Witness Name: Medora Ann Hithersay
Statement No.: WITN3206002
Exhibits: None
Dated: [ ] February 2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF MEDORA ANN HITHERSAY

I provide this written statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 27 July 2020.

I, **Medora Ann Hithersay**, will say as follows:-

1. My name is Medora Ann Hithersay. My date of birth is GRO-C 1937 and I reside at GRO-C I provide this statement in my capacity as former Director of the Macfarlane Trust ("MFT") and the Eileen Trust ("ELT"). I was employed by the Trustees as Director from approximately early October 1997 to October 2003. I have given considerable background information in relation to my experience and employment with these Trusts and, later, with The Haemophilia Society ("THS"), in my first statement to this Inquiry (URN: WITN3206001).

2. I have addressed the requests raised by this Inquiry in the sequential order in which they are put to me in the Inquiry's letter dated 27 July 2020, as updated on 17 September 2020.

Section 1: Introduction

What induction, training and information did you receive from the Macfarlane Trust and the Eileen Trust as to their functions, aims and objectives?

3. When I took the role at MFT, I first received copies of the Trust deeds. I then met with the Chairman, Reverend Alan Tanner, Deputy Chairman, Clifford Grinstead and the Administrator at the time, John Williams, who had set up the Trust and was also the Director. They explained the background of the Trust to me, including why, and how it had been set up. At that point I knew virtually nothing at all about haemophilia, beyond what you learn in school, and I knew very little about HIV. I received very little training and information, and so it was a steep learning curve. For a week I had a handover from John Williams. From what I could gather, he and one secretary had more or less been a one-man band. I believe they employed a benefits advisor shortly before I joined.

4. I had to do a lot of background reading very quickly. I learned about the existence of THS and I read some of their booklets as well, however beyond that, my training came from what little research I was able to do at the time.

5. Initially, I believed I was joining the MFT alone, and it was not until the first week or so into my time there that John explained the existence of the ELT to me. Obviously the sources of becoming infected with HIV were the same, in other words, infected blood given as part of treatment through the NHS. However, the key difference was that, in the case of haemophilia, practically everybody had been treated with Factor VIII which had become infected with the HIV virus. That was not the case with registrants of the ELT who were most frequently women, and whose infection had come through large donations of blood, often after haemorrhage at childbirth.

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.

6. I gave evidence to the Archer Inquiry, when I was a Trustee of THS. I also supplied evidence as part of a group of THS trustees to the Penrose Inquiry. I was not involved in the Lindsay Inquiry. During my period as Director of the MFT, I was involved in very many discussions with Ministers and with members of the Department of Health ("DoH"), however I do not believe we were actively involved in any Inquiry. The MFT used to meet regularly with the All-Party Haemophilia Group in the House of Commons and these were informative meetings; they were for us to pass on information we came across in the administration of the Trusts, that we felt was of value for the Government to know about.

7. I do not recall being directly involved in any civil or criminal litigation during my time at the Trusts. I do remember that MFT registrants did become involved with a class action which took place in the United States. Those were mostly people from one haemophilia centre, but I do not recall much more than that. I believe we gave them documents, I do not think we did much more than pass on medical records. I do not believe we prepare statements or gave evidence during this process.

8. I would like to make it clear that I did not make any individual statements to either the Archer or the Penrose Inquiry. I would have been involved in discussions about THS' submissions to these Inquiries, together with the Trustee Board, who I recall met with representatives of the Inquiry. I remember one particular meeting held in Glasgow. I cannot recall clearly, however there

was also one at the House of Commons, I believe. Any involvement I had was as part of a Trustee Board collective, not as an individual. Beyond that, there is no other information I am able to provide, and I do not have any documents that would assist the Inquiry.

Section 2: Establishment of the Trusts and Schemes

What did you understand the aims and objectives of the Macfarlane Trust to be? In particular, was it the role of the Macfarlane Trust to campaign and/or advocate on the part of its beneficiaries? If not, why not? When answering this question please consider the minutes of the Macfarlane Trust board meeting of 28 May 2002 in which the Trust agreed to '*put pressure on the Department of Health to provide funding for fertility treatment for Trust Registrants*' (MACF0000011_033).

9. I recall that the first thing I was told when interviewing for this role was that the MFT was not a campaigning organisation. Nevertheless, we were responsible for ensuring that the DoH knew all about the situations in which the registrants of the Trust found themselves. We were expected to regularly update the DoH about any issues that arose within the registrant community. I would say that the phrase "*put pressure on*" simply meant that we should make sure that the DoH were clearly aware of certain subjects, however contentious they were, which affected the registrants.

10. For example, I remember that the matter of fertility treatment was something of real significance to many registrants, particularly to those registrants who had been infected when they were young boys and grew up struggling to have families that they wanted. I think it was later agreed that it was their right to have fertility treatment if this would enable them to have a family life. The treatment that was available, was very intrusive and costly. Very often the number of "tries" were limited. The particular issue for young men with

haemophilia was that they were unable to have direct physical relations with their wives for fear of contaminating them. At the time a treatment was being developed called "sperm washing", which would have resolved their problem in this regard.

11. I think that the Trustees of THS were extremely concerned about the risks involved in this procedure. One of the MFT Trustees, Dr Mark Winter, who represented the DoH and was also the Centre Director for Kent and Canterbury Hospital, was particularly concerned about it. We, on the whole, preferred registrants to opt for a donor that was in no way related to the father to limit the risk of infection, but of course that would have been very difficult. Everyone had their concerns, and so it was a very contentious subject, a subject that we debated with the DoH for a long time. I do not recall what the eventual resolution was; the debate may have continued after I left. In the context of matters such as this, I do not consider "pressure" to be a form of "campaigning" at all. In my view, it was very much part of mine and the MFT's responsibility to let the DoH know, as far as possible, important details of the major issues facing the registrants of the Trust. The one that was uppermost at that particular time was fertility treatment.

Please set out how, as a charity, the Macfarlane Trust was regulated.

12. The Government, the DoH in particular, had set up the Trust in 1988 with the purpose of providing support, financial and otherwise, to those people with haemophilia who through their treatment with infected blood had become infected with HIV. At that time, a large proportion of those affected were boys who were still at school. A number of young men, and older men who were established and had families of their own, were also affected but their needs were slightly different. The DoH set up the Trust in order to see that they could have extra help over and above that which was provided normally through the NHS for people with HIV. In particular, the input from the haemophilia centre

Directors and the haemophilia centre staff was relied on by the MFT to give us information about treatments that were available, and the changing needs in the registrant group. The needs of the Trust, the needs of the registrants and the development of the Trust over the next few years changed very dramatically with the introduction of the combination therapies, which was around 1997.

13. The MFT reported regularly to the DoH and had regular meetings with them. Usually there was a "nominated person" who would be the MFT contact with the DoH. At intervals of one to two years we would have a meeting with the Minister of State responsible for the infected blood scenario. Over the years I think I must have met with three Senior Officers of the DoH with responsibility to the Minister of State for Health for Blood Policy. Two were named Christine Corrigan and Charles Lister, and there was one other although I cannot recall their name. They acted as liaison between the Trusts and the DoH. Initially, the MFT was viewed as a developing Trust which would have a short life because, at that time, it was expected that there would be no treatment and no survival of anyone diagnosed with HIV. The intention was that the Trust would help ease the life of those people who were infected and make their final years as comfortable as possible. What happened during the succeeding years was, of course, that treatments improved.

14. By the time I joined, combination therapies were becoming more widely available and the management of HIV developed into a completely different scene. On joining the Trust I was in a position to be answerable to the Trustee Board who, in turn, reported directly to the Minister of State through the DoH nominated contact. It was for the Trustees and I to create together, a different organisation than originally envisaged. One that would have the facility to support people who were not all terminally ill with HIV, but who would face the challenges of an indeterminate life living with HIV. This changed how the Trust operated over time and, gradually, very considerably.

15. The Trustee Board was made up of appointed people from both the DoH and THS, creating a group that had great knowledge and experience, not just of haemophilia, but also of every medical aspect related to HIV and haemophilia. I am sure that the appointees from the DoH would have had a reporting line upwards, independently of any activity that we reported through Trustees and through our direct meetings with the DoH. As an individual, I did not report to anywhere but the Trustee Board. I prepared reports for the DoH, and met with appointees in the DoH, however, this was as a representative of the MFT and on behalf of the Trustee Board.

What did you understand the aims and objectives of the Eileen Trust to be? In particular, was it the role of the Eileen Trust to campaign and/or advocate on the part of its beneficiaries? If not, why not?

16. The aims and objectives of the ELT were, in my view, very similar to those of the MFT. At the time of my involvement, THS and its registrants were a united group formed by past parent bodies to represent people with haemophilia. They were powerful at agitating, so the MFT had no need to be. The ELT was formed of people that were affected through other means, either through haemorrhages giving birth or through traumatic accidents. They would have been given large transfusions of blood and the development of HIV, in many cases, would have appeared to be completely inexplicable. It was a very difficult situation that only came to light gradually. As identification of a group of people that had been infected in this way grew, the need for another Trust was recognised by the DoH. Whilst the situation of infections was different, our role was exactly the same as it was for the MFT, in that we were providing support and services for them, we were not campaigning for them.

17. Over time, I am sure we came across similar causes that were important to the ELT in the same way that, for example, fertility treatment was for the MFT. Most frequently, causes that were important to ELT registrants would have been in

relation to widows with children, infected children, or children of mothers who had died, all of which had growing needs as a group. I think it would have been a question of highlighting these matters in an exchange of letters, rather than drawing up a report. In fact, I do not recall that we were ever asked to draw up a report on registrants of the ELT.

Please set out how, as a charity, the Eileen Trust was regulated.

18. The ELT was regulated by a Trustee Board. That Trustee Board, as I recall, was set up by the DoH. It was made up of some members of the MFT Trustee Board, some independent individuals, and some social workers. My recollection of the make-up of the ELT Board is such that there was at least one HIV worker, and they would have been nominated by the DoH. We had no part in determining who made up that Board, save for there being some Trustees who served on the Board for both the MFT and ELT.

19. I do not believe there was any overlap between the regulation of the MFT and the ELT. They were dealt with as two entirely separate entities, and we kept all of the records separate for each one also. The only things that they shared were the staff group, which I managed, and some of the Trustees.

20. In a letter from the Inquiry, dated 17 December 2020, I was shown a list of all trustees and trust staff who worked for the ELT during my tenure. I recognise all of those names, save for Frank Fix, and they were not HIV workers. Having said that, the HIV worker would not be considered a member of the "trust staff", and so they may not be part of the list that the Inquiry set out for me. That does not mean that there were not HIV workers on the ELT Board.

Please describe your involvement with and/or recollection of the circumstances leading up to the establishment of the Skipton Fund. In particular, please address the following:

a. levels of funding proposed and discussed for the new scheme;

b. views as to the appointment of Trustees and joint administration of the Macfarlane Trust, Eileen Trust and the new scheme;

c. the role of medical needs assessments under the new scheme;

d. changes to cut-off dates used by the Macfarlane Trust and Eileen Trust;

e. whether the 1991 HIV litigation waiver or other litigation settlements raised concerns about eligibility under the new scheme.

21. In around 1997 a need had been identified to provide help for those people with haemophilia who had not been infected with HIV. Whereas everybody had known that the Factor VIII treatments that had been administered in the 1970s and 1980s had often or almost always contained the HCV virus, this was not seen as a significant problem for many years. Sadly, in the very early years of my tenure at the MFT, this growing problem was already the topic of discussion because some people with haemophilia, who had contracted HCV, were becoming very seriously ill, and it was clear that the Government needed to have this brought to their attention. After the introduction of combination therapies in the late 1990s, it soon became apparent that for those co-infected people who were registrants of the MFT, the combination therapies could have a very adverse effect on their liver, and so there was a great deal of discussion about this and an intensification of the efforts to get another fund set up for people with HCV.

22. In my recollection, there were two key areas of concern. The first was about people with haemophilia who contracted HCV and, over the years, became ill with it. The second group of people were those who were co-infected and, due to their treatment with combination therapy, developed very severe liver problems.

23. In respect of the specific points raised in the question above, firstly, on the issue of funding for a new scheme, the first discussion I recall having about this was

with Karin Pappenheim, who was the CEO of THS at the time. I think that was probably in the very early 2000s. She had referred to a compensation scheme that had been set up in Canada, and she wanted me to inform her of the specifics of how we had worked out the regular payments and special payments for the MFT registrants. Over a period of years, we looked at how to set up a proposed scheme of payment.

24. The Inquiry has referred me to documents SKIP0000031_081 and SKIP0000032_290. In respect of reference to an expert report within this correspondence, I do not recall much about what this said, however I do remember that there was discussion about a very expensive scheme that was used in Canada. I do remember that, as a result of that, I highlighted the differences between the scheme there and the scheme we used here and how the MFT arrived at their decisions around what payments to make. As I recall it the eventual proposals that we made to the Trustee Boards of both the MFT and the ELT were based on a model that was a lot nearer the MFT model than the Canadian model. This was right at the very end of my tenure as Chief Executive. In fact, my successor, Martin Harvey, was already in post by then so although Karin and I had the discussions and we made the proposals, I was not involved beyond that until I later became a Trustee of THS.

25. In respect of my views as to the appointment of Trustees and joint administration of the MFT, ELT and the new scheme, I do not feel I can comment as the relevant discussion and decisions in this respect were taken after I had left my role.

26. The matter of medical needs assessments under the new scheme was something that was discussed a great deal at our Trustee Board meetings and also between Karin at THS, myself and others in our staff group. In my view, it was entirely a matter for the medical teams in hospitals and HIV centres, as well as in the haemophilia centres, to bring to our notice anyone they felt should be

registered. I expect this would have continued with the new Skipton fund, in that it would have been the primary responsibility of the medical community through the specialist centres and occasionally through GPs to bring people to the notice of the DoH, and thus suggesting that they could be registered under this new Trust. We would have relied on medical recommendation, and it would not have been up to either the MFT, ELT or, indeed, the new Trust to make any decisions ourselves.

27. In respect of the issue of changes to cut-off dates used by the MFT and the ELT, we did bring this matter to the attention of the DoH. As it became clear that the use of combination therapies was leading to the registrant groups of these Trusts becoming a group of people who were not all terminally ill and, in particular, there were younger registrants who thankfully seemed able to go on and have "normal" lives, that the 2012 cut-off date in place was going to be far too soon. I think in the early years of the new century, we were seeing that there would have been the potential for many of these young men to live an indeterminate life, therefore we did not want there to be any definitive cut-off in financial support from the Government. I believe we recommended that there should be an extension of at least ten years.

28. Finally, the Inquiry asks me to consider whether the 1991 HIV litigation waiver or other litigation settlements raised concerns about eligibility of registrants under the new scheme. I do recall that our Trustee Board felt very strongly that the development of the impact of HCV was an entirely new situation, and that any waiver previously agreed should not apply.

29. My understanding of the situation at the time was that the waivers referred to related to haemophiliacs who had been undoubtedly contaminated with HIV through their treatment, and their records confirmed as such. The waivers related to the scale of payments that had been based on the presumption of a short life expectancy, at the time. There was no reason that the Trustee Board

would have seen any reason to carry those waivers forward to a future scheme, and I expect they would have reminded the DoH of this in their reports.

30. I recall that a number of the issues I have discussed in response to this question came up towards the end of my involvement at the MFT. Having said that, a number of us there felt that the emergence of HCV and its consequences were not matters that had been contemplated when waivers were agreed to in 1991.

31. The original proposal, from what I was told when I first joined the MFT, was that the Trust was set up to run for 25 years, which would have taken it to 2012. Quite early on in my tenure, we highlighted the changing needs of the registrants, their children, and infected intimates. I recall that reports on this matter were prepared keeping in mind that we had to make this very clear to the DoH.

32. We did not ask the DoH for an extension as such, rather, we highlighted the support that registrants would continue to require after 2012, and how the needs of the registrant body had changed considerably since the MFT was originally set up.

33. Any changes that may have followed these reports occurred after I left the MFT. By then there was a probability of another Trust being set up. I was engaged in some early discussions on this, however, I had left some time before the eventual establishment of the Skipton Fund ("SF") and so I am unable to assist the Inquiry with their questions about this.

34. As I have stated above, I had no hand in setting up the SF and so I cannot explain why particular decisions were taken by those that administered that fund.

Please consider the report entitled 'Recompense payments to people with haemophilia and HCV' dated 9 January 2002 (MACF0000080_032, enclosed). To what extent were the proposals in that report implemented and why? In particular, please address the absence of stage 1/stage 2 payment distinction.

35. The initial payments to beneficiaries were agreed by Government and were implemented when the Trust was first founded in 1988. It is my recollection that the special payments banded into stage 1 and 2 came about as the situation changed. The payments that were made at the time of the Trust being set up were different according to the age and stage of life of the individuals applying. At that time I think stage 1 payment just drew attention to the fact that the younger registrants had been paid less. My recollection is that the first special payment for a young registrant was £18,000, as against a married man receiving considerably more. As such, these payments were being made in recompense to recognise that the situation for these young men had changed and therefore they should receive a larger payment. I cannot recall what the stage 2 payment was for, however I do know that the Trust administered both of them.

36. Both stage 1 and 2 payments were specifically related to people with haemophilia, and the changing nature of the illness they were dealing with due to advances in medical science. Therefore, these special payments would not have been replicated in the new scheme. I do not recall, in my time at the Trust, that payments were altered in any way for people with haemophilia and HIV. Neither was this the case if a registrant developed severe illness because of HCV. A fund to make that possible had not been set up when I left.

37. The document that I have been referred to is a schedule was put together during my discussions with Karin Pappenheim, who was the Chief Executive of the Haemophilia Society at the time, close to the end of my tenure at the MFT.

She had been researching the viability of a scheme of recompense payments such as those granted to people with haemophilia in Canada, who had been diagnosed with HCV. She asked me to provide her with information from the MFT relating to the recompense payments that the Trust paid, which is what is contained in this document. I am not aware of what Ms Pappenheim did with the information, or if the SF based anything that they did on the figures that I provided.

Was there any discussion about the discrepancies in the schemes' treatment of those 'infected' with HIV and/or Hepatitis, and those 'affected' such as widows and dependents? Please consider your email to colleagues at the Haemophilia Society from 28 June 2007 (HSOC0021255, enclosed).

