show that it was probable, i.e. more likely than not, that the applicant had developed cirrhosis based on all the data they have available. If it was unclear, and the medical directors felt further tests were required to be able to determine this, then we would make a written request to the completing doctor. Note that a biopsy would never be requested solely for the purpose of making a Skipton Fund application due to the associated risks. For stage 2 applications the only procedural requirements that changed over time were as and when new methods to diagnose cirrhosis became available.

31.2. The DHSC designed the scheme so that the burden of proof was with the applicant. The Skipton Fund was asked to consider applications on the balance of probabilities, i.e. it had to be considered *probable* rather than just *possible* that the applicant had been chronically infected with hepatitis C through treatment with NHS blood or blood products prior to September 1991 and for a stage 2 payment that it was probable that they had developed one of the qualifying conditions.

31.3. The applicant's doctor had to provide evidence of chronic hepatitis C infection from blood test results and evidence of treatment with blood or blood products prior to September 1991. For other risk factors the doctor was not asked to provide evidence but instead answer questions about other possible risk factors and then give their opinion of whether treatment with NHS blood or blood products was the probable source of infection. For a stage 2 payment the doctor had to provide evidence, in whatever form that took, that it was probable that the applicant had developed a qualifying condition.

31.4. The model referred to was designed by the Skipton Fund to help consider applications from the estates of bereaved people who had passed away many years ago and for whom there were no medical records available to confirm whether or not the deceased had developed cirrhosis. These estates were originally ineligible to apply for a payment under the terms of the scheme set out by the DHSC as the deceased had died before the scheme was established. They later amended the terms to include these estates, but evidence of hepatitis C and/or qualifying treatment and evidence of cirrhosis was often no longer

available such a long time after the person had passed away. For stage 1 applications the vast majority of applications were from the estates of people who had haemophilia, which could be confirmed by the haemophilia centre they had been registered with. In the absence of medical records either way the Skipton Fund could determine that it was probable that a person with haemophilia, who had been treated with Factor concentrate, had been exposed to hepatitis C. Likewise it could determine that on the balance of probabilities the infection was more likely to have been chronic than acute as only a small minority of people clear the virus naturally without treatment. However, we were receiving a number of stage 2 applications from these estates who recalled that their family member had been diagnosed with cirrhosis but there were no medical records available to confirm this. With the help of Professor Thomas the Fund created a model using evidence from a medical study that estimated the speed of fibrotic progression in people with hepatitis C and the speed of progression in people co-infected with HIV and hepatitis C. Using this information we were able to estimate if it was probable that someone would have developed cirrhosis based on the number of years they probably had hepatitis C and/or HIV. Applicants were made aware that where they had been unable to provide evidence from medical records that this study on fibrotic progression was being used to assess the claim instead. We also carried out a lookback on all such applications that had been rejected up to that point to see if the model could help to overturn our original decision.

31.5. This method was applied to all applications from the estates of deceased people where conclusive medical records were no longer available.

32. Were these procedural requirements written down and available to applicants? If so, where were they available and how could they be accessed by applicants? If not, why not?

32.1. It took some time to research and agree upon a model that could be applied to these applications, by which time the majority had already been received. While the method was being finalised, decisions on affected new applications were put on hold and, once finalised, all previously unsuccessful applications were reviewed to see if the decision could be overturned in light of the new model. There was therefore no reason to publish our internal methodology of how we assessed such claims in the absence of medical records, however we made no

secret of this model and I believe we did indeed share details of the study with a few applicants who enquired.

33. **Were the eligibility requirements (both substantive and procedural) amended during your time at the AHOs, and if so, how did they change and were you involved in their amendment? Were they kept under review by the Board of the SF? If so, how often? If not, why not? In particular please set out whether changes were made in or around November 2013 as referenced in the letter from Professor Makris to SF [SKIP0000031_103].**

33.1. There were eligibility criteria changes on a few occasions during my time with the Skipton Fund. All of these were the decision of the DHSC as the Skipton Fund was unable to make recommendations, our involvement was limited to providing data (not applicant specific) requested by the DHSC whilst policy changes were under consideration. The DHSC would therefore be better placed to answer this question as it is likely I will have forgotten some of the less significant changes which they could provide, as well as specific dates. However, by far the biggest changes occurred around 2011 which involved an increase in the stage 2 payment from £25,000 to £50,000, the introduction of regular payments for living applicants who qualified for a stage 2 payment, an expansion of the scheme to allow the estates of people who died before 29 August 2003 (I believe this is the date, which I believe is the date the original scheme was first announced in Parliament) to apply for stage 1 and 2 payments and the addition of a new stage 2 qualifying condition, B cell non-Hodgkin's lymphoma.

33.2. At that time the Government also announced that they would be setting up a discretionary payment scheme for people mono-infected with hepatitis C similar to the Macfarlane Trust for people with haemophilia who were infected with HIV. A few years later the DHSC then introduced regular payments (at a lesser level than the stage 2 regular payments) for living applicants who had qualified for a stage 1 payment and a bereavement payment of £10,000 for the partners of deceased applicants where hepatitis C had been a contributing cause of death. I cannot now recall the specific qualifying criteria for the bereavement payment but I'm sure the DHSC will have already provided comprehensive details.

33.3. Each of these changes required procedural changes to enable the Fund to administer the new types of payments which would have had involvement from

myself, the Board and the DHSC. From time to time there were also slight tweaks to the way the Fund administered applications, for instance when transient elastography (such as Fibroscan) became a common method of testing for the level of liver fibrosis. Again, such changes would have been made in collaboration with myself, the Board and the DHSC who would have had to approve the amendments to the wording of the application form and guidance notes. The procedures the Fund used to assess applications were constantly under review and improvements were made whenever there was an opportunity to do so.