38. I believe my comments in this e-mail are self-explanatory. It was clear that I felt that it was very important indeed that the needs of the widows and dependants should be met as fully as possible, and that applied to both Trusts.

39. This e-mail was, as far as I recall, part of a much larger submission that we made to the Archer Inquiry and it was at that point that I was a Trustee of THS and no longer had any role within the MFT. Nevertheless, it did not change my view in any way that the needs of widows and dependants were absolutely as important as that of registrants, in that they needed ongoing support for very complex bereavements.

Section 3: The AHOs

Appointments of Trustees

In relation to beneficiary Trustees, please set out any factors in favour of or against the appointment of this type of Trustee during your tenure as Director of both Trusts, including potential conflicts of interest and any limitations on

the number of Trustees as a result of the relevant trust deed. In doing so, please consider the following enclosed documents:

a. **Minutes of Macfarlane Trust meeting from 12 July 1999, in particular at pages 4-5 (MACF0000017_068).**

b. **Email from Peter Stevens to you and others dated 21 April 2005, forwarding the previous email chain (HSOC0027816).**

40. When I joined the MFT I came from a background of working with User Trustees, which are referred to here as registrant Trustees, in two other charities. I understood from John Williams that when the MFT was originally formed there had been User Trustees on the Board appointed by THS. This had led to some contention and so the practice had stopped. I felt very keenly that there should be User Trustees on the Board, and when we established the Partnership Group, that they should also be involved with this. This started a debate which lasted over a number of years. Trustees and myself had various discussions with the Charity Commission about this, most likely because the Charity Commission may have become concerned about the involvement of User Trustees. They felt that those who were getting any direct payment from the Trusts were in some way different to those User Trustees who received services from them, and that for that reason, the Charity Commission were of the view that we should not have User Trustees at all.

41. To my recollection I became part of a very small group working with the Charity Commission to consider the role of User Trustees in charities, and the MFT being set up to provide cash payments to registrants. This was in contrast to most charities being set up to provide services rather than direct payment. I believe that by around 2000, User Trustees were again appointed to the MFT Board.

42. One of the main barriers we faced to the inclusion of User Trustees on the Board was that a registrant should not be present when another registrant was

being discussed. However, the point at which these concerns may have been valid was when grant applications were discussed at the end of a Board meeting. Those grant applications were, however, referred to using randomly assigned numbers, rather than the registrant's name and so I did not accept the validity of this argument.

43. The applications themselves were considered by an Allocations Committee and, as far as I can recall, the Allocations Committee definitely did not have any User Trustees involved. This committee was made up of the MFT social worker, the finance officer and one other. I did not attend those meetings, and the grant applications drawn up at those meetings were anonymised.

44. One other reservation I recall was in relation to medical issues, although I cannot remember the specific detail around this. I think the medical side of the Trust, the Centre Directors and Nurses, felt that it would inhibit free discussion of developments or pitfalls on the medical front if registrants were present at meetings. Whilst I cannot recall the debate around this, I do remember that there were User Trustees at Board meetings before I left the MFT, as I have advised above.

45. In respect of the Inquiry's question around limitations on the number of Trustees as a result of the relevant Trust deed, six Trustees were appointed to the MFT Board by THS, and four by the DoH. The User Trustees, which I remember were not more than two members, were to come from THS and they would be proposed by the Partnership Group.

46. In respect of the ELT, I cannot recall that the issue of User Trustees was raised at any time.

What was the process for electing/re-electing Trustees at the Macfarlane Trust and the Eileen Trust? In particular, what involvement did (a) the Department of

Health (or any other Government department) and (b) any other organisation or person have in this process? Did these matters change over time?

47. I believe that Trustees were nominated – I do not recall there being any election process. As I have stated above, the DoH nominated four Trustees and THS nominated six. My recollection is that for each organisation the term of tenure for a Trustee was two years, and that they could serve two terms. I am not certain that that was strictly adhered to because I think for most of the time I was at the MFT as Director, the same haemophilia centre Director, represented the DoH. The haemophilia centre nurses, who were also nominated to the Trustee Board by the DoH did rotate. I recall there being three or four of those. I do not believe that the process of nomination changed during my tenure with the MFT.

48. Beyond the above, I do not believe that the Government or the DoH had any other part to play in who made up the Trustee Board. In the original trust deed there may have been some indication or expectation that there would always be at least one Centre Director nominated by the DoH permanently sitting as a Trustee, and always at least one, if not more, haemophilia centre nurse. I do not recall the position of other nominees from the DoH. Any nominee would have specific skills that the DoH felt were relevant to our Trustee Board, certainly we often told THS which skills we felt it would be useful to have on the Trustee Board and they would nominate Trustees accordingly. For example, I recall that the Trustees suggested that someone with a legal background would be useful to have on the Board, and in time, a solicitor member of THS was appointed as a Trustee. When it became apparent that the original Chairman was going to retire, the Trustee Board of the MFT requested that someone with business experience be nominated to take his place. This process did not change at any time whilst I was at the MFT.

How, if at all, were positions advertised?

49. I know that my position was advertised, however I was not a Trustee. I have no recollection at all of any other Trustee positions being advertised. Due to the nature of the original deed, I do not think that advertising for Trustees would have necessarily been relevant or appropriate. There may have been internal advertisements at the DoH or THS, however, if there were I did not hear about any.

Were there sufficient applicants of sufficient quality or did you struggle to appoint suitable Trustees?

50. Further to my comment above, this question is not relevant.

How many Trustees were appointed by the Government, how many by the Haemophilia Society and how many were 'beneficiary Trustees' during your tenure at the Macfarlane Trust and the Eileen Trust respectively?

51. As I have advised above, four Trustees were appointed by the DoH, and six by THS in the case of the MFT. In the case of the ELT, the Trustees were appointed by the DoH, however I cannot recall how many there were. I believe that towards the end of my tenure, two of the appointees from THS were User Trustees. I have no knowledge of how these appointments were arrived at.

How long did each Trustee serve on the board? Could a Trustee be re-elected? If so, how many times?

52. As I have stated above, each Trustee served for two years, and could serve two terms in total. Again, I am not certain that this rule was strictly adhered to.

Were Trustees remunerated for their work? Please include details of any policies on this, including policies for allowances/expenses.

53. Trustees were paid expenses, which would have related mainly to travel and overnight stays where they were attending conferences.

Was there an overlap of Trustees between the different AHOs? Please explain how this worked and what if any impact it had on their ability to carry out their respective roles.

54. There was overlap of Trustees between both the MFT and the ELT. However, when Trustees operated, they did so as Trustees solely of the organisation that they were meeting to discuss. They did not exchange views on or discuss the other Trust at any point, so there was no overlap of information, and I do not believe that these dual roles had any impact upon their effectiveness as Trustees for each Trust. Whilst there was no overlap of information, there was overlap of staff and premises as detailed further below.

Structure of the AHOs

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 beneficiaries aware of this?

55. Firstly, I would like to clarify that we did not refer to registrants of the Trusts as "beneficiaries", as we did not consider we were providing them with charity. We administered payment of a fund that had been allocated to be paid to them by the DoH. Where I have referred to registrants as "beneficiaries" in this statement, it is in response to the terms of a question that the Inquiry has put to me. We did not refer to registrants that way.

56. We operated in the same offices, in Alliance House in Caxton Street. The staff group who supported both Trusts were the same, and administration resources were also the same. The same staff group served both Trusts and they were meticulous about ensuring a distinction between the two. Records were kept completely separate, meetings of staff were restricted only to discussion of the particular AHO that was under consideration at the time, the Trustees met at separate Trustee meetings for each AHO, each with their own agenda and minutes. I do not believe that the fact that both Trusts shared premises, staff, and resources had any impact whatsoever on the independence of each Trust from the other, during my tenure.

57. In respect of data sharing, confidentiality and storage of documents, at the time I joined the Trust everything was on paper, and records were stored in paper files which were kept in different parts of the office. As time developed, a lot of records became computerised, and they would have been stored and accessed completely separately from each other. The financial records and the administrative records would have been kept entirely separately from each other also.

58. As I have said above, I managed the staff team in respect of both of the Trusts. The staff supported both the MFT and the ELT. I had my own office, where I often held meetings, and the staff team shared a large central workspace where all the administrative and filing systems were also kept. Files were kept in separate filing cabinets at different ends of the office. When records became computerised, they were separated by use of separate passwords, and access to those passwords were only given to staff members who needed it.

59. On the matter of data security, the ELT would have had one set of passwords and the MFT another. However, since the staff group was the same, in the course of their duties they would all have been involved with both.

60. Information was not shared across AHO's in relation to beneficiaries however, general medical information, such as the development of combination therapies, would have been shared across both Trusts, since it applied to registrants of both Trusts. Accordingly, we had no need to inform beneficiaries of this.

Please set out your recollection of the relationship between the different AHOs.

61. As advised above, there were two sperate Trustee Boards, with at least three common Trustees, and the staff groups were the same. Those Trustees who were not Trustees of the MFT but were of the ELT were treated specifically as part of the Trustee group of that charity. They would not have needed to have any relationship with the MFT Trustees because they would be dealing with a different group of clients.

In general, what was the impact of such relationships on working practices at the Macfarlane Trust and the Eileen Trust, such as in relation to (a) processing of discretionary payments, (b) evidential standards and (c) appeal procedures? Please explain the concerns raised in the following documents:

a. Letter by you to Frank Dobson MP, the Secretary of State for Health, dated 24 October 1997 (EILN0000009_038, enclosed).

b. Email from Peter Stevens to several recipients in relation to a Charity Commission complaint from 29 August 2002 (HSOC0028385, enclosed).

62. As advised above, there was no contention in relationships between both Trusts, as they both had overlapping members who were clear about their separate purpose on the Board of each Trust.

63. In 1997 Dr Winter raised the difficulty of determining whether or not ELT registrants had got HCV through infected blood, or whether they had contracted it through all the other sources by which the public contract HCV. I recall that as being a tricky issue when I first joined the MFT, however I do not believe it came up frequently. I do not know how it was eventually dealt with bearing in mind the eventual emergence of the Skipton Fund. Whilst it was known that the ELT registrants had received large blood transfusions, some of which had been infected with HIV, it could have been assumed that if they subsequently developed HCV it was most likely that they would have got it in the same way through their treatment. If other people in the community were to appear who had HCV and had had a blood transfusion, the difficulty of actually determining whether or not they had got that treatment through the blood transfusion or other means was going to be a difficult one. I think it was raised as a potential issue to be considered in the development of any new funding scheme, rather than a major issue between both Trusts.

64. This discussion was very early on in my tenure as Chief Executive. The letter I wrote to the Secretary of State for Health was at the behest of Dr Winter to look at an emerging possible problem that was some six years before we actually had a Skipton Fund. The eventual resolution, if there was one, was not within my time at the MFT and ELT.

Please describe the working relationship between the Trustees at the Macfarlane Trust and Eileen Trust respectively and the senior management. Were you aware of any difficulties? If so, what were they, how did they impact on the running of each Trust and how, if at all, were they resolved?

65. Again, I cannot recall there being any difficulties between Trustees at both Trusts. The senior management was the same, which is why I cannot really see how there could have been a conflict. There obviously were Trustees of one organisation who were not Trustees of the other, but the Chairman and

the Deputy were the same, the Chief Executive was the same, the social worker, benefits advisor, finance officer were the same people, and as I referred to earlier, they kept apart their discussion and dealings with each specific Trust. I do not recall any time when any Trustee who was not a Trustee of the other organisation brought up any reference or conflict.

Relationship with Government

To what extent was the Macfarlane Trust and the Eileen Trust independent from Government? How much oversight did the Department of Health (or any other Government department) have? In particular, did the Department of Health have any involvement with and/or give any direction/guidance to either Trust (and if so, what?) as to the following:

a. the composition of the board of each Trust;
b. the content of any policies adopted by each Trust;
c. how each Trust should discharge its responsibilities to the beneficiaries;
d. the kinds of applications each Trust should grant; and/or
e. the quantum of the grants/payments it should make?

66. Both of the Trusts were set up by the DoH, and Trustees nominated by the DoH sat on the boards of both Trusts. Funding received by both Trusts came from the DoH, and we reported to them regularly. Beyond that, as far as involvement in the specific work of the Trusts, the DoH and the Government played no part. They did not attend individual Trustee meetings, partake in discussions about individual clients, or have relationships with individual social workers or Centre Directors. Nevertheless, it cannot be said that they were not "involved" with the Trusts as they had a fundamental role to play in the Trusts' existence.

67. Originally, at the establishment of the Trusts, there would have been proposals for areas of registrant need, and possibly a schedule of the kind of payments for grants that would have been addressed by both Trusts. Regular payments, as a principle, were agreed as part of the original Trust deed for both Trusts, in which the DoH was involved. Over the course of time the payments of special grants changed with the changing nature of impact of HIV on the lives of registrants. In the early days, grants would have been very much related to care and support for the family. As time went on we moved into whole areas of support for people's accommodation and support for aids and equipment, support for alternative therapies, and establishment of support groups. Also, as time went on it became clear that people who had been young when they had first contracted HIV and therefore were not expected to have a life, had changing needs. Matters of further education had not been addressed initially, and as time went on they later felt that they would quite like to study, possibly even go to University. With these changing needs, the Trustee Boards would have advised the DoH of a need for such an enhancement of payments, and this applied to both Trusts.

68. Referring to the Inquiry's question, the DoH and, by extension, the Government, had an involvement in the composition of the Board of each Trust and the content of their policies to an extent. However, on the issues of discharging responsibilities to beneficiaries, the kind of applications that each Trust should grant, and the quantum of grants and payments, the DoH had no involvement save for funding. Their only continuous reminder was that the Trusts had been set up to compliment, not replace, what the statutory services provided.

Did you or others within the Macfarlane Trust or the Eileen Trust raise any concerns and issues with the Department of Health about the funding, structure, organisation or running of the AHO, or about the involvement of the Department of Health, or about any other matter? If so, please explain what

concerns and issues were raised. What was the response of the Department to those matters being raised? In answering these questions, please consider the following enclosed documents:

a. The Strategic Review Update Report (MACF0000005_036 at pages 46-47).

b. Letter from you to Charles Lister at the Health Services Directorate dated 19 February 1999 (EILN0000009_029).

69. As I recall, the setting up of the Strategic Review had been mooted as long ago as 1996, and had not in fact come to be carried out until 1998. We were at that point aware of changing needs in the registrant group, and it was decided that the best thing to do would be to review the workings of the Trusts in the first ten or so years. We were of the view that the life of the Trust was going to need to be extended beyond the original time and that it would be necessary to have ongoing funding promised from the DoH for a longer period than had first being anticipated.

70. The Inquiry has referred me to a letter to Charles Lister date 19 February 1999, I note reference to the deed of confirmation and a variation amending the ELT, however due to the passage of time, I have no recollection of the circumstances and details of such amendment.

71. I am not aware of any concerns or issues raised in relation to any of the matters raised by the Inquiry in their question, save for the ongoing knowledge that the growing and change needs of the registrant body would lead to a need for the DoH to provide more funding, and extend the life of the trust.

72. At the time that the Strategic Review Update Report was prepared, it was beginning to become apparent that the combination therapies were causing difficulties for people with HCV and that co-infection and the treatment for it was having a detrimental effect. Certainly I would have made Charles Lister

aware of that. There would also have been a review of the issue of fertility that would have been raised with him, predominantly during face to face meetings.

What was your involvement in the Strategic Review which resulted in the final report of January 1999? What did you consider to be the main areas of concern or for improvement in light of that review? What steps were taken within the Macfarlane Trust and on the part of the Government or Department of Health in response to the findings of this Strategic Review and were those steps, in your view, adequate? In answering these questions, please consider the following enclosed documents:

a. The Final Report of the Strategic Review of the Macfarlane Trust dated January 1999, in particular the main recommendation at paragraph 10.3(i), page 26 of 42 (MACF0000045_019).

b. Minutes of Macfarlane Trust meeting from 29 October 2002, in particular the section "Department of Health Report" (pages 5-8 of 11) (MACF0000011_002).

73. I recall that when the first Strategic Review was suggested, we prepared a sort of proforma of how this review task would be undertaken. There was a review group which was chaired by the Chairman. That group met regularly with me, and I think the social worker was also on it, and we worked through the areas that would be important to highlight in any review. We did draft in extra support to assist with this task. It was difficult to ensure that we had the resources to carry out this review as well as all our day to day work. We used a professional to draft questionnaires that were sent to registrants, and we consolidated and reviewed the answers that were returned.

74. There were a number of key areas of concern and potential improvement. In my view we needed to give more direct support to the registrants, and should have involved them more in decisions taken about the Trusts. I think this was generally recognised by the staff group and Trustees, and I believe the idea of

setting up a Partnership Group was greeted with some enthusiasm. We felt that the DoH should also welcome more involvement with the registrants, and I believe that the Trustees wanted to make that clear. At the time of preparing the Strategic Review, the Trust was very concerned about the continuing funding that was needed to keep up with the changing life expectancy of the registrant group. In addition to bringing this to the attention of the DoH, we also wanted to show how we hoped to mitigate the effects of living with both viruses.

75. Following the Update Report, the DoH were pleased to hear about how these developing needs could be managed, and about the setting up of the Partnership Group. I can say with hindsight that following the Review the DoH continued to support our work and I cannot recall any instance where they tried to curtail it. There were areas of continued difference of opinion, such as in relation to sperm washing and fertility treatments, however I do not think we ever came into serious conflict over these matters. The recommendations in the Review were taken seriously and implemented as far as possible, and the steps taken were adequate.

76. As far as I am aware, there was no disagreement between the Trustees and the DoH about any of the findings in the Review. Nevertheless, the Trustees came to the decision to undertake a second strategic review a few years later, and again I was charged with organising it. This second review covered a huge panoply of issues for consideration. The staff group at the time would have been enhanced by the employment of a finance officer which helped resource.