33.4. With regards to Professor Makris's letter there were no associated changes to the substantive or procedural requirements in connection with this. The Skipton Fund was not asked to take into account the cause of an applicant's cirrhosis when assessing a stage 2 application, provided they had already qualified for a stage 1 payment. The issue here with alcohol intake was not whether that was the cause of the liver damage but rather how that can affect a transient elastography reading (Fibroscan) which is one of the markers that could be used to assess the degree of liver stiffness and therefore the probability that someone had cirrhosis. I learned from our medical directors (both hepatology Professors) that high alcohol intake can lead to inflammation of the liver, and therefore a higher Fibroscan reading. Likewise a high BMI can lead to fatty liver and a higher Fibroscan reading.

33.5. When assessing a stage 2 application the Fund had to conclude that it was probable that the applicant had developed cirrhosis, so if a high Fibroscan reading was the only evidence submitted, but the applicant had other factors that may be causing an increased reading, this had to be taken into account. Of course, if the raised Fibroscan was accompanied with other markers of cirrhosis as per the various sections of the application form, then any other factors potentially causing the high Fibroscan reading would become less significant. It is important to stress here that stage 2 applications such as this would have been considered by one (or both if more complex) of the medical directors who would use their clinical expertise as hepatology professors to assess the probability that the applicant had developed cirrhosis rather than pre-cirrhotic fibrosis based on all the evidence submitted.

34. **Were you aware of any concerns about or dissatisfaction with either the substantive or the procedural eligibility requirements for the SF? If so, what were these and what did you/the Board do in response? Please see for example [SKIP0000031_100].**

34.1. Due to the nature of the scheme from time to time there were applicants who expressed dissatisfaction at the outcome of their application, most frequently because there were no medical records available regarding past treatment with NHS blood or blood products. In such cases we would try and suggest other avenues that applicants could go down to try and gather evidence in support of their claim and, failing that, all unsuccessful applicants had the right of appeal, details of which were set out in the letter of decline. In any such cases where the dissatisfaction was with the rules of the scheme itself (e.g. if someone had naturally cleared the virus in the acute phase of the infection or they disagreed with the cut-off dates within the scheme) they were provided with contact details for the DHSC as they were the only ones who had the power to amend these.

34.2. With regards to the letter from Liz Carrol please see my answer to question 33 which sets out the difficulty in assessing an application where the only marker of possible cirrhosis is a raised Fibroscan score. The applicant's lifestyle was not being questioned as the scheme did not prevent payments to people with high BMIs and/or a high level of alcohol intake, it was the Fund and its medical directors' job to consider all available evidence to determine if it was probable that an applicant had developed cirrhosis. For this reason there was no hard and fast cut-off score for Fibroscan which was used to make a decision on an application, although it was an important tool that was used to approve many applications on the balance of probabilities. Contrary to the penultimate paragraph of this letter I believe the success rate of stage 2 appeals was low across the board, although I have no access to statistics to confirm this unfortunately. Finally, I should point out that a stage 2 application would only have ever been deferred and applicants were able to re-apply as and when there was a change in their condition or there were new test results indicative of probable cirrhosis.

35. Was it common for applicants to have to pay fees for their treating consultants to provide supporting medical evidence for applications? (See for example the letter from Dr Giangrande dated 15 August 2011 [SKIP0000031_106]). Who was expected to pay such fees; the SF or the applicant? If the latter, why and what impact did this have on the number of applications being made?

35.1. Occasionally we would receive an invoice from the completing medical practitioner (almost always a GP surgery) at which time we would write to explain that the application was not like an insurance request form and reiterate that the form was an application for an ex-gratia payment due to an infection with NHS treatment and the patient should therefore not be charged. As per guidance from the DHSC, we explained that the Fund could also not cover any such fee. However, I would certainly not say it was common for applicants to be charged, although we would have only known about cases where the invoice was sent directly to the Fund. Unfortunately I therefore would not know what, if any, impact this had on the number of applications we received but, as I believe it was rare for a clinician to charge, and nobody ever contacted the Fund to say that they would not be applying because of a fee, I suspect it had little or no impact. When the scheme was first established I understand the DHSC contacted hospitals to confirm that a charge should not be levied for the completion of a Skipton Fund form so hopefully they can clarify if this is correct and how they went about this. They would also be able to confirm why the Fund was not permitted to routinely cover fees.

36. A judicial review was brought against the SF in relation to the exclusion of applicants classified as 'natural clearers' [SKIP0000030_111, SKIP0000030_014].

a. How many applicants classified as 'natural clearers' applied to the SF?

b. Was the decision to exclude 'natural clearers' made by the DHSC or the SF?

36.1. I do not have access to the data to be able to answer this question but I recall it was somewhere in the region of 200-300, although it could have been more.

36.2. This was a DHSC policy decision.

Decisions on substantive applications within the Skipton Fund

37. To the best of your recollection and referring to the documents provided to you:

a. How many beneficiaries were assisted by the SF during your time there?

b. What proportion of applications was granted (wholly or in part) and what proportion was refused?

37.1. It is obviously very difficult to answer this question with any degree of accuracy but I would say it was somewhere in the region of 3,000 to 5,000 applicants that I assisted during my time with the Skipton Fund.

37.2. Again it is very difficult to recall but I believe the success rate was around 90%.

38. Who was responsible during your time at the SF for assessing whether an applicant met the eligibility criteria to become a beneficiary?

38.1. When I started in November 2004 until early 2006 applications were approved by the then Scheme Administrator and one of the Fund's directors. When I became the Scheme Administrator in early 2006 the responsibility was on me with one of the Fund's directors.

39. If it was you – please answer the following questions:

a. Did you make these decisions alone or as part of a group/committee? If so, please give details.

b. Were you applying a written criteria when assessing these applications?

c. How clear was the criteria and how straightforward to apply? Please describe any difficulties you had in doing so.

d. What if any assistance could you obtain from someone with clinical training?

39.1. During my time as the Scheme Administrator all approvals were made by me and one of the directors, both of whom had to sign the approval box on the front of the application form. If the application was more complex then it was common for the application to be referred specifically to one or both of the medical directors and occasionally the full board.

39.2. I have covered the qualifying criteria in previous answers, namely that we had to conclude that it was probable, i.e. more likely than not, that the applicant met the qualifying criteria as set out by the DHSC.

39.3. This was dependent on the circumstances of the individual application. For instance someone with a bleeding disorder who was treated with clotting factor before it was screened for hepatitis C would almost certainly have been exposed to hepatitis C, and blood test results would usually be able to conclude if the infection was chronic. Stage 1 applications where the suspected source of infection was treatment with NHS blood or blood products became more difficult to assess as time went on and the availability of supporting medical records became worse. For instance, where the applicant's doctor could only provide partial records of a procedure their patient underwent that didn't explicitly mention the use of blood or blood products. In such cases the views of the medical directors became important. Likewise, with stage 2 applications they would be straightforward where the applicant had received a liver transplant or had developed primary liver cancer or cirrhosis had been diagnosed by biopsy, but more difficult where the evidence supplied was in the form of blood tests, Fibroscan scores etc. which could often be on the border between advanced fibrosis and cirrhosis, i.e. did the applicant have fibrosis that had not yet probably developed into cirrhosis, or vice versa. Again, the medical directors were very important in assessing such difficult claims.

39.4. As above I had regular contact with one or both of the medical directors. Prior to their appointment Elizabeth Boyd was able to refer medical queries anonymously to colleagues/contacts she had at the Royal Free Hospital.

40. In reference to document [SKIP0000031_101], it is noted that straightforward applications could be considered by any member of the board and more complex cases would be referred to the medical director. What factors were considered in order to decide whether decisions should be referred to the medical director? How often were cases referred to the medical director?

40.1. Any applications that were not considered clear cut would be referred to a medical director. A stage 1 application would be considered clear cut if we received evidence of chronic hepatitis C infection, evidence of treatment with NHS blood or blood products prior to September 1991 and the doctor completing

the form had confirmed there were no other risk factors (such as the use intravenous drugs). I would arrange for a director to visit the office frequently to assess applications, and a medical director probably once every 2 weeks on average.

41. What if any role did the SF's budgetary constraints play when determining the outcome of individual applications?

41.1. Budgetary constraints had no bearing on our decision-making process since we did not decide on the value of payments and all applications were assessed on the balance of probabilities as per the scheme's qualifying criteria. Funds were received in advance from the DHSC based on forecasts and we would raise the next invoice early if funds were running lower than expected; furthermore, we had a buffer in place to prevent potential delays to applicants receiving their payments.

42. SF applicants whose form's noted any history of intravenous drug use received rejection letters citing an 'Expert Report' [SKIP0000031_217]. This report detailed a calculation of the risks of infection via intravenous drug use as being considerably higher than the risks of infection through NHS Blood Products. In an email correspondence between yourself and the Health Protection Authority on 31 August 2007 [SKIP0000031_215], you advised that the author of the report had given permission for the report to be forwarded to anyone who requested a copy. As to this:

a. Did the SF rely upon this report when assessing applications for stage 1 payments?

b. If so, how was this generic report factored into the decision as to route of HCV infection, when weighed against other evidence from the applicant's treating clinician and the applicant's own evidence?

c. Was this report disclosed to rejected applicants? If not, why not?

42.1. When I started with the scheme this report had not been commissioned, I was instructed during my training period that intravenous drug use was a far greater risk factor for hepatitis C transmission than treatment with NHS blood prior to September 1991. I do not know the origin of these instructions but presumably it was the DHSC to the Fund when the scheme was initially set up. The report, after it had been commissioned by the Appeals Panel, backs this up.

42.2. N/A

42.3. After the report had been commissioned it was referred to in any rejection letters that applicants were sent where intravenous drug use was the reason for rejection.

43. SF applicants whose forms noted anti-D immunoglobulin as a source of their HCV infection received rejection letters citing a literature review provided to you by the National Blood Service that anti-D immunoglobulin produced by Bio Products Laboratory (BPL) in England and Wales and the Scottish National Blood Transfusion Service (SNBTS) in Scotland was safe and therefore not a possible route of hepatitis C infection.

a. Do you have a copy of this literature review? If so please provide a copy of this in your response.

b. Was this literature review shared with the rejected applicants? If not, why not?

c. Was anything done to establish the source of the anti-D immunoglobulin given to applicants when deciding the outcome for these types of applications?

43.1. Unfortunately I do not have a copy of this document

43.2. Anti-D applications and rejections were quite rare so I cannot recall 100%, but I don't believe we sent out a copy of this review, which was quite technical, as a matter of course. If an applicant asked to see a copy of the review we were more than happy to share it, which we did on a number of occasions.

43.3. The matter of anti-D immunoglobulin is quite a technical question so it would be more appropriate to seek advice from a relevant medical expert. The way I understand it is that anti-D, which was given during labour if the blood types of mother and baby were incompatible, was manufactured in a similar way to a common vaccine and therefore not a possible source of hepatitis C, whereas other types of immunoglobulin (or gamma globulin?) that were manufactured in a different way and even administered in a different way (I cannot now recall if it was intramuscular or intravenous) may have been a risk factor, but even then it was dependent on the specific manufacturing process. The source of the anti-D was not therefore considered relevant to the application process according to the medical advice we had been given. I must stress that this information is as I recall it from many years ago whilst working with the Skipton Fund so it may not be

accurate and should be checked by a qualified expert; obviously at the time my knowledge around the whole subject matter was better.

44. Please provide your view on the consistency and fairness of decision making by the SF when assessing eligibility for stage 1 and stage 2 payments.