77. I do not believe that commissioning a second review meant that the DoH had no regard for the first one. I think, because changes in the survival and quality of life of the registrant body were happening at such a fast pace, the Long Term Review was a positive decision to determine what could be done to

improve the outlook for those people we were supporting. On that occasion the Trustees decided to use an external consultant to carry out this review. I believe they felt that this task would add a considerable burden to the in-house staff. By that time we had developed a number of activities and projects involving the registrant body. Certainly the Chairman, the MFT social worker and I were visiting more and more haemophilia centres around the country and holding meetings with registrants. It simply would not have been possible to have conducted another detailed review in-house.

What if any contact did the Macfarlane Trust and the Eileen Trust have with the Department of Work and Pensions ('DWP')/its predecessors in relation to welfare benefits and/or tax exemptions? In particular:

a. Were you aware of any beneficiaries having their benefits and/or tax exemptions stopped as a result of the assistance they received from the AHOs? Please consider the letter from Charles Lister to you dated 27 January 2003 (EILN0000009_004, enclosed).

b. Did each Trust take any steps to prevent this happening? If so, what? If not, why not?

c. Did each Trust raise this issue with the DWP/its predecessors and if so what was the response?

78. The Trusts had a benefits advisor, and our benefits advisor would have been in touch with the DWP on the behalf of registrants, where such help had been asked for. My personal involvement would not have been great at all. I think I may have written one or two letters about certain issues, but generally, contact between the DWP and the MFT would have been through the benefits advisor who represented our registrant group.

79. The Inquiry have referred me to a letter from Charles Lister dated 27 January 2003. My recollection is not so great, however I expect that a question must have been raised through the benefits advisor following queries from a

registrant about their tax status, and how their payment may be regarded for tax purposes after it was paid to them. This letter from Charles Lister clarifies the position. Unfortunately, I cannot recall any great deal without review of my letter to Charles Lister, which we do not have sight of. As I recall, income from the Trust, be it in the form of regular grants or special payments, were free from income tax. Nevertheless, when the money was spent it fell under standard taxation rules. The agreement was that once a payment is made to the registrant, it is theirs to do as they please with. I think that is what this query came down to. I expect a registrant who had invested the money they received from the MFT may have wanted there to be a tax exemption applied to the increase in value of the investments.

80. As to whether any beneficiaries had their benefits and/or tax exemptions stopped as a result of the assistance they received from the Trust, I do not recall that happening at any time. Had that happened, the MFT social worker and the benefits advisor would have heard about it first and reacted. In turn, the Trustees and I would have become aware of it. I would have written to Charles Lister in these circumstances, however at this distance I am afraid I cannot recall whether in fact that did happen. Having said that, I cannot believe that anyone would have sustained impact on their benefits status in any way, as a result of these ex-gratia payments made by Government, through the Trusts.

81. In response to the further questions raised by this Inquiry, it is most likely that our benefits advisor would have taken steps had she seen the slightest possibility of an impact on a registrant's benefits due to payment received from the Trusts. She would have most likely quoted the terms of the trust deed and given explanations to the DWP as to why the registrant should be exempt from such impact. I have no recollection of any specific instance where this happened.

Section 4: Funding/finances of the AHOs

Please set out the process by which the Macfarlane Trust and the Eileen Trust received funding from the Government. Did this change over the time you were involved? If so, how? Were there problems with this process? If so, what were they and what were the consequences? Please give more detail about what you say in paragraph 10 of your witness statement of 19 October 2019 to the effect that members of the Board at the Macfarlane Trust were not willing to approach the Government for additional funding:

a. Did this remain the case throughout your tenure?

b. What was the rationale behind this stance as far as you understood?

82. The Trusts received an initial capital grant; in the case of the MFT that grant was given in late 1987 or early 1988, and the amount was £10 million. It was agreed at that time, and it continued throughout the time I was at the Trust, that the administration of the Trust, the funds needed for staff, premises and administration, were funded under Section 64 grant funding. This was normally agreed for a three year period but it was reviewed annually, and during my time there were a number of increases in funding.

83. Funding from the DoH would be provided when we applied for it. We reported regularly to the DoH and our reporting included financial reports. It was made clear in our reports that, as the needs of registrants significantly changed over the period of my tenure due to the introduction of combination therapies, the nature of funding provided would also need to change, and so did the amount that we needed to give to registrants in their regular payments. Registrants did receive other amounts of money from the Government twice during that period. These were special payments 1 and 2.

84. The changes in the amount of funds that we sought were usually in the form of capital top-ups. Originally, the plan had been for the MFT to be a short-lived

trust. It was believed that everybody was terminally ill and it would just be a matter of time before funding would cease. It did not turn out like that.

85. During my tenure I do not think we ever had problems obtaining an increase in funding. The Trustees and I would meet with our representative at the DoH and make our case. There were sometimes delays, usually due to wider budgetary issues within the DoH, not problems that were related specifically to the Trust. On one occasion we requested funds which were not paid until one year later however we were kept up to date about this situation, which had to do with the general economic situation in the country at the time, rather than the Trust itself.

86. One of the consequences of this delay was that we had to use capital funds for day to day payments which had not been planned. I think we may have also delayed the introduction of a staff post or the conducting of a review, but these were not critical delays and we found ways around it.

87. The Inquiry refers me to paragraph 10 of my witness statement dated 19 October 2019. I would point out that I did not have any papers in front of me when I made that statement. The enormous amount of documents provided now throws a lot of light on many issues. When I was introduced to the Trust by the Trustees, in particular by my predecessor John Williams, it was explained to me that the Trust had been set up by Government with a grant of £10 million, and that the way that this fund was to be managed, according to the Trustees, was by investment in two funds. One was a private investment fund and one was the Charities Fund, which was a fund that invested money specifically on behalf of charities. The income from those investments would be used to meet the cost of the regular payments. The single grants might require us to dip into capital funds and when I joined, to the best of my recollection, the amount of capital left was about £7.5 million and the Trust had been in existence for nine years. It was therefore very clear to me from their

instructions that we should be carefully nurturing the investments and be frugal or careful in making grants.

88. I believe the first time that I said we would need more significant funds was related to the "Y2K bug", when a large part of the population believed that computers worldwide would crash and a lot of data would be lost. I suggested that we would need to apply for additional section 64 funding in order to meet the cost of protection from that, and I did get in touch with our contact at the NHS Executive at that point. I cannot remember whether it was Christine Corrigan or Charles Lister at that time.

89. I believe we also requested a top-up in 2002, although I cannot recall the details of this. It was subsequently agreed that the capital fund would be reviewed in light of the grants paid by both Trusts, and those funds would be topped up regularly if necessary, on a three-year rolling programme, subject to substantiation of a request.

90. I would suggest that the reason we did not repeatedly request top-up funds was because the capital and investment funds were well-managed and sufficiently replenished to allow us to serve the needs of the registrants as and when they arose. When this changed, we made the relevant requests supported by a business case and we were not turned down, I would like to think, because the DoH could see that the Trusts and funds were well-managed.

What do you know about how the Government set the budget for the Macfarlane Trust and the Eileen Trust? What input did you or each Trust have in this process? What input do you consider you should have had in this process? Did the Government take account of any representations made by the relevant AHO? Please consider in particular issues raised in relation to (a) increased expenditure projections and (b) the needs of widows and

dependants in the minutes of the Macfarlane Trust meeting from 28 May 2002 at paragraph 17.02, page 6 of 10 (MACF0000011_003, enclosed).

91. The Trust budgets were set according to our reports to the DoH on the nature of our activities and the changing needs of registrants which we brought to their attention when necessary. We created what we hoped were realistic budget proposals for the DoH to consider each year.

92. By the time of the preparation of documents referred to above, we had a finance officer who worked with the Treasurer of the Trust to oversee the development of budgets based on what the staff group recognised as the Trust's needs for the forthcoming year.

93. In terms of my input in the finance process, we had a fully qualified finance officer in post, and an experienced Treasurer for whom I had a lot of respect. My input was therefore comparatively limited, as it should have been. I did not have their expertise. I felt we worked well as a team and that we presented realistic budgets. That did not mean that there were never any changes that necessitated our seeking more funds where necessary, however we anticipated these and responded accordingly.

94. The Inquiry asks whether the Government took account of any representations made by the Trusts. I believe they did, we had a good working relationship. There might have been a time later on, towards the end of my tenure, when they outright refused to fund something, but I do not recollect the detail. It was very rare that our requests were refused though.

95. I am referred to minutes of the Macfarlane Trust meeting from 28 May 2002, and paragraph 17.02 of that document in particular. I recall that 2002 and 2003 was a difficult time financially in the wider economy, not just for Trusts and charities. I think that where the minutes speak of the section 64 award

being likely to be reduced, I surmise that was a general tightening of the purse-strings, rather than a rejection of our proposals. Obviously, a reduction of funds would have been disappointing, but we had to recognise the circumstances under which any potential reduction might be made.

What information, if any, did the Macfarlane Trust and the Eileen Trust have about the beneficiary population and what was required to meet their needs? Where did this information come from? Was this information provided to the Government? If so, how and when? If not, why not?

96. We gathered as much information as we possibly could about each of our registrants. Each registrant had their own file, and when a registrant flagged a need or sought a grant they would be visited by the MFT social worker and, if necessary, the benefits advisor. On occasions there would be meetings at haemophilia centres around the country, and on those occasions we would have an "open session" which was for any registrant who wanted to come and meet us. The team would comprise of myself, the Chairman and the MFT social worker, and on occasion also the benefits advisor. The MFT social worker and the benefits advisor in particular frequently visited registrants of both trusts. I used to visit registrants also on rare occasions, often in hospital. We learnt as much as we could about our registrants in this manner.

97. Over time, as we developed conference events and other activities for residents to meet together, such as the Bereavement Project and the Partnership Group, we gathered more and more information about them. I would say that, during my tenure with the MFT, we had a pretty good knowledge of a high percentage of the registrants. We would use this information in our reports to the DoH to indicate trends and changing needs of the community.

98. Reports to the DoH did not contain specific information about individual registrants. We would discuss trends such as accruing debt problems seen in a large number of registrants, and explain why this was happening. As an example, when the younger registrants received their capital payments, this went to the parent who would have spent a large proportion helping their children with the problems of growing up with HIV and haemophilia, and so by the time that child reached majority there would not be much left. More frequently, registrants throughout the entire age range had felt that they had a limited life span and that they should spend their capital payments living the limited lifespan they thought they had, such as on holiday or a house. Later on they ran into problems such as mortgage debt, and we had a financial advisor who could help with that, which the DoH was made aware of so they could see we were trying to solve the problems that presented themselves as registrants were living longer than anticipated.

Were the Macfarlane Trust and/or the Eileen Trust underfunded in your view? If so, what was the impact of such underfunding by the Government? In answering these questions, please consider the following enclosed documents, by way of example:

a. Minutes of the Macfarlane Trust meeting from 15 September 1998, in particular the reference to Baroness Hayman's comments at page 1 (MACF0000017_064).

b. Chief Executive's Report dated 16 January 2001 (MACF0000006_033).

99. The simple answer to this question is, no, I do not consider either of the Trusts were underfunded.

100. The Inquiry has directed me to two specific documents, the first of which discusses the overspend on the Strategic Review that had been carried out. I recall that the DoH did eventually increase our next core Section 64 funding, to replace the money that had been overspent on the Review. I do not have a

clear recollection however I expect this was because they did not question our explanation of the overspend.

What opportunities or procedures were there for the Macfarlane Trust and the Eileen Trust to seek additional monies and/or apply for top up monies from the Government as the financial year progressed? Was this ever done? If so, provide details. In answering this question please give more detail about what is set out in paragraph 10 of your witness statement dated 19 October 2019 in which you state that as a result of a contact that you had in the NHS you were able to obtain additional funds. In particular:

a. Who was this contact?

b. What kind of application did you make?

c. What funds were provided in response to the application and for what?

d. What was the attitude of the Board to your actions?

101. The opportunity for the Trusts to seek additional monies was given in the regular meetings between the Trustee Boards and the DoH, at which finance was obviously discussed. My predecessor and Trustees of the board at that time did not ever ask, as far as I know, for any additional funding before I joined the MFT. When I joined as Chief Executive it became clear to me that it would be necessary to ask for extra section 64 funding. There were two key reasons for that. The Y2K panic throughout the country was one reason, the second was that, in my view, we needed to improve the quality and the qualifications of our small staff team. Accordingly we did seek extra section 64 funding, in particular to appoint a finance officer.

102. At these meetings with the DoH, the Trust would make a case for extra funding, and as far as I can recall, those cases were met. They were acknowledged, debated, and in the next round of section 64 we would get an increase unless there was a specific reason that this was not available, as

there was in the 2002-2003 period, where there was a national financial difficulty.

103. The contacts I have referred to were personnel appointed by the Secretary of State to be our contacts with the DoH. Christine Corrigan and Charles Lister were the individuals that we always met with in the DoH, and on the rare occasions that we met with the Minister of State, that would be organised by these contacts. They were our channel to the DoH and all contact was directed through them.

104. In respect of applications, there was a formal application procedure for seeking a top-up to the Section 64 funding. We had to present financial budgets and papers supporting our application, costed with the help of our finance officer and Treasurer. These grants were provided as requested.

105. The Inquiry has queried the Board's reaction to my proposal that additional funding should be sought. I believe that, at first, they were surprised. For example, when I suggested that we would need to at least have our computer equipment surveyed by someone who knew whether it would need updating, since some of it was very old, I think there was a little amazement at what may have been seen as cheek. Nevertheless, I believe the staff team had a robust and harmonious relationship with the Trustees, and whilst there may have been surprise, this did not lead to any significant challenge or conflict.

Were there annual or other regular reviews between the Macfarlane Trust and the Eileen Trust and the Department of Health? If so, please provide details including who was involved, what was discussed and what records were kept. In particular, please refer to the letter to you from Charles Lister in relation to Eileen Trust funding dated 14 June 1999 (MACF0000082_017, enclosed).

106. The matters I refer to below apply to both the MFT and ELT. The DoH review of both Trusts would usually be at the same meeting, since both Trusts shared the same senior management, Chairman and Chief Executive.

107. I do not recall the review meetings ever being more frequent than annual. As in the case of the MFT, the ELT grants would be given for three years, and they would be reviewed annually. The letter referred to comments on there being quarterly reviews, however I do not recall that we met that frequently. If this was what the DoH requested then this is what we would have done, with reports being prepared ahead of each scheduled meeting.

108. The meetings would have been attended by myself and the Chairman. The finance officer might have accompanied us, however I do not recall if there would have been other members of staff at the meeting. The DoH would have prepared the Agenda, kept meeting minutes, and would have had a secretary there at the meeting to manage this. We were sent copies of the records of the meeting.

109. In respect of matters that were discussed at these meetings, they related to both the MFT and the ELT. We would have discussed finances, changing trends we were observing, and common needs. Within the ELT, these common needs related to the growing needs of the children of women who had died, and I do remember giving quite a lot of information about one particular family on one occasion, which was not common. The ELT were a very different group of registrants from those of the MFT.

Did the Macfarlane Trust and the Eileen Trust have ad hoc meetings with the Department of Health? If so please provide details.

Specifically, by way of example, was the meeting with Baroness Hayman, Minister of State for Health, to be held on 17 June 1999 a regular review or ad

hoc meeting (please refer to the meeting agenda: MACF0000081_009, enclosed)? Was it typical to prepare a formal agenda and keep minutes?

110. I have responded to both of the above questions as one, as I believe they feed into one another. If a Minister of State showed particular interest in the Trusts, and if they wanted to meet us then that would be arranged by our DoH contact. I do not recall frequent meetings with ministers, in fact I cannot recall more than about three in all the time I was Chief Executive of the Trusts. They were Frank Dobson, Baroness Hayman, and Yvette Cooper. Ad hoc meetings were not normal. I seem to remember having one with Charles Lister about the issue of fertility treatment and sperm washing in particular. At that meeting I would have been accompanied by Dr Mark Winter and it was for a specific purpose rather than the discussion of additional grant funding or any general update. If something specific had arisen during our day to day work that it seemed important to raise with the DoH, it is possible that I or one of the Trustees would have suggested that we did seek an ad hoc meeting through Charles Lister.

111. An agenda and minutes would certainly be prepared even in the case of an ad hoc meeting. This was managed by the DoH. There was certainly an agenda for the meeting with Baroness Hayman to which the Inquiry refers above, and I believe minutes were taken by the DoH and circulated to attendees afterwards.

Please consider the methodology and conclusions of the Final Report of the Long Term Review concluded in 2003 (MACF0000172_001, enclosed). What steps were taken in response and how were they implemented? In particular, please consider the following in your response:

a. 60% of responding beneficiaries stating financial support was not sufficient to support their households.

b. The issue of inequality of grant payments.

c. **Implications of longer life expectancy of individuals with HIV, both as to obtaining funding for the Macfarlane Trust and the criteria applied.**

d. **Suggestions as to restricting the Macfarlane Trust, both internally and in its relationship with the Department of Health.**

112. I should say before responding fully to this question that although I was closely involved in the whole business of setting up the Long Term Review, the conclusion of this Review and its presentation took place after I had left the MFT. As such, I cannot comment upon the implementation of any proposals or conclusions. To set this Review up I worked with the external consultant, ensured that the programme of meetings took place, focus group meetings with individuals took place, and conducted a huge amount of work with the Partnership Group to finalise the questionnaire to beneficiaries. My recollection is that the final meeting at which the review was presented to the Trustees was during my final week.

113. It was a review carried out independently of the staff group within the Trust. The Trustees and I found a facilitator named Hilary Barnard and he worked very closely with the Chairman, the social worker, the Partnership Group, and I to work out a strategy. Hilary's method was very much aimed at finding out about the changing and the newly emerging needs of registrants of the Trust. He knew that it would be necessary to include financial implications of this in the report, but those were really not his main focus at all. The changing needs and the future outlook of people with haemophilia and HIV was at the heart of this Review.

114. I am puzzled by the reference to inequality of grant payments. These were made according to a Schedule which was set out by the Trustees and amended from time to time so a grant application would have been under a category referred to on that schedule and would have been, for the most part, in the range of the amount that is referred to in the Schedule. Grants were

presented anonymously to the Trustees who would have in front of them only the information relevant to the application. This would have come from social workers, either within haemophilia centres or possibly in the community, or other professionals. TheAllocations Committee would ensure that as much information as possible was presented to the Trustees. The application wold then be put before the Trustees who would decide to either approve the grant or request further information.