44.1. I believe we made fair and consistent decisions and I always tried to do the best by applicants within the constraints of the scheme. For example, an application would usually not be rejected without a round or two of correspondence with suggestions of what the applicant could do to try and gather further information to support their claim. The reason I say usually is that occasionally we would receive applications where it was clear that the applicant did not meet the qualifying criteria, for example because they didn't have hepatitis C, they had not been treated with NHS blood or blood products etc. During the ten years or so that I was the Scheme Administrator of the Skipton Fund it was rare that we would receive negative feedback, especially that wasn't concerning the qualifying criteria of the scheme itself, and I had a good rapport with most applicants.

45. What approach did the SF take to applications from those with HCV infections, who had been declined access to the fund due to their medical records having since been destroyed or lost by the DHSC?

45.1. These were the most difficult applications as, other than correspond with the applicant with suggestions of where else they might be able to access supporting medical records (their own GP records if the form was completed by the hospital, the hospital where they received the blood or blood products, the hospital treating them for hepatitis C, previous GP surgeries that they may have been registered with etc.), there wasn't a great deal we could do within the constraints of the scheme.

The conduct of Keith Foster

46. What measures were in place at the SF to guard against fraud, prior to the measures implemented by the SF at the suggestion of the NHS CFSMS in response to the actions of Keith Foster [SKIP0000025_102]?

46.1. The measures in place were those set by the DHSC when the scheme was first set up, namely the applicant had to sign the form (although I cannot recall the wording prior to the review by the CFSMS), the doctor completing the form had to tick that they had seen medical evidence of chronic hepatitis C and qualifying treatment with NHS blood or blood products, that they knew of no other risk factors for hepatitis C and then sign the back of the form providing their contact details and General Medical Council number.

47. Did the NHS CFSMS alterations have any detrimental effect on the application process for beneficiaries?

47.1. Following the CFSMS review the doctor completing the form now had to supply photocopies of the test results and medical records that they previously had to confirm they'd seen, so this shouldn't have had any impact on the application process for beneficiaries. Other than that, the applicant had to provide their NHS number on registering and sign and return a receipt of payment slip to the Finance Department if their application was successful, neither of which could be considered detrimental to the application process. All other checks were done internally by Skipton Fund staff in different departments.

48. How much money did Keith Foster embezzle from SF in so far as you are aware?

48.1. We believe this was £400,000.

49. Was the SF able to recover/recoup any of this money? If so, how much and from where?

49.1. The Skipton Fund was able to recoup, I believe, approximately £160,000 of this from his former employer who he had also embezzled funds from and he had been using Skipton Fund money to pay back. There were further funds recovered

from his bank accounts but I cannot recall how much, although I don't think this was a significant sum.

50. Did the DHSC make up the shortfall? If not, what impact did this have on the SF and on its beneficiaries?

50.1. There was no impact on Skipton Fund applicants as the DHSC had already paid the Fund the money prior to Keith Foster claiming them illegally and continued to pay invoices in advance based on projected future payments. In that sense you could say they covered the loss as the Skipton Fund never experienced a shortfall in terms of not having enough money to make the necessary ex gratia payments.

Section 3: The Skipton Fund Appeals Panel

51. Please set out what the recruitment process was for members of the SF Appeals Panel in so far as you are aware. What role did the DHSC have in this, and what role did the SF have?

51.1. The recruitment of the members of the Appeals Panel was carried out solely by the DHSC using the Public Appointment Commission (I believe) so I cannot comment on the recruitment process. My first involvement with the Appeals Panel was either when I wrote to the Chairman to welcome his appointment or he wrote to me to introduce himself.

52. In a minute of a Directors meeting on 6 May 2006 it was noted that the DHSC were having difficulty recruiting a specialist haematologist and hepatoligist for the Appeals Panel, causing a delay in the start date [SKIP0000030_146]. When and how was this resolved?

52.1. The DHSCS should be able to answer this question as the Fund was not involved in the recruitment process at all. They would be able to confirm how they filled these two posts and confirm when the Appeals Panel was officially established as I cannot now recall exactly when that was.

53. Please confirm if the appeals process was to accommodate appeals:

a. by applicants who did not meet the eligibility criteria for a stage 1 payment, or

b. by beneficiaries against decisions that they did not meet the criteria for a stage 2 payment, or

c. both?

53.1. The Appeals Panel considered both stage 1 and stage 2 appeals.

54. What guidance was provided to those seeking to appeal against a decision made by the Skipton Fund in relation to:

a. The procedural requirements for an appeal?

b. How the appeals were processed by the Appeals Panel?

c. Any additional evidence they could provide to assist their appeal?

54.1. Rejected applicants received a letter and a detailed 3 page guidance covering how to lodge appeal, how the process would work, how appeals were considered by the Panel and what further information they could supply to assist with their appeal.

55. Were there any time limits on appeals, or fees payable by those bringing an appeal against a Skipton Fund decision?

55.1. There were no time limits within which an applicant had to make an appeal nor any fees payable for doing so.

56. Applicants appealing decisions from the Skipton Fund were advised that they were not able to attend the meetings of the Appeals Panel or make representations in person. Can you advise why the decision was made to not allow applicants to attend the meetings of the Appeals Panel? Was the decision made by the DHSC?

56.1. I do not know if this was the DHSC's decision or the Appeals Panel themselves. As the Panel was independent of the Fund I can confirm it was not the Fund's decision.

57. How often did the Appeals Panel meet to consider appeals? Do you think this was sufficient?

57.1. Initially the panel met frequently (perhaps once a month – I cannot recall exactly) to cover off the backlog of applicants waiting for the panel to be established. After that the panel met approximately once a quarter, or sooner if there were sufficient cases to consider. Ideally you would probably want meetings every couple of months, but there were not always sufficient cases to be able to justify this, particularly in the later years of the scheme when new applications, and therefore rejections and appeals, were much less frequent.