115. The issues of inadequate funding and the implications of longer life expectancy were matters the MFT Trustees and I were alive to. The introduction of combination therapies and, happily, the increased life expectancy that this gave a number of beneficiaries was the ongoing purpose of seeking top-up funds, and the reason we suggested that the life of the Trusts be extended beyond 2012.

116. Finally, the Inquiry asks about restrictions internally and externally with the DoH. I am not certain what is meant by this. I cannot recall there being any such restrictions during my tenure at the MFT and ELT.

Please specify any other streams or sources of funding/income other than that provided by the Government available to the Macfarlane Trust or the Eileen Trust during your tenure. If there were such other sources, please identify the source of funding, the amount and how it was managed/spent by each Trust.

117. To my recollection, there were none, certainly not to the Trusts themselves. Obviously there were other sources of funding given by Government to beneficiaries, such as state benefits, but these were not paid to the Trusts.

Financial management/governance

Were budgets/budget forecasts made by the Macfarlane Trust and the Eileen Trust prior to the start of the financial year? If so, how were the needs of the beneficiary population forecast and was any expert or beneficiary input sought in forecasting the needs? If not, why not?

118. Budget forecasts were presented annually, and the expert or registrant input would have been received from our social worker and from our benefits advisor in particular. There might occasionally have been input from the Centre Director who was on the Trustee Board. The Partnership Group would have provided input also. They held a number of conferences each year and funding for those conferences would have been budgeted for with input from the registrant population as to what programme of events they would find helpful.

What was the impact on the Macfarlane Trust and the Eileen Trust of any spikes in applications and the amounts of funding being applied for?

119. Grant giving did vary from time to time. This would have related to situations such as increasing debt, housing issues, and fertility treatment, all which were, as I recall, the main issues of concern at the time. The impact on the Trust was that the money that had been budgeted was being spent more quickly and in greater amounts. This would be highlighted in reports to the DoH in which we would apply for top-up funding. Whenever we requested this, it was always in response to the changing needs of the registrant population.

What in your view was the reason for delays at the NHS Executive in processing payments to the Eileen Trust? To what extent did the delays impact on the functioning of the Trust and quality of service provided? Please consider the following enclosed documents:

a. Minutes of Eileen Trust meeting from 7 May 1999 (EILN0000006_055).

b. Letter from Charles Lister dated 5 July 1999 (EILN0000010_110).

120. Reference is made above to **EILN0000010_110** which is a letter dated 5 July 1999 received by Charles Lister from me, rather than the other way around as noted in the question. Both of the documents referred to highlight an instance when payment of the Section 64 grants was delayed. Obviously the Chairman was not happy about it, neither was I, but at no time did it affect the service that we were able to provide to the registrants. The Trust held sufficient funds to enable us to meet the needs of beneficiaries, we were just concerned that if delays continued then we would have to realise investments which we did not want to do. This was brought up by the Chairman when he met Baroness Hayman, and I expect the matter was resolved. To my knowledge, the ELT never had to realise investments for this reason.

Who decided on the level of reserves the Macfarlane Trust and the Eileen Trust should maintain? Were you involved in those decisions? What was the justification for the level of reserves?

121. The level of reserves is something that was notionally proposed and accepted by the Deputy Chairman of the Trust, who was also the Treasurer at the time that the MFT was set up. The principle that applied to the ELT was the same as the MFT, in that wherever possible, the capital fund should be used to provide investment income, and that the investment income should be used to meet the day to day needs of the Trust. Over time, that became impractical. I know that the idea of keeping a reserve of £4 million in the MFT was one that current previous and future Treasurers were eager to keep to if possible. This did mean that we sought regular top-ups from the DoH, and there certainly was an occasion when our reserves went very far below that to about £2 million.

122. Whilst I was involved in discussions about the reserves, any specific decisions were taken by the Trustee Board.

Did the level of reserves impede or otherwise have an impact on the Macfarlane Trust or the Eileen Trust's negotiations with the Government for increased funding?

123. Not that I recollect. Because the DoH had agreed this original policy, they recognised that revenue from investment was important to the running of both Trusts and that in order to provide such revenue, a basic amount was needed to make that a practical proposition.

What, if any, steps did the Macfarlane Trust and the Eileen Trust take to cut operational costs so as to maximise the monies available for beneficiaries? Please address in particular the trend of continuous budget overspend on administration or management costs, especially from 1998 to 2002. What were the causes and the consequences of such budget overspend? What corrective steps were taken or implemented during your time at the Macfarlane Trust? In answering these questions, please consider the following enclosed documents, by way of example:

a. Minutes of the Macfarlane Trust meeting from 23 February 1999, heading "Monthly Report and Summaries" (MACF0000017_066).

b. Letter to you from Pinkney Keith Gibbs (chartered accountants) dated 15 May 2002 (MACF0000065_023).

124. We were in a process of change in the way that the Trust was run during the period referred to above in that, when I joined in late 1997, the Trust had really had a very simple structure. It grew over time, employing more professionals and staff. There were unbudgeted redundancy costs and unbudgeted recruitment costs. I cannot recall exactly what any specific overspend relates to but I think that it would be to do with the cost of the Strategic Review work and consequent use of some agency staff.

125. I do not think there was a pattern of overspend, but I do believe that the need for growth in management cost changed as time went on. I do not think that the growth was unjustified. Nevertheless, the idea that the Trusts and their beneficiaries suffered due to operational costs is a complete misunderstanding. The section 64 funding was the sum that met the administrative, staff and premises costs. The capital grant and periodic top-ups of this, as well as the investment profits from the capital investments made were the sums used to fund the beneficiaries' payments. There is no way that those two sources of funds or uses of funds would have been mixed up. That interpretation is completely incorrect.

What, if any, steps did the Macfarlane Trust and the Eileen Trust take to ensure that the salaries it paid its staff were proportionate and/or commensurate with the charitable sector? Please consider the following enclosed documents, in particular as to an ex gratia payment of £4,000 to John Williams upon retirement from the Macfarlane Trust:

a. **Minutes of Macfarlane Trust meeting from 3 June 1998, final page (MACF0000017_063).**
b. **Minutes of Macfarlane Trust meeting from 4 July 2000, heading "Finance" (MACF0000006_059).**
c. **Report on a meeting with the Department of Health dated 6 April 2001 (MACF0000006_019).**

126. At an early point in my tenure at the MFT, we adopted a national salary framework, which may well have led to increases in salary, particularly to the finance officer or the social worker, I cannot quite recall. I believe we adopted either the Local Authorities salary band structure, or a national Government one. After this was adopted, that was the structure within which staff salaries were determined. In my view, we did take active steps to ensure that salaries were appropriate, proportionate and commensurate with the charitable sector.

The Trustees accepted and endorsed those proposals, without which the structure could not have been adopted.

127. In relation to the ex gratia payment to John Williams, I can only say that that was not a decision in which I was involved in any way. It was a decision that the Trustees had taken when they realised that John was going to retire and that they would need a new CEO. They wished to recognise his service to the Trusts. I anticipate this would have been taken from the operational fund rather than the capital fund, as that money was solely for beneficiaries. I cannot comment as to whether or not this was discussed with the DoH as I simply do not know.

128. The DoH minutes that I have been directed to refer to a comment from Charles Lister which notes that "*despite recognition that section 64 funding was not really an appropriate vehicle for funding the Trust's administration no alternative had been found*". In my view, this is precisely why the ex gratia payment for John Williams was taken from the operational fund. There was nowhere else that we knew about that could have funded that or, for example, the review of staff grading pay. These were operational expenditures and to the best of my knowledge, all of the routine administration cost of both Trusts were borne from section 64 funding, which was most appropriate.

Section 5: Identifying beneficiaries for the AHOs

Whose responsibility was it to identify potential beneficiaries for the Macfarlane Trust and the Eileen Trust?

129. For the MFT, almost certainly it would have been the haemophilia centres and the Haemophilia Centre Directors Group that identified potential beneficiaries. A Director of the Centre would have been the one who would have received

information from his staff and would have confirmed that an individual had been diagnosed with HIV, that this was related to treatment, and that they would be an eligible registrant for the MFT.

130. In the case of the ELT, this would have been trickier because, as I have advised, members eligible for this Trust would be members of the public at random who may have received very large blood transfusions which included infected blood. They may also have contracted HIV or HCV from a whole range of other causes. The issue would have been for the medical professionals responsible for them. There was no specific section of the community that you could group these beneficiaries into. It could have been anybody. For that reason, it would have been an alert haematologist, perhaps in a hospital, who would have considered the medical notes and questioned, first of all, if the patient had had a large transfusion. The random nature of infections was why, occasionally, questions of eligibility arose for ELT registrants.

131. I have been asked by the Inquiry in their letter dated 17 December 2020, if the MFT took any steps to alert or remind Centres of their existence and the need to refer patients to them. Half of the MFT Trustee Board were nominated by the DoH. They were either Centre Directors or Centre nurses, and so we would not have had any need to remind them of the existence of the MFT, by virtue of their very presence on the Trustee Board. Throughout most of my tenure as the MFT Chief Executive, Dr Mark Winter represented the Haemophilia Centre Directors Group on the Trustee Board. I expect he would have frequently discussed the MFT at his meetings. I do not know what steps the Centres took to tell patients about the MFT. This is not something the Trustee Board would have had any control over, and this is not something that the MFT would have considered doing on a proactive basis as this was not a part of their role.

132. I do not recall that we took any steps at the MFT to advertise the existence of the ELT, nor do I recall the ELT Board specifically going out of their way to advertise the presence of the trust.

133. In the case of infected intimates, if we knew of an MFT or ELT registrant who, for example, had died leaving children, we would have had a close relationship and sense of responsibility for them, and we would become aware if they had become infected as a result of their mother or father's infection. In response to the question though, no, we did not advertise the existence of either Trust because that was not really our role. Our role was to administer the fund. If the DoH or Haemophilia Centre Directors had felt that the existence of the Trusts was not reaching potential registrants, then it would have been for them to take appropriate action.

How were potential beneficiaries identified? Please comment on inconsistencies between the number of beneficiaries of the Eileen Trust and those who have sought payment from the NHS (see your letter to Derek Dudley at the NHS Executive dated 16 March 1998, EILN0000009_011, enclosed).

134. The inconsistencies referred to in the question above are entirely due to the nature of the different groups of beneficiaries. The beneficiaries of the MFT were all people with haemophilia, and in most cases, had been known to the haemophilia centre that referred them, since birth. All of their treatment would have been recorded and there would have been no doubt that HIV had been contracted because of the blood transfusions they had had there.

135. In respect of the ELT, as I say in response to the preceding question, the inconsistencies were due to the completely random nature of the potential beneficiaries' infection. Unless there was a way of screening everybody who had received a large blood transfusion over the years, which I do not think the

NHS could have done, there would have been no way of knowing whether you were tracking down everybody that might have become infected.

136. The letter that the Inquiry directs me to is fairly self-explanatory. Unless an exercise had been carried out to check those who had large blood transfusions, I do not think we would ever know how many people ought to have been referred to the ELT. If a young woman, for example, had appeared to her doctor and had been diagnosed with HIV, the idea of infected blood received in a transfusion is not the first thing that would have occurred to most medical professionals as an explanation, I imagine.

What, if any, steps were taken by the Macfarlane Trust and the Eileen Trust to advertise their existence and/or raise awareness of their work? Do you consider that more should have been done (and, if so, what and by whom) to reach people who might be eligible for assistance?

137. To my recollection, we did not in any way advertise or promote awareness of these Trusts. When I attended interview for my role as Director, I was advised of the nature of these Trusts and that they had been allocated by Government through the DoH for a registrant group that was referred to us by them. It was our role to simply administer the Trusts, no more than that.

138. In respect of the ELT, it was possible that more could have been done to locate potential beneficiaries however this was not in our hands, it would have required medical professionals to ask the right questions and recognise a connection. I am sure that there are still people out there, or their descendants, who probably were infected in a way that would have made them eligible for payments from the ELT, but this was not something that we could have changed at the time. In hindsight, we could have persuaded our contact at the DoH that the existence of the ELT should have been promoted more widely. I believe that they sent information to the NHS network of

haematologists, but perhaps more aggressive measures should have been taken. It was not, however, the role of the Trust to advertise and promote, or campaign in anyway. we simply administered the fund that the DoH had given to us. We had no independent existence as an organisation or a charity. In common parlance, we were a quango, carrying out work on behalf of the DoH. As I have explained above, the MFT had been set up to administer a Government fund, and nothing more.

Did the Macfarlane Trust and/or Eileen Trust have any policy about contacting beneficiaries or registrants who had not been in contact for a certain period of time? Please consider your letter dated 28 March 2002 (EILN0000025_064, enclosed).

139. The letter that the Inquiry has referred me to was part of an exercise that we undertook to go through all of the files we held for our registrants. I think it was in 2002 that we were in the process of transferring all of our paper files onto a computerised system of records. This meant working through every file of every registrant. When we came across a registrant that we had not heard from in a while, we would write a letter such as this one. I believe we conducted this exercise for both Trusts, although not simultaneously.

Please comment on the use of census forms by the Macfarlane Trust (and, if used, the Eileen Trust). What was their purpose? How often were they used? Who decided on their content and format? In answering these questions, please address the criticism recorded in the Partnership Group meeting notes from 21 May 2001 (MACF0000088_020, enclosed) that registered beneficiaries ought to have been consulted before finalising census forms.

140. Census forms were usually used if we were carrying out a Long Term Review, or a review for the first ten years, which I seem to recall was the reason that this particular census form was created. It would have been drawn up almost

certainly by the Chairman at the time, and the social worker. I expect they would have put it to me for comment although at this distance of time I cannot specifically recall. What I do recall is that when we came to the second Long Term Review, the Partnership Group, the social worker, the Chairman and others struggled for a long time to finalise a census form that everyone was happy with.

141. The document that the Inquiry refers me to notes specifically that the format of the census form could have been improved, had there been better consultation with the registrant group. This is not a matter I can comment on as I did not have any involvement with it. Representatives from The Partnership Group, who were members of the Review Group, were heavily involved in preparation of the census form. It was up to the Review Group that was actually developing the census, to finalise and send out to registrants. My involvement would have been to ensure that distribution of the forms took place, and how we dealt with them when they were returned. I seem to remember that we found someone externally to help with that task.

142. The Strategic Review in 1999 would have been the first review that was carried out. It had been agreed that it would take place before I joined the Trusts, but it was not carried out for various reasons, partly because John Williams was retiring and partly because funds had not been identified in the budget for it. The second review, the Long Term Review in 2001 was definitely Trustee-led. It was felt that it was time to take a fresh look at the information available and determine where the Trusts should be going in the future. It was brought about because of the awareness of the change in needs of the registrants. There was an increasing awareness that the Trust would need to last a lot longer than originally anticipated and the Review was a way to be able to look at that potential future in an informed way. The census form in respect of the second review in particular was very much a product of consultation with the Partnership Group.

Section 6: Eligibility for the Macfarlane Trust and the Eileen Trust

Who set the eligibility requirements (i.e. what an applicant had to show in order to be accepted as eligible) for the Macfarlane Trust and the Eileen Trust?

143. I would clarify here that any discussion of eligibility relates only to single grants rather than the regular payment. Eligibility would have been different for each Trust, and set by the Trustee Board for each. MFT registrants all had haemophilia and a large number were known to also have HCV. HIV was, in many cases, contracted when registrants were quite young and so, as their age progressed, so their needs changed. The eligibility requirements would have been established probably at the initial outset when the Trust was formed, and payments would be made by monthly regular payments, to supplement their general income. Specific single grants would be paid upon application in accordance with a list of single grant areas, which were established more or less when the Trusts were set up.

Were they written down? If so:

a. Was the written policy publicly available or otherwise accessible to applicants? If not, why not? Please consider the document "Single Grant Information to Registrants" (MACF0000005_007, enclosed) and the use of newsletters, for example in March 1998 (MACF0000004_073, enclosed), Christmas 2000 (MACF0000004_066, enclosed) and Christmas 2001 (MACF0000004_063, enclosed).

b. Did the Government, to your knowledge, have a view as to the publication of policies about eligibility criteria? If so, what was it?

144. All the registrants would know about thelist of single grant guidelines, which have been set out in the documents referred to in this question. Single grant guidelines were published regularly, and a letter was sent to each registrant

enclosing a copy of these. Registrants would also have received a newsletter which would have advised of any significant changes in new grants according to changes in circumstance. I do not recall any registrant ever saying they did not know about a single grant. The way applications were made was that the registrant would have the help of a social worker or their haemophilia centre. Some were encouraged to apply by their Local Authority social worker. The social worker employed by both Trusts would then consider the application and discussed it if necessary with the referring social worker and the registrant. The application would be put forward to the Allocations Committee, which I believe included the Chairman, who would consider the application. I believe the Committee also included the finance officer. When the application had been considered by the Allocations Committee, it would have gone forward to the next meeting of the Trustee Board. Applications would be considered anonymously by the Trustees at each Board meeting. At each stage the registrant would have assistance to ensure they were making an application that could be approved. It was the role of the Allocations Committee to ensure that the best possible case with all relevant information was presented to the Boards.

145. I do not think the Government published the eligibility criteria policies, however, registrants were given as much information about this as they required throughout the application process. The Government had appointed Trustees and delegated this responsibility wholly to them.

Were you, in your role, consulted about the eligibility requirements or otherwise involved in formulating them? If so, please provide details.

146. The eligibility requirements were set down before I joined the Trusts. Having said that, I was involved in discussion of how the eligibility developed in relation to people known as "infected intimates". This was the wives or partners who would have become infected either through intimate relations, or

what they called needle stick injury, usually sustained by mothers treating children with haemophilia. Their awareness of their eligibility for grants after their children had grown up and left home, or after their husbands had died, may have been an area of weakness. I say this because I can recall one infected intimate whom we discovered during my time as Chief Executive, living on her own supported by her small local community. She had spent years sleeping and living in the same reclining chair. I think we became aware of her through a haemophilia centre and we were able to provide her with a lot of contacts and help.

147. Infected intimates who had lost contact with the MFT or ELT because the original person who had infected them was no longer alive, was an area of eligibility that developed during my tenure. I am certain they were included within the original eligibility requirements but their own awareness of this was not as great. It was also the case that a number of them did not wish to retain any connections with either THS or the Trusts. They did not want anything to do with that part of their life after the infected person had died and any infection they had was most likely being controlled with drugs.

Were there discrepancies or differences in the eligibility requirements between the different AHOs? If so, what were they and were they justified in your view? If not, did you raise this with anyone, and if so, who and when? What was the response?

148. If there were discrepancies, it will have been due to the circumstances in which the registrant had become infected. There certainly were no policy or procedural differences. The grants were the same, as I recall it, and they were for the same range of things. The amount of money that was given to set up the ELT was obviously very much less, and there were far fewer people who were actually infected as far as we knew. This had no impact upon the value of individual awards given to ELT registrants. The guidelines for payment were

the same for both Trusts. The capital payments made by the DoH were smaller for the ELT simply because there were fewer registrants. The ELT had 64 registrants at maximum, and the MFT was approaching a registrant list of 3000 when I joined.

Was a medical opinion required to determine eligibility? If so, from whom and what issues was it expected to address? How were applicants alerted to the requirements for medical evidence?

149. The medical opinion would have been provided at the outset when the registrant was recognised as infected, so that they could receive the regular payments. There would have been social work input in respect of eligibility for single grant payments from the Trusts. It would have been unusual for there to have been a further medical opinion sought at this point. The area in which this may have been the case was in relation to fertility and sperm washing.

150. Had further medial evidence been required for any reason then applicants would certainly have been made aware of this. In relation to fertility, it was a very contentious issue. Medical evidence would most likely have been dealt with through haemophilia centre doctors. Concerns related to the risk of further infection and whether or not the procedure of sperm washing was safe. I know that where people were only interested in using donor sperm, that was a much simpler matter and it would have been easier for the Trusts to decide whether there was any help that could have been given to assist with the ancillary costs. If not, the risk was greater and it would become a far more contentious issue.

Who set the procedural requirements an applicant needed to satisfy before being accepted as eligible as a beneficiary for the Macfarlane Trust and the Eileen Trust?

151. As advised above, the requirements for eligibility as a registrant of the Trusts was set by the DoH. The success of an application for a single grant was a process whereby the application would be considered by the Allocations Committee to ensure all available information had been prepared, and then approval or rejection of the application was by the Trustees.

What were the procedural requirements for establishing eligibility? 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 kind of evidence or information did an applicant have to provide?**

c. **Was there a requirement for an applicant to have evidence of receipt of blood/blood products in their medical records (even in circumstances where such records (i) have been lost/destroyed by the NHS, (ii) are otherwise unavailable through no fault of the applicant or (iii) were not adequately created in the first place)? If so, why?**

d. **What other documentary evidence was required?**

e. **How were the requirements for evidence and any policies on the burden and standard of proof brought to the attention of applicants before they made their applications?**

152. First of all, before I address the points set out by the Inquiry above, establishing eligibility would not have been an area in which I or the Trustees would have had any responsibility. It would be entirely for the medical professionals to establish a potential registrant of the Trust. Registrants were referred to the Trusts by the DoH. We had no involvement in determining who was referred to us as a registrant. Any comments I make below are from my general recollection of advice from the DoH.

153. Addressing the points raised in turn:

a. I would have thought it very unlikely that there would have been a burden of proof on the applicant. In the case of either Trust it would have been picked up by the medical professionals connected with their care and treatment.

b. A blood test would have provided the evidence required. In the case of the ELT, if it could be immediately established that they had received a large blood transfusion during the period where the infected blood was being used, I do not think they would have had to prove or been asked anything else. If they had not received a transfusion and they felt they were eligible for the ELT, it is likely that those in charge of their care would have looked at alternative likely causes of HIV.

c. No, evidence of blood products in medical records was not required for establishing eligibility in all cases. If a potential registrant was registered with either Trust, all of that would have been initially established. If they were not registered for any reason, then research would be done into their medical notes and their medical care in the past. HIV was also passed to "infected intimates"; partners and children of those infected through transfusion of blood products. They would not be registered by medical professionals in the same way.

d. I do not know if any further documentary evidence was required.

e. The beneficiaries were not "applicants". They were registrants of either Trust as soon as their medical position had been established by members of the DoH, which was before they were referred to us. The only applications made to the Trusts related to single grant payments, as I have explained above.

154. Applications would only be made in the case of a single grant, which was a one-off payment separate from the regular monthly payments. This was assessed on a case by case basis by the Allocations Committee, and approved or rejected by the Trustees on a case-by-case basis. Whether or not their application for a single grant succeeded, this did not affect their position as a beneficiary of regular payments that they would receive by virtue of being a registrant of the Trust.

The Inquiry understands from documents HSOC0027939 dated 2 May 2003 and MACF0000077_003 dated 8 May 2003 that the Macfarlane Trust supported about 20 patients of the Manchester Royal Infirmary or their dependents involved in a joint action against American drug companies. Please describe the circumstances further. To what extent were similar exemptions as to medical records requirements made when deciding on eligibility for regular payments and/or grants awarded by the Macfarlane Trust in this period?

155. With the passage of time, all that I can recall is that this matter was brought up at Trustee Board meetings and that the Haemophilia Centre Directors' Group had felt they had a responsibility to let patients know about this. I do not know if they were encouraging people to join. It is a recollection rather than a firm memory, that we did in fact advise those beneficiaries who wanted to join the class action, or help them find a solicitor who could help them.

156. I am a little puzzled by reference to exemptions as to medical records requirements. I cannot see that there would be any connection. I think those registrants who took part in the class action took part in it because it had been suggested that it would be a useful thing for them to do. I do recall, and whether it was that class action or something else, that some of the registrants had considerable difficulty obtaining medical records which, as far as I can understand, must have been required by whoever was running the case in the United States.

157. In respect of any impact in relation to the eligibility for regular payments, there was no connection whatsoever.

Were the eligibility requirements (both substantive and procedural) kept under review by the board of the Macfarlane Trust and the Eileen Trust? If so, how often? If not, why not?

158. We had the schedule of standard grant-giving areas which beneficiaries would have been aware of. There may have been occasions, such as with the introduction of fertility treatment, where we would have brought in a new grant-giving area, however I do not recall there being changes in the grant eligibility requirements.

159. I do not believe the Board kept these requirements "under review" as such, however, following the Long Term Review, there may have been a review of the range of grants given. I know that one of the things that was highlighted in that second review was the need for help with education and help into employment. This was after my time however, and so I cannot really comment further on the implementation of these suggestions after the final report.

Who determined whether a person met the eligibility requirements to become a beneficiary for the Macfarlane Trust and the Eileen Trust?

160. The DoH would make this determination on the basis of referral from a medical professional, although in the case of haemophilia, the Haemophilia Centre Director's Group may do. In the case of the ELT, one would hope the medical consultants responsible for their care would make this assessment. They would have received a blood transfusion that led to them being infected with HIV, but when this was diagnosed, the connection between the infection and the earlier blood transfusion was often not made.

Were you aware of any concerns about or dissatisfaction with either the substantive or the procedural eligibility requirements for the Macfarlane Trust and the Eileen Trust? If so, what were these and what did you/the board do in response?

161. In respect of many of these questions, it has not been clear whether the Inquiry refers to the eligibility for registration with the Trust, or eligibility for single grants. As I have advised repeatedly above, eligibility for registration of the Trust was determined by medical professionals and the DoH before the registrant was referred to the Trusts. In respect of the concerns about eligibility for a single grant payment, I am not aware of specific concerns. I anticipate the Partnership Group would have, over time, heard quibbles about grants applied for but I do not recall anything of this nature coming before the Board.

In your previous witness statement dated 22 October 2019, at paragraphs 7 and 15 you refer to beliefs on the part of the Macfarlane Trust (and the Haemophilia Society) that those treating haemophiliacs "had been trying to do their best" and to perceptions on the part of the Macfarlane Trust about what kind of support victims of HIV and their families deserved. Did you consider it appropriate for those running the Macfarlane Trust to hold any views about the actions of clinicians and/or what had caused infection, rather than simply administering funds? If so, why and how did this influence the policies and/or decisions of the Trust?

162. I believe it is important to remember that the MFT and ELT Trustees were from THS and the DoH. They were experts in their field, as opposed to volunteering members of the public. THS members all had a lot of experience with the impact of transfusion of blood products, either personally or through a family member. Their expertise derived from their experience. It was certainly conveyed to me early on in my tenure that it was their sincere belief that the Centre Directors at the time, who had been responsible for the care of the haemophilia community, had been doing their best. These medical professionals were utterly devastated when their patients began to die, and at first they had no idea why.

163. The Inquiry appears to question whether it is appropriate for professionals from the DoH and the Trusts who were, social workers, Centre Directors, parents of infected patients, and in many cases people with haemophilia themselves, to have a view about the treatment situation in haemophilia centres. I would say that to suggest they should not hold opinions on these matters is expecting an unrealistic ability to be completely detached from their role as Trustees. It almost goes so far as to suggest they should have ignored their significant knowledge and experience of these matters.

164. When I initially took on the role at the MFT, I may have had the impression from the Trustee Board that they felt the regular payments that had been initially set up with the Trust should have been enough for beneficiaries, except for in exceptional circumstances which is where grants were provided. They felt that beneficiaries deserved those regular payments to make their lives easier, under the impression at the time that they would not have long lives. Knowledge at the time told them this was a terminal condition and that within three or four years practically everyone would have died. So they hoped that regular payments were large enough to make the last three of four years of their lives comfortable.

165. After combination therapy was introduced in 1997, I think, and by the end of the century it was becoming apparent that such therapies were working successfully. Sometimes registrants were faced with untenable side effects, but for many more with HIV, the therapies transformed their lives. As I have previously stated, this is why we met with the DoH to discuss extension of the capital fund to match what we could see were becoming changing needs for, thankfully, much longer lives.

Section 7: Decisions on substantive applications within the Macfarlane Trust and the Eileen Trust

The process

Please explain who made decisions on applications to the Macfarlane Trust and the Eileen Trust and how this changed over the time you were involved. In particular, please explain:

a. **When, if ever, staff employed by each Trust were able to determine applications, and which staff did so.**
b. **Which committees were formed for the determination of applications, how they were formed, who was chosen (and why) to sit on them, how often they met, who they reported to and the process they adopted for the determination of applications.**
c. **Which (if any) kinds of decisions on individual applications were made at board level and why?**
d. **What your role was when attending meetings at which applications were determined.**

166. The ultimate decision on applications for single grant payments to the Trusts was made in each case at the Trustee Board. The applications which had been researched were put before them by the Allocations Committee, as I have explained above. I was not a formal part of this Committee, although I do recall stepping in at those Allocations Committee meetings if the social worker was on holiday.

167. Turning to the specific matters raised by the Inquiry:

a. The staff were not engaged in determining applications, their role was in presenting the applications to the Trustee Board.

b. The Allocations Committee had this role. I have set out their formation above. They prepared a case which they put before the Trustee Board, together with their research and recommendations, and these were usually agreed by the Board. The Allocations Committee usually met every one or two months, ahead of the Trustee Board meetings.

c. The nature of applications varied however they were all put before the Board. It could be something as simple as a family needing to go on a holiday, which was a frequent type of application. We would have made sure that the cost, duration, and details of the proposed holiday were all included. The areas of complication would have been the medical ones such as sperm washing or in the case of equity loans charges on a property. Those were areas where the Allocations Committee would have either felt that they needed a lot more information or they would have felt that these were in the area of policy decisions and so could not make recommendations. They would not have been able to do anything more than to present the facts to the Trustee Board who would most certainly have advised what further information they needed, and from where, before coming to a decision.

d. My role at such meetings was simply to assist the Trustees. For the first few years I wrote the minutes of the meetings as well. I would not have added to the discussion unless invited. So had I been invited to comment on a particular application, if I knew any more information that would assist, I would have provided it. However, these were rare occasions.

Please explain whether the Macfarlane Trust and the Eileen Trust developed written or unwritten policies for the determination of applications. If so:

a. Who developed these? Were they publicly available? If so, where were they available?

b. Was any expert (medical or other) advice sought to inform those policies? If so, what advice? Please give examples.

c. Were the views of the beneficiary community taken into account when setting the policies? If so, how was this achieved? Please give examples.

d. Please describe the policies.

168. The areas of grant giving were written at the outset of the establishment of the Trusts. I do not recall specific policies around this, save for the process involving the Allocation Committee and presentation of cases to the Trustee Board, which I have previously described. There were no unwritten policies. Certainly none that I was aware of. New areas of grant giving, such as fertility treatment and equity loans, were specialist areas and discussion around these issues were minuted in Trustee Board meetings.

169. The schedule of areas in the guidelines for single grant applications and the newsletters would have been the means by which information about the procedure was conveyed to each registrant.

170. In respect of expert advice, if an area of grants about which little was known came up, such as sperm washing then there would have been a great deal of medical information that would have been sought and the Trustee Board would have considered that medical information very carefully indeed. There could have been a policy arising to deal with that particular area, although I cannot recall if that was the case. Similarly, in the matter of equity loans, expert financial and legal advice would have been sought. Those were the two contentious areas that I remember where the Allocations Committee would simply have presented the facts and it would have been for the Trustee Board to determine what expert advice they needed to assist. In both of those cases the response was complex and detailed, and the outcome was not always unanimous. They were two very tricky areas of grant-giving and I anticipate there would have been policies developed around those areas, accounting for the expert advice received, although I did not see these.

171. In relation to whether the views of the registrant community were sought, the registrant themselves would be submitting their application through their social worker or Centre Director, and would have the opportunity to explain how the grant would help them.

172. In respect of the policies discussed in relation to the complex area of grant-giving, such as fertility treatment and equity loans, I believe the Partnership Group was consulted. I expect these were often areas of discussion. Like any other community they would have had a range of different views on either of those issues and, indeed, they did.

What test/criteria were applied when considering grants? Was it charitable purpose and/or exceptional need? Did this change over time?

173. It would primarily have been a matter of charitable purpose because that is what we were set up to do. Every regular payment and most of the single grant payments were aimed at making the life of beneficiaries easier to cope with. Applications based on exceptional need occurred from time to time, although such cases were rare.

174. In my view, the threshold of "charitable purpose" is much lower than that of "exceptional need", and it was that lower threshold that was generally applied to applications for single grants. "Exceptional need" was considered where necessary. Certainly, during my tenure, the driver for grant payments remained "charitable purpose" irrespective of how registrant needs developed, although what would be considered to fall within this purpose developed in line with those changing needs.

175. It is a test that would have been applied very rarely indeed, hence the description of "exceptional" need. This would have arisen, for example, if someone had been identified as a registrant at a late stage, and there had

been a need to provide financial support for them extremely urgently, before the due process of registration had taken place involving the necessary formalities of forms and paperwork.

176. As I have previously described, it is my recollection that, in particular, there were widows who fell on very hard times following the death of their husbands who had been registrants of the MFT. I recall one or two examples where they could not cope with their situation at all, and we had to provide immediate financial help. However, these were very, very rare occasions.

177. Rather than there being a checklist to consider when someone might fall into the category of showing "exceptional need", ad hoc situations would arise that came to the attention of the Trustee Board and myself which we agreed were "exceptional" circumstances. These situations were considered on a case by case basis.

178. I cannot recall if the recognition of a case as "exceptional" was ever challenged within the Trustee Board. If it had been, then the Chairman and Treasurer would probably have had a conversation with me, the social worker and any other advisor relevant to the circumstances, such as the benefits advisor or the financial advisor. We would agree a way forward following discussion.

In your view, was the shift in the levels and strictness of criteria for grant payments due to (a) long-term funding concerns at the Macfarlane Trust, (b) a policy of reducing beneficiary dependency on individual grants and/or (c) any other factor? Please comment in particular on:

a. **The Partnership Sub-Group Meeting minutes from 16 November 1999 (MACF0000088_027, enclosed), which record "the strong view" at the preceding Payments Review Group meeting that the Macfarlane Trust**

"should be gearing payments towards higher Regular Payments and fewer, more restricted Single Payments".

b. **The Partnership Group Meeting minutes from 19 November 2001 (MACF0000088_019, enclosed), which record that the Macfarlane Trust decided to impose restrictions in November 2001 on grants for (i) heating and new windows for beneficiaries who were buying another home and (ii) second applications to move home in less than 5 years.**

179. There was definitely no such policy and I do not recall the levels of strictness of criteria for grant payments changing much over time. I do not recall that the Trustee body, who made the final decisions, changed their "*levels of strictness*" during my tenure.

180. I have considered the documents to which the Inquiry refers me, and unfortunately I have absolutely no recollection of the matters discussed. I can see that Pat Latimer, the Chairman of the Partnership Sub-Group at the time, does refers to a "*strong view*" that the Payments Review Group ("PRG") had that the Trust should be moving towards regular payments and fewer, more restricted single grants. I think that would have been a personal view, indeed, I knew some Trustees were inclined to think that people ought to be able to manage better on their own. Many may have disagreed with him, in fact, I have to say that I did not always share the views of all of the Trustees. A difference in perspective or interpretation was inevitable in a group such as this.

181. In respect of the second document referred to I do not think that, behind these decisions, there was either a concern about long-term funding, or a push to reduce registrant dependency on grants. The examples referred to in this question were, to my recollection, simply an effort to apply some sensible criteria to how grant-giving was approached. I do not think they were prescriptive conditions that would preclude someone from applying for a grant

for those reasons, however the Trusts would expect to see strong justification for accepting applications for reasons such as these. Our purpose was to ensure that the available pot of money was spent fairly for all registrants and accordingly, some sensible limits had to apply.

Were the grants means tested? If so, why? What were the income brackets applied? Were the income brackets published? If so, where and how could the beneficiaries access this information? Were the income brackets kept under review? If so, how and in what intervals?

182. The grants were not means tested at any point during my tenure.

What were the procedural requirements an applicant had to satisfy when making an application for a grant? Who set these requirements? In particular:

a. **What was the burden and standard of proof for such applications?**
b. **Were you aware of beneficiaries who were unable to satisfy the procedural requirements such as providing supporting documentation? What if any adjustments were made for determining such applications?**

183. Each application was assessed on its merits and so it is a little difficult to answer this question with a general answer. If, for example, a registrant applied for funding to have a bathroom adaptation, which was a common request, and for some reason their Local Authority could not comply with their statutory obligation to provide this in a timely manner, then we would have provided such a grant once we had this information from the Local Authority. This was often the case in relation to beneficiaries who were terminally ill.