58. At a Directors meeting on 1 August 2007 you reported that since the Appeals Panel's first meeting on 3 October 2006 the Appeals Panel had considered 97 appeals, 50 of which had been successful [SKIP0000030_017]. It was minuted that 'the fact that over half of the cases that went to appeal were upheld was not a poor reflection on SF's decision to decline certain applications because the Appeal Panel were able to take many more factors into account when reaching their decision'. As to this:

a. Was the SF and the Appeals Panel applying different tests to applications for stage 1 payments? If so, what were the differences?

b. Were these different criteria written down and available to applicants?

c. Were applicants who were declined by the SF told that they may well be successful at the appeal stage because of the different test applied at that stage?

d. Why did the SF consider it fair and appropriate to apply a different test to that applied at the appeal stage?

58.1. No, both the Skipton Fund and the Appeals Panel assessed applications on the balance of probabilities. The main difference with the Appeals Panel was the additional information they requested from appellants, namely photographs of surgical scars (if applicable) and witness statements.

58.2. The Appeals Panel's guidance notes, which were sent automatically to all rejected Skipton Fund applicants, mentioned all the additional information that appellants were encouraged to provide in support of their appeal (which included photographs and witness statements).

58.3. As all appeals were considered separately it would not have been appropriate to inform all applicants that they may well be successful at appeal, for instance the Appeals Panel rarely received appeals from somebody who had naturally cleared hepatitis C in the acute phase, and when they did they were always (as far as I can recall) unsuccessful. Likewise appeals where the applicant had a history of intravenous drug use were almost always unsuccessful. It would therefore be misleading to indicate to these applicants that they may be successful at appeal.

58.4. However, the letter of decline had a paragraph setting out the appeals process and included the Panel's comprehensive guidance notes that would enable applicants to make a reasoned decision. When speaking with applicants on the telephone I would encourage them to appeal if they disagreed with the Fund's decision and explain that there would be no cost to them in doing so. It is also worth noting that the success rate at the first few meetings of the Appeals Panel, which considered the backlog of applicants who had been declined and were awaiting the establishment of the Panel, was very much higher than at later meetings. I no longer have access to any Skipton Fund data but the success rate in later meetings was much lower at around 10-20% I believe as all those with the strongest cases had already appealed.

58.5. The same test was applied but the DHSC had set the scheme up to be administered by lay people with details on what evidence was required as per the application form, i.e. they had not appointed a legally qualified Chair nor experts in the fields of hepatology, haematology or general medicine to sit on the board. As the scheme evolved we felt it necessary to recruit medical expertise onto the Board ourselves which helped us to assess the increasingly complex cases that we would receive as time went on.

59. What criteria, in so far as you are aware, did the appeals panel use to assess the likelihood of an applicant having been infected via NHS blood or blood products in circumstances where the applicant did not have medical records covering the relevant period?

59.1. The Appeals Panel used the same balance of probabilities criteria, i.e. they had to be able to conclude that it was probable, rather than just possible, that the appellant had been chronically infected with hepatitis C through qualifying treatment with NHS blood or blood products or that it was probable, rather than

just possible, that the appellant had developed a stage 2 qualifying condition when considering a stage 2 appeal. Although I was not present at any of their meetings, I believe appeals where there were absolutely no medical records available to be able to assess the probability that somebody had received qualifying treatment were far less likely to succeed than ones where they had at least some records to go on to be able to make a judgment. In both cases they would want as much additional information from the appellant as possible in the form of witness statements and photographs of scarring (if applicable).

60. In a letter from yourself to Dr Ramsey at the Health Protection Authority dated 11 October 2006 [SKIP0000031_221], you request she prepare an expert opinion on IV drug use and transmission of Hepatitis C for the Appeals Panel. This expert opinion report is extensively referred to in rejection letters from both the Skipton Fund and the Appeals Panel. As to this:

a. Why did the Appeals Panel decide to seek a generic expert opinion on IV drug use?

b. Was the SF using the Dr Ramsey report when dealing with applications involving IV drug use?

60.1. It is my understanding that although it was/is commonly accepted that the prevalence of hepatitis C is far higher amongst people with a history of intravenous drug use compared with people who have received a one-off blood transfusion prior to September 1991, the Panel wanted an independent expert opinion which they could use (or otherwise if it had come back contrary to what they had expected) to be able to reference when assessing such appeals. However, you would need to ask one of the original members of the Appeals Panel for a definitive answer as I was not present at the meeting when this was discussed.

60.2. The Skipton Fund did not use the report per se, as it did not affect how we considered such applications, but we did begin to reference it when declining applications where intravenous drug use was considered a greater risk factor so that the applicant would have access to an evidenced report setting out the difference between the two risks factors if they wished.

61. How common was it for decisions to be appealed? How frequently did appeals succeed?

61.1. Unfortunately, as I do not have access to any Skipton Fund data, I cannot answer this question with any degree of accuracy. I believe circa 400 stage 1 appeals were heard with around a 40-50% success rate which was skewed towards the earlier appeals (i.e. the success rate at early appeal meetings was better than at later ones). In total there were approximately 800 stage 1 applications that were rejected so approximately half of unsuccessful applicants appealed the decision.

61.2. Anecdotally I would say the majority of people whose stage 1 claims were rejected due to a lack of evidence made an appeal, very few of the 200-300 or so who were rejected due to 'natural clearance', and a small proportion of those who were rejected due to intravenous drug use. There were far fewer stage 2 appeals considered, probably around 50, with a lower success rate of approximately 15-25%. This is most likely because stage 2 applications were deferred rather than rejected, and applicants were encouraged to re-apply if the condition of their liver deteriorated or they had further test results which were indicative of cirrhosis.