184. In the case of an application for a holiday, which is another common example, we would just want to know the cost and details of their trip as I have explained at paragraph 156 above. I suppose if I looked at the list of grants I could probably explain what supporting information we would have sought

from beneficiaries for each, but the requirements for proof were simply what general common sense and reason would make obvious. There was nothing necessarily onerous about what we were looking for, but the Trustees did have to have something before them to provide reasoning for spending money from a fund that was in place for the benefit of many beneficiaries, not just one.

185. If supporting documentation or explanations could not be provided for applications, without doubt, we would go back to the social worker involved with the applicant, either from the Local Authority or the Haemophilia Centre. The Trusts' social worker may also have become involved. The role of the Trusts' social worker was solely to help clarify elements of the registrant's application and give specific advice for that purpose. There were always means for determining the reasonableness of the application for a grant even if the registrant did not have everything confirmed in black and white. We would do our best to ensure that by the time the application got to the Trustee Board, we had gathered as much information as possible. None of us wanted applications to be turned down for anything except a wholly justifiable reason, for example, a situation where someone would have applied for funding to move house more than once in a short space of time.

Were reasons for refusing an application provided to an unsuccessful applicant?

186. Yes, there would have been, but refusals were very rare.

Was there a procedure in place to consider applications made on an urgent basis? If so, what was that procedure? If not, why not?

187. I am sure there was, and it is likely to have been a referral to the Chairman or Treasurer. By virtue of them being considered "urgent" I expect they would

have fallen outside the usual cycle of Trustee Board meetings and therefore representations would have been made by the social worker.

Was it typical for you or others at the Macfarlane Trust or the Eileen Trust to intervene personally in priority or urgent cases? If so, how were such cases identified? What steps would you or others typically take in such cases? Please refer to the following enclosed documents:

a. **Letters to the Housing Department of Northamptonshire County Council dated 28 November 2000 (MACF0000220_009).**
b. **Letter to Charles Lister at the Department of Health dated 17 January 2003 (MACF0000086_116).**
c. **Letter to Hart & Co Solicitors dated 21 July 2003 (MACF0000218_029).**

188. I would have only intervened in an application where I felt that the need was urgent, and that the usual process was either going to take far too long, or was too onerous upon the registrant. Such matters as have been exemplified in the letters referred to by the Inquiry would probably be brought to our attention either by a specific Trustee of either Trust, or by a social worker.

189. Upon receiving a letter which I felt required my intervention, I would probably get in touch with the sender of the letter and find out more information about their situation. I would say to them that there were steps I could take to intervene, if that was what they wished. I would not have intervened without their agreement.

What practical support or assistance was given to applicants to help them in making applications?

190. As I have advised above, the applications usually came via a social worker from either THS or the Local Authority. In the case of the ELT that would not necessarily so readily have been the case, and the assistance that we would

initially offer would be from the social worker, unless it was a detailed financial debt problem, in which case we did have a finance and debt counsellor who we could send to see the individual to discuss what could be done to help them, before their application came before the Trustee Board.

Please set out the number of beneficiaries/applicants assisted by the Macfarlane Trust and the Eileen Trust during the time you worked there.

191. I have neither the data nor recollection to be able to respond to this question, and of course, it was common that individual beneficiaries would make multiple applications over many years. I would say we are talking about thousands of applications over the six-year period of my involvement with the MFT.

192. The number of applications to the ELT would be significantly less. At any one time, the highest number of registrants that the ELT had was 64. A number of those died quite quickly, and in some cases left families who became beneficiaries. I recall one family with, I think, four children, the youngest being aged two, the eldest being a teenager. They were given a lot of grants and a lot of help over a very long period of time. In fact, long after I left the Trust I continued to be a Trustee of a trust that was set up to manage their money, because unfortunately they could not cope. That was an unusual set of circumstances though.

To what extent, if at all, did the Macfarlane Trust or the Eileen Trust allow payments to be backdated (i.e. to cover a period prior to first registration or a specific application date)? Please refer to the following enclosed documents:

a. **Letter dated 5 August 1999 (EILN0000020_038).**

b. **Macfarlane Trust note 'Backdating of payments for dependent children' dated 26 June 2000 (MACF0000006_115).**

c. **Macfarlane Trust note dated 28 June 2000 (MACF0000006_116).**

193. Yes, backdating did take place. It was not common. It was usually when an infected intimate was revealed whom we had not known about. Payments would have been backdated for as long as was relevant. The Trustees would make the decision to do this. I would have alerted the Chairman of the circumstances and would add a note to the Trustee Board meeting agenda accordingly. The Allocation Committee would not be involved because the matter would have gone straight to the Trustees via the Chairman.

To what extent were applications presented anonymously? Even so, were there cases in which the decision-makers at the Macfarlane Trust (or Eileen Trust) would be aware of the identity of the applicant? What further steps, if any, were taken to prevent favouritism in dealing with applications? Please refer to:

a. Your letter dated 9 September 2003 (MACF0000229_004, enclosed).

b. The criticism in W3000 GRO-B witness statement dated 18 December 2019 at paragraph 43 (enclosed).

194. The Allocations Committee would be aware of the identity of applicants however Trustees would not be. Each application would be identified in a Trustee Board meeting with nothing more than an assigned number. I do not believe that there was ever cause or opportunity for favouritism in dealing with applications.

195. In respect of the letter I have been referred to, I do not recall the case or what happened. I do not believe there was any favouritism of any kind intended in that letter. I was just giving the recipient advice based upon my knowledge of the assistance available to him. If he was a User Trustee, and I presume it is a "him", then I would have known him personally, but that would not have changed the nature of the advice that I gave. The decision-making process by referral to the Allocations Committee and then to the Trustee Board, would remain the same.

196. In the case of the criticism set out in GRO-B statement, I emphatically deny her accusation. As I have said repeatedly above, I was not involved in decision-making processes on the Trustee Board, and only sat on the Allocations Committee very infrequently. There was no opportunity for me to exercise any kind of favouritism, and I regard this as an insult to my professionalism.

Determination of applications by the Macfarlane Trust and the Eileen Trust

Who set the level of payments to beneficiaries? How were the level of payments set? In particular, please address the role played by the Payments Review Group set up in 1998, including its members and procedure. In answering these questions, please also consider the following enclosed documents:

a. **Macfarlane Trust meeting update 14 April 2000 (MACF0000007_082).**

b. **Macfarlane Trust meeting minutes from 24 April 2001, heading "Monthly Grants Summary" (MACF0000006_003).**

c. **Macfarlane Trust meeting minutes from 17 July 2001, heading "Monthly Grants Summary – Single Payments" (MACF0000006_002).**

197. The Payments Review Group ("PRG") was proposed by the Chairman. He intended to chair the group, and its membership would include social workers, Dr Winter as a Centre Director, and the Chief Executive. The purpose of the PRG was to monitor the cost of living with HIV and to recommend when increases in payments should take place. This was done by considering the average cost of items for which we would have provided single grants also, but the main focus was to do with the cost of living award.

198. The individual grants were set up by a schedule which was reviewed fairly regularly, probably once a year, by the Trustees of both Trusts. I recall the

existence of the PRG that was set up to help guide the Trustees in their reviewing of the level of grants. That would have been single grants of course, not anything to do with the regular payments.

Please describe the regular payments that were made to beneficiaries and how they were assessed/quantified. How did this change over time? Please consider the paper proposing to revise the regular payments structure described in the minutes of the Macfarlane Trust meeting from 30 July 2002 (MACF0000011_004, enclosed).

199. The regular payments were made to the beneficiaries of the Trust in order to try and make up for the deficit to their lives that had been caused by HIV. The amounts given were reviewed by the PRG and recommendations made to the Trustees over years. I cannot recall the particular proposal set out in the documents referred to in the question, however it would seem that the regular payments were initially related in some way to the state benefits system. I do not recall that we ever referred to the state benefits system in order to assess whether, and to what extent, regular payments should be increased.

200. When I joined the Trust it had been in existence for nine years, and over those years I imagine that the payment level had increased. The PRG recommended regular increases in line with the cost of living index, as advised above. This was nothing to do with state benefits.

201. Whilst I note the comments made by the Chairman in the document referred to by the Inquiry, I do not recall any reduction in single grants or in regular payments during my tenure. Regular payments were monthly payments that depended upon the age of the registrant and also their status, whether they were single, married or had a family. This may be why reference to the state benefits system might have been used as a comparator.

Please describe the type and range of lump sum or grant payments that were made to beneficiaries and how they were assessed/quantified. How did this change over time? In answering this question please address the role played by the social worker employed by the Macfarlane Trust. Please also consider the following enclosed documents:

a. Strategic Review Update Report (MACF0000005_036 at pages 46-47).

b. Macfarlane Trust meeting minutes from 24 November 1998 (MACF0000017_065).

202. The assessment of lump sum payments was in accordance with the DoH schedule that had been decided upon before I joined the Trust. The grant payments were decided on a case by case base depending upon what the registrant was applying for.

203. The documents explain that the Strategic Review should be carried out by the three social workers. One social worker is Fran Dix who was the Trust's social worker. The other two social workers were the social workers appointed to the Trustee Board by the DoH. Their role was to make assessments for a particular grant or to look at the overall level of regular payments. Specifically, the MFT social worker would have been part of the Allocations Committee for the payment of single grants and would have been involved in the review of single grants.

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

204. Having considered the minutes, I can only respond with an estimate owing to the passage of time. I think it would be well over 90% of applications that were accepted. Refusals were rare and occasionally more information was sought before the approval was given. Flat refusals were very, very rare. I can recall

one example where a second grant was refused in relation to a registrant that wanted to move house twice in a very short space of time.

Please explain the basis, if any, for the concern expressed by Macfarlane Trust Trustees that "if Registrants were given too much information about the range of grants which they might apply for, this might become a 'shopping list', leading to unrealistic levels of demand for grants" and your views on this subject (see Minutes of Macfarlane Trust meeting from 23 February 1999 at page 5, MACF0000017_066, enclosed). In this respect, please consider the issue of limited funds for Single Grants noted in the Minutes of Macfarlane Trust meeting from 23 January 2001 (MACF0000006_013, enclosed).

205. I recall that this was a view held by one of the Trustees who felt that that is what might happen. She was part of the response group to the Strategic Review. It was not a view held by me, nor was it shared by the social worker, or many of the Trustees. I recall she was a fairly new appointment, and keen to stress her early concerns. I do not believe any action followed this comment, in fact, quite the reverse. Most Trustees agreed that more information should be provided to beneficiaries, or any information that they requested should certainly be provided.

206. In respect of the issue of limited funds for single grants, I cannot remember specifically, however I think that could have been where the Chairman felt that if we continued to give grants at the rate that we currently were doing, that we would need to ask the DoH for a top up. The likely outcome was that we requested a top-up, and this was provided.

207. Following the Strategic Review there was a lot of activity around reviewing the level of regular payments and grants. I remember some Trustees were anxious not to give away too much since we were becoming aware that the needs of beneficiaries were extending beyond initial expectations. Others felt

that where our funds were limited that the best thing to do would be to try and get some more, which, I believe, is what we did.

Why was there a concern on the part of the Macfarlane Trust Trustees that granting a particular application may set a new precedent when making such payments? Please refer to the email from Peter Stevens to you dated 4 June 2003 (MACF0000261_078, enclosed).

208. There was concern that I erred on the side of helping people, particularly if they were a bereaved widow, in accordance with the recommendations of our financial advisor. I cannot recall precisely the recommendations made in this case, but clearly we were dealing with a young lady who was left with not much ability to cope, and she needed help to reorganise and redirect her life. Yes, she got into debt as well, which is why she had come to our attention, because she had asked for help. I think that Peter Stevens, the Chairman at the time, felt that I was being over-optimistic about her future chances if we helped her.

209. I do not believe that differing opinions affected the services provided by the Trusts whilst I was Chief Executive. Of course, there were occasions on which I would have argued strongly in favour of a particular registrant, and the Chairman, or possibly the Vice Chairman, would have felt that I was being either over-optimistic about their prospects, or over-generous in what I was recommending. Nevertheless, I do not recall a single occasion when our service was in any way threatened as a result. Where opinions differed, we would go back to the relevant social worker or advisor for more information to assist in reaching a decision.

210. In relation to the idea of avoiding "*setting precedents*", by making decisions based on this concern, we would restrict newly emerging needs of infected intimates, widows in particular who, after the death of their partner could get

into significant debt and their life could go quite seriously awry. For this reason we had the benefits advisor and the social worker available to help them. The idea of never setting a precedent was, I think, an early one in the life of the Trust that was quite widely held. This meant that we needed to be careful in bringing evidence to show the Trustees that the needs of beneficiaries were changing, and that there were groups of people, such as infected intimates, who had needs which had not originally been considered. I proposed and that we should deal with such matters on a case by case basis, rather than applying more restrictive rules in every case. The Inquiry's letter dated 17 December 2020 has queried whether the act of avoiding setting precedents was a "policy". No, this was not a "policy". When the MFT was originally set up, and before I joined, I believe there was almost certainly a situation where Trustees were setting out the guidelines for the giving of grants and regular payments. For the first years of the Trust I do not think there was any variation of that. I joined the Trust at a time when the situation with regard to HIV and its treatment was rapidly changing. With those changes came questions of the relevance of the earlier guidelines in every case, and so these would be frequently discussed. The reference to "avoiding setting precedents", certainly in my earliest years, was a suggestion that we should be careful with our decisions in new circumstances, rather than a principle that "this is our policy, we do not move from this".

211. I do not believe that this approach of taking steps in a thoughtful and circumspect manner affected the development of services at all. I have described in previous statements, that the Trust's services did change and develop with the evolving needs of the registrant body. By the mid to late 1990's, with the introduction of combination therapies for example, these changing needs were becoming very apparent.

What were the eligibility requirements, including for regular payments or grants to widows, widowers, surviving same sex partners and other family members? Did they change over time and, if so, how? For example, were there periodic reviews of such requirements?

212. There were periodic reviews of requirements in line with the evolving needs of the registrant community. The whole issue of same sex partners was one which had to be taken to the DoH legal department, and eventually changes to the deeds were accepted in response. The needs of widows and other infected intimates, such as children of beneficiaries, probably did change over time and our response to them would also have changed over time. Regular payments would have been subject to the same reviews by the PRG from time to time, as grants were.

213. The eligibility requirements for registrants of the Trusts were simply that they were registrants. The eligibility requirements for an infected intimate was that they had become HIV positive following intimate relations with their partner and consequently, the children would have become infected with HIV through the wife/partner, their mother, being infected herself. All of those who were infected and able to show that the infection was due to either immediate or second-hand treatment with contaminated Factor VIII, would be eligible for grant funding from the Trust.

214. With regard to infected intimates, the approach was exactly the same as to any registrant with HIV. As the treatments improved and became widely available, the outlook for the registrant would change with them, and therefore, our services had to be responsive to this. We regularly spoke to the DoH about those changing needs. In response, the DoH made changes too. For example, I recall that they changed their method of payment to three-yearly increases in payments and annual financial reviews of payments. The idea of

the original fund becoming exhausted before we could apply for more funding was no longer relevant, because "top-ups" were agreed at regular intervals.

215. In respect of evidence of the above, this was not commonly required as we usually knew the families of the beneficiaries that came to the Trust. Such information would be kept on their case files and the haemophilia centres, which had known their patients usually from a very young age, would keep similar files.

Please set out the educational support available to beneficiaries and children of registered beneficiaries of the Macfarlane Trust and Eileen Trust. Please refer to the examples in MACF0000009_139, MACF0000218_028 and EILN0000021_114 (enclosed).

216. From time to time we were asked to help people with their studies to gain qualifications in some form or another and we usually were able to do that. It was one of the headings under the single payments criteria for assistance that we could give to beneficiaries in relation to applications to both Trusts.

217. Turning specifically to the examples referred to in this question:

a. The lady discussed in **MACF0000009_139** was a very new widow, who had been left with a number of issues. The matter considered here was the aspect of planning to study to become a teacher. I recall she wanted to do a degree in theology, and we advised that we would support her during her studies. This could have been in the form of fees, I cannot recall. We would speak to the applicant and ask what help they needed, then do our best to support them in whatever form they required.

b. The young man referred to in **MACF0000218_028** had been accepted to study for an MBA at a very competitive and highly regarded European business school. We would have helped within reason but I do remember this being a very costly request, and the Trust would expect the burden of finance to be shared with other organisations and sponsors, bearing in mind that we had a limited pot to spend on many registrants that all had differing needs. It may be that we assisted this registrant with the cost of travel and accommodation, and it is likely that we directed him to organisations that could provide sponsorship for fees, and helped him to make applications.

c. The registrant referred to in **EILN0000021_114** was similarly advised as to the help we could offer not just in relation to fees, but also with the practical cost of further study, such as a computer, college books and special equipment.

Please explain your role in the Bereavement Project and in dealing with beneficiaries or families experiencing bereavement. What practical steps were taken during your time at the Macfarlane Trust, including as to (a) application forms, (b) types of support offered and (c) style/format of condolence letters? Did these steps reflect any specific Macfarlane Trust policies? In answering the above, please refer to the following enclosed documents, by way of example:

a. A condolence letter dated 23 April 1998 (MACF0000184_002).

b. Minutes of Macfarlane Trust meeting from 4 July 2000, heading "Bereavement Project" (MACF0000006_059).

c. Minutes of Macfarlane Trust meeting from 23 October 2001, heading "Bereavement Project Report" (MACF0000006_001).

218. I can remember the condolence letter well. It was an active decision that these letters would be handwritten because we did not want to come across as remote and corporate in these situations.

219. When I joined the Trust John Williams showed me examples of condolence letters, and it was explained to me that when someone was newly bereaved it was important to express sympathy, and also to identify the kind of immediate help we could give. By the time of this letter in April 1998, it was established that a bereavement grant of £1,000 would be immediately payable. No

application form was required. We would also provide information about help that would be available over the first year or so, which would then be reviewed, most likely by the PRG.

220. The two sets of Minutes referred to in the questions both contain sections on the Bereavement Project. Chris Hodgson, Chairman of THS at the time and a Trustee of the MFT for most of the time that I was there, was instrumental in ensuring that the Bereavement Project was set up. It arose, I think, from the Strategic Review, but also from Partnership Group meetings and his own relationships with people that he knew had been widowed in these circumstances, and was keenly aware of their needs. We put together a proposal that we should fund a bereavement advisor and counsellor, and this was taken to the Trustee Board who fully supported it.

221. The minutes referred to above appear to be an update on our pilot project, which we ran in the south-east from London. Our bereavement counsellor was based in Surrey and we used to hold meetings in a hotel near her. After the project had been extended, we also engaged another counsellor who was based in the north of England. In addition, we had an annual seminar for widows and bereaved family members.

222. The bereavement letters had nothing to do with the Bereavement Project, however both were in line with the Trusts' intention to be as supportive to beneficiaries as they could be, not just financially but emotionally too.

223. I believe the Trust newsletters would tell beneficiaries about the Project and the social worker would also have made personal approaches where necessary. Once the Project was up and running, this became something we would tell new widows about at the very outset. All of this tied in with the Trust policies that already existed, in my view. I believe the Project was immensely valuable, especially the annual meetings which gave people an opportunity to

share the kind of burdens they were carrying, often to do with confidentiality and stigma. It also gave the children the opportunity to meet other children who were in the same situation, which was also incredibly valuable indeed.

Please describe and explain steps taken by the MFT in reviewing the recognition of same-sex relationships, in particular the definition of a homosexual partner for the purposes of eligibility. In answering these questions, please consider the following enclosed documents:

a. **Minutes of Macfarlane Trust meeting from 29 October 2002, heading "Recognition of Homosexual Partners" (MACF0000011_002).**

b. **Minutes of Macfarlane Trust Partnership Group meeting from 12 September 2003, subheading "What is a partner?" (MACF0000009_195).**

224. When the Trust was originally set up, the position on same-sex relationships had not been considered at all, possibly through a lack of awareness of the difficulties this might cause rather than an active disregard for same-sex couples. Even when the special payments were made to younger registrants in, I think, about 1991, there was still no consideration that any of the registrants would be homosexual or lesbian. At that time, the immense stigma attached to being HIV positive was the automatic assumption that it must have been caused by homosexual relations and when the Trust was set up, the beneficiaries that were referred were generally married individuals and infected wives and mothers.

225. The issue of payment to same-sex partners had not been considered by the Trustees as I recall, and so when it did come up as an issue at the Partnership Group and when we received requests from registrants that felt that their partner might be at risk if they died, we realised we needed further advice on the matter. The Trust deed only referred to the 'spouse' of a registrant, their marital partner, which at the time we are talking about, was not legal in this country for a same-sex partner to be. To change the deed to accommodate

same-sex partnerships was a legal issue. I remember that the matter went to the DoH legal department, although I cannot recall whether we raised it in a meeting with the DoH or sent a letter saying that we would like guidance. At some point after that we did change the Trust deed with advice from our solicitors, who would have discussed the matter with the DoH legal department, to include such partnerships. That took some time. The discussions that the Trustees and the Partnership Group had on the issue are evident in the minutes referred to.

Specifically, please explain the circumstances in which the opinion of Dr Winter was sought by the Macfarlane Trust and the basis on which the decision was taken not to provide grants for fertility treatment. In particular, please identify any evidence available to the Trust at the time which proved that the NHS did routinely meet such treatment costs. Please consider the following enclosed documents:

a. Letter to Paisner & Co dated 5 January 1999 (MACF0000003_009).

b. Macfarlane Trust meeting minutes from 24 November 1998, heading "Risk Reduced Conception" (MACF0000017_065).

c. Macfarlane Trust meeting minutes from 23 February 1999, heading "Risk Reduced Conception - An Update" (MACF0000017_066).

d. Macfarlane Trust Strategic Review Response Group meeting minutes from 11 March 1999, sub-heading "Fertility Treatment" (MACF0000174_021).

226. The documents that have been referred to really spell out very clearly what the situation was. I think that the risk of any other method of fertility treatment other than either sperm washing, which had not been approved, or gene therapy which had not yet really developed, safe conception between a HIV positive partner and their partner had been shown to be so high risk that the Trust did not feel that it could safely recommend fertility treatment of that

nature. The other type of fertility treatment to the fertilisation by donor egg or donor sperm would have been the safest route to take.

227. The first step would have been approaching the local health authority for funding and I think Dr Winter felt very clearly that funding should be the responsibility of the DoH. However, where that failed, I do not recall that we refused funding if there was agreement to involve a donor rather than the HIV positive partner.

228. Dr Winter was the Centre Director appointed by the DoH. He would be the person with the expertise on these matters and he would have recourse to the Haemophilia Centre Directors Group as well as to all his professional contacts about the issue, and so it was natural that the Trustee Board and the Chairman asked him about this developing issue.

229. In respect of treatment costs being routinely met by the NHS, I am not sure this was the case, and our point of expertise on the matter was Dr Winter. I remember he felt very strongly that the method of sperm washing as fertility treatment had not been proved safe. Whether Health Authorities were using it in the wider HIV community, I do not know.

230. I can see from the Macfarlane Trust Strategic Review Response Group meeting minutes from 11 March 1999 that a decision was taken not to provide funding in the future at all. My recollection is that Dr Winter felt so strongly about the risks, and that there was such a body of evidence within the Trust of people who had become infected, both children and widows, that he did not feel able to support any recommendation that it should be funded. What the DoH did was obviously not relevant. If they continued to fund the treatment for people with HIV who wanted to have families, that was one issue, but the Trustees of both the MFT and ELT decided not to do so. I remember this being a discussion that was very, very difficult at the time. It was difficult for

registrants, for the Partnership Group, for the social worker and for Trustees too.

Please explain the subsequent decision by the Macfarlane Trust that it "should be prepared to fund ancillary costs related to treatment and should also assist couples to apply for Health Authority funding and to appeal against decisions not fund" (see Macfarlane Trust meeting minutes from 28 May 2002, MACF0000011_003, enclosed); see also in particular, please address the following:

a. **To what extent and, if so, why was Macfarlane Trust funding for fertility treatment only considered a fall-back source?**

b. **Whether your proposal to fund ancillary costs of fertility treatment for beneficiaries of the Macfarlane Trust that may need it in the sum of up to £3,000 made at the Macfarlane Trust meeting of 23 July 2002 ('A proposal to fund ancillary costs of fertility treatment', MACF0000011_073) was taken forward?**

231. As is evident from the July 2002 meeting minutes, we came to a subsequent agreement with the DoH that the Trust would assist with ancillary costs if treatment was approved, rather than the cost of the treatment itself. These were usually in relation to travel and accommodation where a registrant had found a Health Authority that was willing to treat. The change in view was not about the treatment, it was about the costs around the treatment.

232. Where there was donor sperm or a donor egg used for treatment, which was often seen as a last resort from a registrant's point of view, then we would continue to fund that fertility treatment. The Trust's reasoning is evident in the minutes. Statistics showed that at least three treatment cycles were needed for such treatment and even then, the success rate was only 30%. In respect of MFT funding as a fall-back source, the Health Authority would usually bear the cost of the first three cycles of treatment. Bearing in mind the financial

position of the Trust and the low success rate, the Trustees thought it unwise to bear significant costs without reserve, because this would have ultimately been at the expense of how we could meet the needs of other beneficiaries.

In what circumstances, if at all, were exceptions to the general policy as to funding for fertility treatment made by the Macfarlane Trust in this period? Please comment on the case referred to in the letters to you dated 16 May 2003 (MACF0000257_169) and 22 May 2003 (MACF0000257_168).

233. I do not know whether it was agreed to help this particular man and his partner, who have been referred to in the documents. The documents suggest that an exception was made but I cannot recall either way. Obviously where a Centre Director and their social worker recommended something, the Trustees would almost certainly accept it, but I speak generally.

234. I am sure that exceptions to the policy were made from time to time but that was not something that I would have decided. It would have been something that the Trustees, after quite a lot of debate and soul searching, might have agreed. I cannot recall what happened in this case unfortunately.

Please explain the proposal made by the Payments Review Group to provide a "special" one-off payment to beneficiaries who were children when the previous payment was made by the Macfarlane Trust (minutes of the Strategic Review – Response Group meeting from 24 May 1999: MACF0000174_024, enclosed). What, in your view, triggered this proposal? Why do you consider it was declined? In your view, was this appropriate and, if so, why?

235. I have a recollection that there was a special payment made to the registrants who had been younger because the initial payment had been made to many who were teenagers at the time, and that payment was much less than what had been made to adult, married men.

236. Unfortunately, these documents do not assist me in recollecting which special payments were made when, and for what reason. However, I do recall the Partnership Group, and possibly others, raising that the young men who had received a lower payment were now grown men and were often married, with families and houses. It was recommended that they should have an uplift.

Did the success or otherwise of an application depend on the number of applications made per year or was each application considered on its merits, irrespective of the overall demand on the relevant fund?

237. Each application was considered on its merit. If it looked as though the funds were running low then there would be a request to the DoH for a top-up. Certainly there was a view within the Trustee body that we were being too generous, and that idea came up many times from one Trustee in particular, who did not remain on the Board very long. The remainder of the Trustee Board was generally balanced and reasonable, and often had personal experience of the circumstances that registrants were in. The DoH did not once refuse our request for a top-up of funds, and so the need to re-consider applications or limit payments did not arise. I have referred previously to a time when payment from the DoH was postponed, which was due to the financial situation in the country at the time. Nevertheless, the top-up was received.

238. As to whether the number of applications for grants by an individual registrant were capped in anyway, I do not believe this was the case. Applications would have come to the social worker first. If they felt the application was unnecessary or unrealistic they would have gone back and talked to that registrant and possibly visited them to discuss their needs and the context of their application. If the social worker judged that it was a valid requirement of that applicant, then they would have put this forward to the Allocations Committee. It would never have been a question of them deciding that too

many applications had been made. As I have explained at paragraph 34 the Trustee Board considered applications that had been assigned reference numbers, and so the number of applications made by a registrant was not information they were given.

239. If an application was considered to be a matter that needed even more evidence or might be unreasonable then that would be dealt with by the social worker or Allocations Committee requesting more information and discussing the application with the registrant. This would be before the Trustee Board saw the application. If they considered further information was necessary when they came to assess it, the process would start again.

Did the Trust consider the amount of money previously given to an applicant (a) from the relevant AHO and/or (b) from other AHOs and/or (c) as income from benefits when determining each application? If so, why?

240. No, the Trusts did not consider how much someone had previously had and did not consider their income from benefits. Having said that, I see that in one of the letters from the haemophilia centre in Newcastle, to which I have been referred above (**MACF0000257_168**), did produce such information. That was not something that the Trustees normally asked for because it did not feature within the decision-making process.

Please provide your view on the consistency and fairness of decision making by the Trust when assessing applications.

241. I believe that the Trusts were entirely consistent and fair in their approach. I do not recall cases where they were not, because each one would have been assessed on its own merits. As such I do not believe that there would have been a comparison made with a similar request from a different applicant, and any scope for perceived unfairness, as far as I was aware.

242. Of course, this may not have prevented a registrant believing that the system was unfair, such as Mrs GRO-B to whom I have referred in paragraph 181, which I maintain is just not the case. I had no hand in saying whose applications were granted.

Loans made by the Macfarlane Trust

Please describe the different types of loans and advances provided by the Macfarlane Trust to beneficiaries. How did these change over time?

243. I think most of the loans that I recall would have been related in some way to housing. There might have been an exchange of letters for a loan to make improvements, which would have been secured by an exchange of letters. An equity share loan process was also used from time to time. That had its downside as well as its merits. Very rarely a loan may be requested to help pay a debt. I think usually that would be given as a grant rather than a loan. Advance of regular payments was also a form of loan where we would have advanced a regular payment in order to help a particular registrant meet a crisis. Loans and advances were sometimes used in place of a grant.

244. Loans would have been secured either by an exchange of letters or a written agreement. We would almost always refer to our solicitor who would either produce a draft of the letter or would make the full agreement, if the request was over a certain amount, which I seem to recall was around £10,000 throughout my time at the Trusts. I am sure the equity loan agreements were also drawn up by Paisner & Co, our solicitors during my tenure. I do not believe any fees or interest was charged to the registrant at any time.

Please describe any role you had in approving loans and/or advances made by the Macfarlane Trust to beneficiaries.

245. The only role I would have ever have had would have been in presenting a case to the Trustees. This would not necessarily have gone to the PRG. Such requests would have been researched with the social worker and possibly the haemophilia centre, and then I would have made a presentation to the Trustees to advise what was recommended. They made all financial decisions.

Please describe the criteria used to select recipients for the different types of loans made by the Macfarlane Trust to beneficiaries, and confirm who drafted those criteria.

246. Unfortunately, I do not recall any criteria at this distance of time, although I doubt there was such a checklist of criteria. In presenting the case to the Trustees we would have had to consider the applicant's ability to repay a loan. Letters which would be drawn up by Paisner & Co in relation to loans would explain that the loan would not be repaid until the registrant had died and their widow also no longer had any further use for the house. I expect any children would not be expected to repay the loan either, however, upon sale of the house the Trust would have received a return of the loan. If a loan related to anything other than a home, then there would be a consideration of their ability to repay the loan and the realistic nature of whether or not that repayment would ever come back to the Trust.

247. When faced with a registrant whom we did not believe had the ability to repay a loan, the Trustees would take this into account when making their decision. I think at this point the advice of the Trusts' financial advisor would have been sought. She would either say that the Trust was just increasing the burden of debt for this individual and advise against the loan, or say the loan was realistically repayable over a period. The financial advisor, with input from the social worker, would have been the person to advise the Trustees either way.

Please confirm that the Macfarlane Trust sought legal advice with regard to loans made by the Trust. What was the advice provided by Paisner & Co (please note that legal professional privilege has been waived by the Trust)? Did you agree with the advice given on each occasion? Did each Trust act in accordance with such advice? In answering these questions, please consider the following enclosed documents and comment on (a) the use of equity share arrangements and (b) widening the Trust's power by deed of variation:

a. **Administrators Report to Trustees (Macfarlane Trust) dated 13 January 1998, heading "Members Debt Problems and Equity Sharing Arrangements" (MACF0000005_055).**

b. **Macfarlane Trust meeting minutes from 10 February 1998, sub-heading "Paisner Report on Equity Sharing" (MACF0000005_041).**

c. **Macfarlane Trust meeting minutes from 28 April 1999, heading "A Deed of Variation..." (MACF0000007_259).**

d. **Note "Loan and Charges to Registrants" (1999) (MACF0000006_110).**

e. **Letter from Paisner & Co to Mr Shepherd dated 23 September 1999 (MACF0000204_002).**

f. **Macfarlane Trust meeting minutes from 12 July 1999 (MACF0000017_068).**

248. The essence of the Administrator's Report is that it was recommended that the Trustees seek legal advice in relation to equity share arrangements, which they did. We were advised that the simplest thing to do in the cases in question was to give grants. Whether that happened I do not know. The Trust also seems to have looked at the possibility of equity sharing. We did agree with the advice given in all of these cases, and acted in accordance with that advice each time.

249. The Paisner Report on Equity Sharing shows a detailed discussion between the Trustees in relation to the pros and cons of such a scheme. I can see that the Chairman expressed concern about the Trust's continuing ability to provide

ongoing financial support to members at a level they had come to expect, warning against an assumption that the DoH would continue to provide top up funding as had been the case in the past. The Deputy Chairman also comments about his concerns as to whether this was the best way of providing help to those in difficulty, which I know was a view shared by the Trust's social worker who felt we should be looking at the underlying problems that led to significant debt in the first place.

250. As a result, the Trustees at that time decided it would not be appropriate to seek a further variation to the Trust deed to allow new equity sharing agreements. This was certainly discussed with Paisner & Co, and the letters referred to above show that we proceeded with a variation to the deed to allow the Trust to make loans.

251. The letter from Paisner & Co dated 23 September 1999 (**MACF0000204_002**) advised the Trust not to enter into any more equity share or loan arrangements without speaking to the Charity Commission or amending the Trust deed. To do this, the Trustees would have had to make a request to the DoH who would refer on to their legal team to draw up the changes, which I believe is what happened.

252. The equity share system was one devised before I joined the Trusts. There were very few equity share agreements entered into after I joined. We asked our solicitors to examine the basis of equity share agreements and they recommended that this was not the best route forward for helping people with housing needs, moving to a system of charges on property instead.

253. I do not recall that the Trustee Board ever recommended that registrants obtained independent legal advice, however that does not mean that they were not advised to do so, or did not think to do so themselves. This is not something we would have known about. Certainly, when the independent

financial advisor came on board, she assisted registrants in relation to this whole area of housing issues and she may well have suggested they obtain independent legal advice if it was considered necessary. These are not discussions we were privy to. Before a case of this nature even came to us, the registrant would have been able to speak with the social worker and independent financial advisor if the social worker thought necessary. They would have visited with the registrant and come back to the Trustee Board with recommendations.

To what extent did the Macfarlane Trust consider it necessary (a) to obtain security for loans (in particular for loans in excess of £10,000) and (b) generally use loans instead of grants? Do you consider this to be consistent with legal advice by Berwin Leighton Paisner on 11 October 2001 as to security and grant-making powers (enclosed: letter dated 11 October 2001, MACF0000006_123, meeting minutes from 23 October 2001, MACF0000006_001 and letter dated 25 October 2001, MACF0000202_010)?

254. Funds provided to the Trusts were for the Trustees to administer in accordance with the Trust deed. Loans was a whole area where we were using the fund in a way which had not perhaps originally been intended. In order to fulfil their fiduciary responsibilities at the time that loans were made, some security did need to be provided. The Trustees felt there needed to be a clear legal pathway by which they could justify giving the loan in that way.

255. We would only have used a loan instead of a grant if we did not think a grant was the right solution for the registrant's situation. The legal advice we received from Berwin Leighton Paisner was that if we wanted to make loans rather than grants, then they should consider our policy on taking security, and that a simple loan agreement would be more appropriate than a charge on the property. I am surprised by the ceiling of £60,000 referred to. If I recall the discussions at the time, the Trustees would have felt that that was far too high

an amount of money to be loaned to a registrant without a charge being taken on the property. They were administering funds provided by the DoH for an entire registrant community, and giving loans of that amount without any security would most likely have been considered irresponsible.