62. Was any action taken to review the eligibility criteria for Skipton Fund payments, in light of the decisions made by the Appeals Board?

62.1. Although the eligibility criteria was unaffected by the Appeals Panel, as these could only be changed by the DHSC, the Fund was able to learn from some of their decision making, particularly once medical directors were in place, to help us assess applications on the balance of probabilities.

<u>Section 4: Macfarlane Trust</u>

63. What did you understand the aims and objectives of the MFT to be? What principles or philosophy underpinned its establishment and working?

63.1. The aims and objectives of the Macfarlane Trust were to distribute the funds they were given by the Department of Health to eligible beneficiaries in as fair a way as possible and to those most in need of financial assistance. As well as financial assistance they were there to provide support and advice to their beneficiaries. I am unsure exactly how the Trust came to be established but believe it was due to

pressure from campaign groups who wanted recognition for the devastating impact that HIV infections, as a result of treatment with NHS blood products, had had and was having on people with bleeding disorders and their families.

64. What did you understand to be the role of the Department of Health and Social Care (DHSC) in the workings of the MFT?

64.1. I was not part of the dialogue between the Macfarlane Trust senior management and the DHSC so am unsure of their exact role in the workings of the Trust other than to allocate funding and appoint 1/3 of the Board. I am not sure, for instance, if the Trustees were completely free to distribute funds as they saw fit or if there were certain policies they were expected to implement. Obviously the level of funding had a big impact on the way the Trust could operate and how much they were able to help their beneficiaries, so in that respect they were certainly influential.

Loans

65. Please describe the different types of loans and advances provided by the MFT to beneficiaries during your time there. Can you recall how the decision to make loans and advances rather than give grants came about as a matter of policy in the MFT?

65.1. I was not involved at all with loans so am not the best person to answer this question. I believe decisions on grants and loans were made by a committee, or committees (I am not sure if there were separate committees for loans and for grants), made up of a sub-section of the Trustees and representatives from the beneficiary community. As far as I am aware the Trust was providing grants and loans many years before I joined the Skipton Fund in 2004 so these decisions would have been made many years ago.

Non-financial Support

66. What, if any, non-financial support was available to eligible beneficiaries of the MFT? Was the availability of non-financial support made known to the potential beneficiaries, and if so how?

66.1. I was not involved in this directly so there are other people who are far better placed to answer this question who would be less likely to miss anything out, but as far as I can remember the Trust offered debt advice, benefits advice, financial advice, possibly bereavement counselling and held various events where different groups of beneficiaries could meet up, for instance one for HIV positive males with bleeding disorders, one for HIV positive females with bleeding disorders, one for bereaved family members etc.

66.2. All of these policies were advertised on the Trust's website and communicated in regular newsletters and other written correspondence.

67. How frequently were the MFT involved in advocating for better services for beneficiaries? (for example, the discussions regarding dental care [MACF0000124_014]). Please explain how it was that you were corresponding about dental services in 2008.

67.1. I believe the Trust would advocate for better services for beneficiaries as and when the need arose. An ongoing example of this was to try and prevent the continual DWP investigations into beneficiaries' income from the Trust that was supposed to be disregarded when they applied for means tested social security benefits.

67.2. I was asked to correspond about dental care by the then Chief Executive of the Macfarlane Trust, presumably because at that time beneficiaries were finding it difficult to access dental care due to having been infected with HIV.

Section 5: The Caxton Foundation

68. In a letter to yourself, as Scheme Administrator of the CF, dated 15 March 2013 [CAXT0000022_014], a beneficiary raised issues regarding certain administrative practices of the CF and SF. Specifically, the CF's heavy reliance on means testing and lack of coordination with the Department for Work and Pensions (DWP). Why did the CF not rely on the assessments already undertaken by the DWP?

68.1. Only 5% (I believe) of my role was allocated to the Caxton Foundation and I was not involved at all with such policy making decisions so unfortunately would be unable to answer this question. Aside from perhaps the first one or two meetings I did not attend Board meetings of the Caxton Foundation where such decisions would have been made.

69. In 2014, applications for registration with the CF spiked by 20%, what was the cause of this?

69.1. I am not sure what caused this spike but I believe around that time there was another drive to find missing stage 2 applicants who the Skipton Fund had lost contact with.

70. In what circumstances would a beneficiary be referred to a debt advisor?

70.1. Again, I was not involved in this process, but I believe any beneficiary who was struggling with debt had the option of being referred to a debt advisor for advice and help in managing this.

71. Were awards conditional on cooperation with those referrals and their advice being followed?

71.1. I am not sure as I was not involved in this process.

72. The CF Budget for 2014/15 detailed an increased allocation of funds towards the provision of debt advice.

a. What was the justification for this commitment?

b. Was there consultation with the beneficiary community on the effectiveness of debt counsellors, prior to this commitment being made?

72.1. I was not involved in this decision, others who worked full time for the Caxton Foundation would be better placed to answer this question.

Section 6: AHO Staffing costs

73. How were staff salaries at the SF and MFT calculated? What, if any, steps did the SF and the MFT take to ensure that the salaries were commensurate with the charitable sector or any other sector?

73.1. My initial salary was paid as an hourly rate through a temping agency until I became full time, at which point I accepted an offer put to me by the board of directors. According to the minutes of 8th May 2006 (which was amongst the documents you provided me access to) I was then put onto a Local Authority Wage Structure after accepting the position of Scheme Administrator. Other than a long-term Skipton Fund scheme assistant who adjusted his role to work the majority of his time with the Skipton Fund from the Macfarlane Trust, and whose salary had already been allocated by the Macfarlane Trust Board, all Skipton Fund scheme assistants were employed through temping agencies. I am not sure how Macfarlane Trust employees' salaries were calculated as I was not involved in this process and the information would have been confidential.

74. What was the 3% 'cost of living' increase made to the remuneration awarded to staff members of the CF. Was this pay rise reflective of any factor other than cost of living in London?

74.1. Other than being notified of any such salary increase I was not party to the discussions of how such decisions were reached. As far as I am aware it would have only been due to the increase in the cost of living rather than any other factor.

75. Did the MFT introduce pay increases by reference to performance? If so, why, and when, how was performance measured and what was the impact on the staffing costs?

75.1. There was no appraisal system nor performance related pay increase system in place at any of the AHO's as far as I am aware.

76. Please comment on whether staff were paid bonuses at the MFT and SF, and if so, how in your view any staff bonuses fitted within the charitable aims of the organisations. What was the criteria for receiving a bonus?

76.1. I recall receiving an ad hoc bonus in one or two of the earlier years of working with the Skipton Fund but they were certainly not paid every year as a matter of course. The bonuses I received from the Skipton Fund were relatively modest (approximately 1 or 2 weeks' pay) and presumably were paid to me in recognition of the additional work I had to take on following the abrupt dismissal of my predecessor, and because my basic salary was relatively low for the level of responsibility the role entailed. All AHO's had separate funding for management costs so did not impact on the funds allocated to beneficiaries.

<u>Section 7: Funding and finances of the Macfarlane Trust, Skipton Fund and Caxton Foundation</u>

77. Do you consider that the funding provided by the DHSC to the SF was adequate? Please provide reasons for your answer, and if you consider that the funding was not adequate, please set out the level of funding that you consider would have been adequate.

77.1. The Skipton Fund was funded adequately to enable us to make the payments as set out in the terms of the scheme. However, the impact that hepatitis C had on applicants' health fell on a broad spectrum, ranging from those who cleared the virus with treatment (although that in itself was an ordeal before the recent improvements) to those who suffer the effects daily to those who sadly died as a result of advanced liver disease. I cannot therefore say that the payment levels were sufficient across the board, although I find it difficult to put a value on what level of payments, if any, would have been considered adequate.

78. **Did the SF have any other streams or sources of funding/income other than that provided by the Government during your tenure? If so, where did this come from and how was it managed and spent?**

78.1. The Skipton Fund did not have any other sources of income other than a small amount of interest generated through its bank account, all of which was put back into the funding pot and offset against future funding requests (i.e. if the Fund forecast it needed £500k to cover the ex gratia payments in the upcoming month, and had £100k still in the bank, some of which was interest, it would only need to invoice the DHSC for £400k).

79. **Do you consider that the funding provided by the DHSC to the MFT was adequate? Please provide reasons for your answer, and if you consider that the funding was not adequate, please set out the level of funding that you consider would have been adequate. (we refer to document [MACF0000012_131])**

79.1. I do not consider that the funding provided to the Macfarlane Trust was adequate to enable the Trustees to fund all of the policies they would have liked to have done to the level they would have wanted to meet the needs of the beneficiaries. I do not have enough information to be able to say how much this shortfall was.

80. **Do you consider that the funding provided by the DHSC to the CF was adequate? Please provide reasons for your answer, and if you consider that the funding was not adequate, please set out the level of funding that you consider would have been adequate.**

80.1. As above

81. **Who decided on the level of reserves the SF, MFT and CF should maintain? Were you involved in those decisions? What was the justification for the level of reserves? (see for example [MACF0000018_006])**

81.1. The level of MFT and CF reserves would presumably have been decided by the respective boards of each charity, probably in agreement with the DHSC; I was not involved in the decision-making process. The Skipton Fund reserves were decided by the board of directors in agreement with the DHSC and were under constant review to reflect the average monthly liability of the Fund at any given

time which fluctuated with DHSC policy changes (e.g. the introduction of regular payments, increase to the stage 2 lump sum payment etc.). I believe the minimum bank balance agreed was usually either £500k or £1m at any given time but it may have been slightly higher in the early days. The justification for this was so that the Skipton Fund was able to make the necessary payments to applicants without delays which may have been caused if there had been no buffer in place between invoices or the level of payments in any given month was higher than had been forecast. The Skipton Fund only had cash at bank, it did not have any invested reserves.

82. Did the level of reserves impede or otherwise have an impact on negotiations with the Government for increased funding?

82.1. From a Skipton Fund point of view the level of agreed reserves did not have any impact on receiving further funding from the Department of Health. I would not be able to answer this from an MFT or CF perspective as I was not involved in such negotiations.

83. What, if any, steps did the SF, MFT and CF take to cut operational costs so as to maximise the monies available for beneficiaries?

83.1. The operational costs of the Skipton Fund were a very small percentage of the overall funds paid out and I consider that the scheme was run efficiently. The AHOs shared costs, such as office space, office equipment, and staff by way of salary splits, all of which helped to reduce operational costs for each organisation. However, I believe all operational costs came out of separate budgets so would not have impacted on the funds available for applicants and beneficiaries.

84. In reference to document [SKIP0000030_112], it is noted that the SF received funding quarterly in advance based on the scheme administrators' prediction of the number of payments for the coming quarter.

a. As the scheme administrator was it your responsibility to prepare the quarterly predictions?

b. How did you go about making these predictions?

84.1. Yes, I was responsible for preparing the quarterly forecasts.

84.2. These forecasts were based on historical payment trends with all other relevant factors taken into account, for instance how many people were due to receive stage 1 and 2 regular payments, if there was an upcoming DHSC policy change to the scheme etc.

85. Can you recall why the SF did not have a media budget in place in order to promote itself? (see [SKIP0000030_027]) Was this decision made by the DHSC when allocating funding?

85.1. When I started with the Skipton Fund there was no media budget in place as promotion of the scheme was down to the DHSC. I believe they advertised the scheme with hospitals when it was first set up as well as when they made significant changes, although they would need to provide the specific details.

Section 8: Engagement with the beneficiary community

86. What steps were taken to investigate the needs of the respective beneficiary communities? If none were taken, why not?

86.1. The Skipton Fund was a payment scheme set up to make specific payments as per the criteria set out by the DHSC so this question is not relevant to the Skipton Fund. I believe the Macfarlane Trust and Caxton Foundation had census forms and grant application forms which they used to help assess the needs of their beneficiary communities but I was not involved in this process so unfortunately cannot provide any specific detail.

87. To what extent did the AHOs actively engage with the infected and affected communities to increase the number of potential beneficiaries applying for support?

87.1. The Skipton Fund undertook an exercise to re-establish contact with stage 1 beneficiaries who had received the stage 1 lump sum payment many years before and had not had reason to contact the Skipton Fund since. During this exercise applicants were notified about the Caxton Foundation and informed that they may be eligible to receive discretionary support depending on their financial circumstances. The Caxton Foundation was promoted in the Skipton Fund's application guidance notes, on the website and in approval letters once a new

applicant had qualified for a stage 1 payment. Again, I am not best placed to answer on behalf of the charities as I was not involved in this process, but I believe they frequently sent out correspondence that promoted the grants and other assistance that beneficiaries were entitled to apply for.

88. **To your knowledge, were resources shared between AHOs in order to improve engagement with the respective beneficiary communities?**

88.1. Personal data of applicants/beneficiaries was only shared between AHOs with the explicit consent of the applicant/beneficiary. Once consent had been given the organisations would then be able share information to improve engagement, for instance to share a change of address. Each organisation could, and did, promote the activities of the others where relevant. For instance, the Caxton Foundation was advertised on the Skipton Fund's website and literature, the MFT would write to their beneficiaries if there was a policy change to Skipton Fund payments that could benefit them etc.

89. **Did any of the AHOs have a formalised complaints process open to beneficiaries? If so, how did it operate and what measures were put in place to ensure it remained accessible to beneficiaries?**

89.1. I am not sure about the MFT and CF but the Skipton Fund's complaints procedure was dependent on the nature of the complaint. If the complaint was with the scheme's qualifying criteria then contact details for the DHSC were shared with the applicant, if the complaint was against a member of staff then the applicant would have been asked to send a written complaint to me as the Scheme Administrator, and if the complaint was against me then the applicant would have been asked to send a written request to the Chairman. If and when an applicant indicated that they would like to raise a complaint then we would establish the nature of this complaint and provide the relevant contact details for the person they would need to raise the complaint with.

90. How successful were the AHOs in addressing the complaints made by beneficiaries? Were any structural changes made to trust practices in response to complaints from beneficiaries.

90.1. I was not involved in the process for the charities. For the Skipton Fund, the majority of complaints received were in relation to the qualifying criteria for the scheme itself and in all cases the applicant would have been provided with contact details for the DHSC. We received very few complaints regarding the handling of an application or an individual staff member and as far as I recall any such complaints were resolved satisfactorily. I do not recall if any complaints resulted in changes in practice, but it is possible as we would have been willing to do so where areas of improvement had been highlighted.

<u>Section 9: Other</u>

91. The Inquiry has received some complaints regarding your decision making and communication, one of which has been raised with you in a separate request for a statement pursuant to rule 9 of the Inquiry Rules 2006. The Inquiry has received a further complaint from witness W0805 at paragraph 43 of the witness statement, who states that it felt like they 'had to battle with Nick Fish from SF to get acceptance', and that they felt you 'didn't communicate well with [them] and that decisions were not properly explained to [them]'. You are invited to respond to this should you wish to.

91.1. I am sorry to hear that somebody felt this way as I always endeavoured to process applications in a fair and reasonable way. As mentioned earlier in this statement, I was involved in processing thousands of applications during my time with the Skipton Fund and, given the limitations of the scheme and the sensitive nature of the reason it existed, it was inevitable that not everybody would be happy with every decision. I have no details of the application in question so cannot comment specifically, but if somebody felt they had to 'battle' to get acceptance it would suggest that either they did not meet the qualifying criteria as set out by the DHSC or that supporting evidence was no longer available; in both scenarios I can imagine it would have been frustrating. We received little, if any, criticism of our communication at the time so I would hope that this was a minority view rather than a commonly held one. I had a good rapport with many of the applicants who I communicated with over the years with a lot of positive

feedback, some of which can be found amongst the files transferred to the firm of solicitors who now hold the Skipton Fund's data.

92. Do you consider that the MFT, the SF and the CF were well run? Do you consider that they achieved their aims and objectives?

92.1. I do consider that the charities and the Skipton Fund were well run and achieved their objectives given the limitations on funding (charities) and the rigid nature of the qualifying criteria (Skipton Fund). Whether or not these were the right types of scheme to set up, with the right lump sum amounts (Skipton Fund) and the right objectives, is another matter. Perhaps the fact that funding has increased significantly since the DHSC transferred the scheme to EIBSS suggests that they acknowledge the previous schemes were underfunded.

93. Were there difficulties or shortcomings in the way in which the MFT, the SF and the CF operated or in their dealings with beneficiaries and applicants for assistance? If so (and to the extent not already addressed above) please set them out.

93.1. I think I have set out the main difficulties and shortcomings in the answers to the various questions that preceded this one. I am not best placed to comment on the operations or dealings of either the MFT or CF as my roles with them were very much a supporting role rather than one of influence or where I had dealings with beneficiaries (other than to attend MFT events in the early years). In terms of the Skipton Fund, although there were applicants who would have understandably been unhappy if their applications were not immediately successful, our dealings with the vast majority of people were positive.

94. Please provide any other information you may have that is relevant to the Inquiry's Terms of Reference.

94.1. I have no further information of relevance.

Statement of Truth

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

Signed GRO-C

Dated 23/02/2021

Table of exhibits:

Date	Notes/ Description	Exhibit number