256. As advised above, the Trust deed was changed so that we could give loans. I believe there was a ceiling and whilst I do not recall what it was, I very much doubt it would have been as high as suggested by the solicitors. I think that we either gave an equity share loan or we took a charge on the property in future cases for loans above the agreed ceiling. I do not recall why we would have chosen one option over the other, this is all just too long ago.

Please comment on the role of financial advisors in the process of the Macfarlane Trust providing secured loans to beneficiaries. In general, were loans or awards made contingent on beneficiaries accepting the services of such a financial advisor? If so, (i) what were the criteria for such a condition to apply? (ii) was the financial advisor working for the benefit of the beneficiary or the Macfarlane Trust? When answering this question please indicate where the duty of advisor Susan Daniels in Cases No. 1512 and 1226W (please see enclosed MACF0000011_054 and MACF0000011_055) lay when faced with a potential conflict of interest between the beneficiary and the Macfarlane Trust.

257. The role of the independent financial advisor was introduced quite early in my tenure at the Trust, by the original Chairman and Deputy. The financial advisor was employed by the Trust and her purpose was to advise the Trustees on the financial and other aspects of requests put to them, particularly in the cases of loans or a mortgage. She was very good at organising mortgages in situations where no one else would have had a chance. She was very good at reassuring, particularly Nationwide, that any mortgage given would be supported by the regular payments that the Trust would continue to pay in the

long term. She worked for the benefit of the beneficiaries of the Trusts, however she was employed by the Trust.

258. In no way were loans or awards made contingent on beneficiaries accepting the services of the financial advisor. I cannot recall any example where beneficiaries were under this impression. In fact, the idea of the Trust employing a financial advisor, free of charge, for the benefit of beneficiaries was welcomed by them. She would visit registrants to support and talk to them about their financial position in some detail.

259. In relation to the examples referred to, I can comment as follows:

a. Case 1512 - I cannot say I remember this particular case about a flexible equity share loan, nor the outcome of these discussions, but I do remember this particular family. It was a very sad situation. Susan would have tried very hard to get a favourable outcome for this widow, she really did need our help.

b. Case 1226W – Again, I do not remember the specific details of this case. I note that Susan's recommendation was that the Trustees give serious consideration to the proposals for this widow. I am certain the Trustees almost always took her advice. I cannot recall more than two or three occasions when they felt that her recommendations would not accord with their perception of what the Trust deed was.

260. The concern precedent-setting would not necessarily have caused the Trustees to dismiss an application like this. They would have raised this as one of their concerns and they would have discussed the matter with the solicitors also. I think that that is what happened here.

261. In respect of any potential conflict concerning Susan Daniels, much like the situation above, where her advice perhaps was not ideal for the Trust but was in the favour of the registrant, the Trustees would obtain legal advice as to the best way forward.

To what extent did the Macfarlane Trust explore part grant-part loan options for beneficiaries, in particular for educational purposes? Please refer to the enclosed case note dated 21 July 2003 (MACF0000009_139).

262. Both the widow and the young man referred to in this document wanted assistance for education purposes in the form of a part grant-part loan option, through charges on their property. I do not think these situations were common. We did, whenever possible, suggest that both widows and registrants, whether or not they were in their own home, should think about becoming better qualified. That was one of our approaches to help them out of the debt cycle. The extent to which this part grant-part loan method would have been suggested is not something that I can recall but it is something that clearly the Trustees, on this particular occasion, went along with. So as I say at the beginning of this note, it was a possible new policy area for consideration. Having made these decisions, it is likely the Trustees could have made similar decisions again, however I do not recall how frequently they did so.

Were there any direct home purchases by the Macfarlane Trust or Eileen Trust? If so, please explain the circumstances. If not, please explain why this was not considered a potential option. Please consider Case 5015 in 2002 under the Eileen Trust (see EILN0000013_249 and EILN0000013_256, enclosed).

263. My recollection in this case is that 5015 did find Council accommodation. Susan Daniels and I became Trustees of the trust fund that the children of this family had inherited until the youngest child reached the age of 18 years. Their guardian was keen that we take the direct home purchase route and I agreed with her. I recall that the capital payment due to the children, who were dependants when their mother died, was used to place a deposit on a house for them. The regular payments were used to pay off the mortgage. I believe

that the Trust's benefits advisor and Susan Daniels managed to work out a package whereby, although the Trust did not fund the capital purchase of the house, they were still able to facilitate the purchase of a house for the family to live in.

264. The circumstances referred to in the ELT documents and described above were those most suitable for a direct home purchase, however, we were not in the property investment business. The Trustees were, rightly so, not keen to become involved in the purchase of property for registrants and the consequent equity surplus issue. We were able to find a way around this, and I do not believe this route was used by the Trust in any other case, at least not during my tenure. Taking a charge on a property was a much preferred, and advised, route.

In what circumstances would the Macfarlane Trust caution beneficiaries against equity loans (for example, where the value of works funded on a house would not increase the house value proportionately)? Please refer to your letter dated 25 October 2001 (MACF0000211_025, enclosed).

265. I think the general circumstances of the matter that the Inquiry has referred me to above, were in relation to adding central heating to add to the value of the house, or add at least as much to the value of the house as it cost to install. I do not recall where this particular registrant lived but if it did not have mains water it must have been pretty isolated. I think the equity share route has been taken here because it was not certain that the work done would add proportionately to the value of the house, at least to the extent where the loan could be repaid to the Trust. It is, however, difficult to remember the detail of cases that I looked at two decades ago.

266. Generally speaking, it was usually the case that an application would come before the Trustees and the Trustees would ask me to advise the registrant that they did not think their proposal was sensible.

To what extent did loan arrangements with the Macfarlane Trust affect beneficiaries' wills or testamentary arrangements? Please refer to your letter dated 18 October 2000 (MACF0000214_050).

267. Any such arrangements would have to be referred to in their will, which we made clear at the outset. If there was, for example, a charge on a property which would go on and remain the widow's home following the death of the registrant, it would need to be made very clear that when she passed away, that the house would not just automatically be passed on to the children. They would be responsible at that point for paying back the loan or the equity share, or whatever arrangement had been agreed with the Trust. If, at any point, the house was sold then the Trust would be re-paid.

In October 1999 the Macfarlane Trust granted a request to transfer the equity share loan onto the beneficiary's new property. The result of this agreement was that the Macfarlane Trust made a profit (please refer to your letter of MACF0000204_041 to Ms Walton and her witness statement to the inquiry, enclosed). Do you consider it appropriate for the Macfarlane Trust to have profited in this way?

268. I believe that this is the case where Paisner & Co advised that the Trust change from giving equity share loans to taking a charge on the property. As to whether or not this was appropriate, that is the nature of an equity loan agreement. There was a times when the Trust did readily adopt such a route, however this was before my time. I believe the only way that the Deputy Chairman would have agreed to give larger loans for properties was that it would be an investment of the capital fund that had been given to the Trust to

administer. I know that he did not think that there was anything wrong in an equity share growing in value and it was certainly made clear to anybody who had an equity share loan from the Trust that that would be the arrangement. Later advice from our solicitors changed this approach.

269. I can see from Ms Walton's statement that she is quite aggrieved by the fact that this charge was not simply removed after her husband's death, in the way that other debts had previously been cancelled. I cannot comment upon the steps she has taken or the advice she was given in 2018, or at any point after I left the MFT in 2003. Nevertheless, I do know that Ms Walton was well aware of the situation in which the loan and charge on the property had been arranged and the consequences of this, before her husband's death.

In 2003 the Macfarlane Trust loaned Ms Walton a further sum of money but this time secured it as a charge against her property. Was the charge in the sum loaned, or a percentage of the value of her home? If the former, what was the cause of the difference in approach to that taken in 1999? When answering this question please refer to your letter to Berwin Leighton Paisner solicitors dated 21 August 2003 (MACF0000204_051).

270. I believe the change in policy from equity share agreements to charges on a property changed in around 2001. The second loan to this registrant gave rise to a charge on their property. This would not have related to value of her house, rather to confirmation that there was enough equity in the property for that extra charge as well as the original equity share to eventually be returned to the Trust.

271. The point of this is that money was given to the Trustees for the benefit of all beneficiaries of the Trust. The view of the Trustees was that every time they gave an equity loan, or took a charge on a property in return for payment, that they were taking that money out of a pot that was intended for all beneficiaries.

This approach meant that the money would be held out of use for sometimes up to 20 or 30 years. I note the point made by Ms Walton that the Trust had more money than she did, but I feel this rather misses the point. These funds were not Trust money to be spent freely, they had to be seen as part of a pot given to the Trust to administer for the benefit of numerous people. If we had given every registrant of the Trust a large loan, whilst we would have had security in properties, we would not have been able to continue to maintain the very large number of single grant payments that were made to the vast majority of registrants, not to mention the inherent risk in tying money up in investments that could not be realised for decades. The people who benefitted from charges on their property or equity loans that enabled them to actually buy a property were not that numerous. The Trustees did not see it as being the right use of Trust funds to hand out large sums of money in this way.

272. I would like to add in relation to this Section, that the staff team, the Trustees and I acted in accordance with our understanding of our role with regard to the registrants. We were keenly aware of the responsibility that we had for administering the Trust in accordance with the grants given by the DoH. Of course, over the years and with hindsight, we may have made mistakes. However, our intentions were solely to support the registrants using those funds as effectively as we possibly could.

Non-financial Support

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

273. Non-financial support comprised of most of the types of activity we were involved in such as giving people grants for complementary therapies, arranging conferences, the Bereavement Project and the HIV Women's

Conference. I think this type of support developed over time after I joined the Trusts.

274. This would have been made known to beneficiaries via the newsletter, the social worker, and the Partnership Group. Means of non-financial support would have been widely promoted, probably through the haemophilia centres as well.

Section 8: Complaints and appeals

Was there an appeal procedure for the Macfarlane Trust and the Eileen Trust?

275. Yes, there was. I do not think that the procedure was fully developed until we had experienced social workers on the staff. We had social workers who were Trustees, both THS and DoH and I do not know if they had input in such matters before my time. I do know that a procedure was developed in the time I was there, and that it was social worker led.

Please describe the process (if any) for seeking a review of, or appealing against, or complaining about, a determination that an applicant did not meet the eligibility criteria of the Macfarlane Trust or the Eileen Trust, or in respect of a decision in respect of a grant. Please include consideration of the following matters:

a. Any right to give evidence or make representations in person;

b. Whether a representative was permitted to accompany the applicant;

c. The standard of review or appeal applied;

d. The criteria for members of review or appeal panels, including whether the original decision-maker was permitted to be present or make the decision;

e. The extent to which written reasons were provided;

f. Any time limits or fees for the bringing of a review or appeal.

276. Again, I would point out that the eligibility criteria for registrants was not decided by either of the Trusts. Registrants were referred to us by the DoH and would receive regular payments by virtue of this referral. Grants were made by application, as discussed in detail in previous questions. As advised above, at least 90% of grant applications were approved by the Trustee Board.

277. Appeals in respect of regular payments did not happen due to the referral mechanism advised. The only scope in which someone may have challenged the eligibility criteria was in respect of same-sex partnerships, which are dealt with above.

278. The initial concern that any registrant may have had about the decision made on a grant application, would be raised to the social worker or it would come to me in a letter, which would be referred to the social worker to investigate. They would meet the applicant and determine what their concerns were specifically. I would be informed and it would be resolved at that stage if possible.

279. If a more serious concern had been raised then it would go to the Trustee Board and they would set up a small group which would consider the decision previously made. My recollection is that that group would have included the Deputy Chairman, maybe User Trustees, and the social worker who would have presented the case on behalf of the registrant. The Chairman would have been the ultimate decision-maker.

280. In respect of the ability to "*give evidence and make representations*", if it was appropriate then I would have met with the applicant, probably with the social worker. I do not recollect any registrant attending a Trustee Board meeting, although it may have happened. If that did happen then it would seem logical that they would be allowed to attend in the company of a representative.

281. As far as the Trust would have been concerned, once the case had been looked at by an Appeal Committee, then it would go to the Chairman. If the Chairman refused the appeal, then that would be it. I suppose they could always try going to THS or the DoH, being the bodies that nominated the Trustees, but as far as the Trust's procedure went, the Chairman's word would be final. I cannot recall if these circumstances ever arose.

282. In respect of complaints, these would have come straight to me, by-passing the social worker. I would have considered the complaint and met the registrant in question. If we were not able to agree a resolution then the matter would have gone probably to an appeal panel, again made up of Trustee members and the social worker. Final resolution would again rest with the Chairman.

283. Written reasons for any outcome of a review, appeal or complaint, would most certainly have been provided. No fees or time limit conditions were attached to any of these mechanisms.

Who determined the appeal and were they the same staff who made the original decision?

284. Both the Trustee Board that made the initial decision on an application, and the Appeal Committee would be made up of the same Board members and the Trust social worker. There was no external involvement in this procedure.

How common was it for decisions to be appealed? How many appeals were you aware of being launched during your tenure? How frequently did appeals succeed?

285. I do not have the data for this, but relying on my recollection, there were very few, no more than 15 appeals at most during my tenure. I cannot say how many were successful.

To what extent were general expectations about earning capacity applied to beneficiaries, in particular on appeal? How did you or the Macfarlane Trust ensure that adjustments were made for beneficiaries who had additional constraints as a result of (a) old age or (b) disability? Please refer in particular to the appeal in Case No. 1656W (MACF0000105_016, enclosed) and your comment "when ... you are able to improve your earnings a little, unless you are yourself disabled" in the letter dated 18 April 2002 (pages 18-19 of 21).

286. The only part of this that I can answer is in respect of my letter that I wrote at the start when this matter arose. I do not think that is what is being appealed, since the appeal was made in 2007, four years after I had left. I would stand by everything that I said in my original letter to this applicant.

287. Generally, I do not believe it was ever considered that there would be expectations about a registrant's earning capacity, certainly not in my time. The Trust changed a great deal subsequently.

288. In respect of adjustments, during my time I would have ensured that our social worker and our benefits advisor would have been fully on the case as it were, and aware of a registrant's changing needs. We would have ensured that wherever possible, the registrant received all of the benefits that they could through statutory means, both in terms of financial benefits and provision of aids and equipment. The social worker may well have recommended additional help that we could give.

289. I recall that the case referred to above was that of a widow that we had been out of touch with for some time. I think we picked her up through a review of

widows that was carried out in late 2001 or 2002. We wanted to find out how she was getting on, and I suggest that she consider further training. If she had been disabled and her disability had been due to HIV, she would have been receiving a regular payment throughout. She would not have dropped out of the picture I would hope. If her disability was unrelated to her husband's HIV status, then we would not have been giving her an extra payment in relation to an unrelated disability, although engagement of the benefits advisor would still have been available to her.

Was there a complaints process? If so, how did it operate?

290. I do not believe that there was in this context.

How common was it for the Macfarlane Trust and the Eileen Trust to receive complaints? How many complaints were you aware of being made? How frequently were complaints upheld? Please consider the following enclosed documents:

a. The letter of apology dated 13 May 1998 (MACF0000078_003), further letter communicating the outcome of an internal investigation dated 14 May 1998 (MACF0000078_001) and the staff letter (MACF0000078_002).

b. The letter of apology dated 1 August 2001 (MACF0000080_158).

c. Was a staff interview by, and/or written letter from, you in your capacity as Director typical when a complaint was made? If so, why? If not, why not?

291. I would not say it was a common event by any means. I cannot accept that staff were routinely rude or impatient with registrants. I do recall the instances referred to in the documents that the Inquiry refers me to, and I do not believe these were common events at all.

292. How frequently any complaints were upheld would depend on the nature of the complaint. In those cases, where the complaint related to a member of staff speaking inappropriately to a registrant, there would be a full apology given, and an investigation would take place. In both of these cases this was by me alone. I would have reported the outcome of my investigation to the Chairman. Only if a complainant had come back and insisted that they got an apology from the Trust, would it have gone any further than me. To my recollection, this never happened.

293. The staff member that is the subject of both of the complaints referred to above was not with us long. She had little compassion or empathy for the work that the Trust was doing. All we could do was to apologise fully in response to these complaints, and hold a disciplinary meeting with the staff member concerned.

294. There is also a letter of complaint referred to from the THS HIV social worker, dated 12 August 2001. This was not from a registrant however it would have been dealt with in the same way as the registrant's complaint.

295. Any letters advising beneficiaries of the outcome of their complaints would always be sent by me.

What information was provided to beneficiaries about the appeal and complaints procedure?

296. I think there would have been general information provided in the registrants' handbook but it is not anything that I can recall the detail of. Obviously from time to time people did make complaints and they always made others in the registrant group aware of the problems they had had.

297. I believe it is also fair to say that there would be somebody from the MFT or ELT in touch with the beneficiaries at regular intervals, and so if somebody had a complaint to raise, they always had a point of contact.

Section 9: Engagement with the beneficiary community

What steps did the Macfarlane Trust and the Eileen Trust take to engage with and understand their beneficiary community?

298. I think that the whole purpose of having staff members such as the social worker, benefits advisor, and financial advisor, was to ensure that we offered as much support and help to the registrants as was possible. Save for times when I was in meetings, or attending visits with registrants at Haemophilia Centres, or at their homes, I would certainly be available, and would respond to letters sent or calls made to me.

299. We set up a whole range of different types of activities and conferences through which we could learn about the needs of the beneficiary community. The Partnership Group was set up initially following the Strategic Review in 1999, but even before that, staff members had a lot of contact with the registrants. There was always an effort to find out and to know as much as possible about the registrants.

300. Notwithstanding the above, it was easier to know about the wider picture for people with haemophilia than it was for members of the ELT, because they did not fit into an identifiable group in any way. Nevertheless, we would have been in contact with them in the same way as MFT beneficiaries, and they were a much smaller group and so it was easier to stay in contact with them all.

301. At the time of both the Strategic Review and the Long Term Review, we did arrange to send out questionnaires and census forms, as well as focus group meetings to ensure we heard as much of what the community had to say as possible. The topics ranged from general changes in daily needs, to life expectancy. They were sometimes more specific, for example, aimed at assessing the needs of the increasing number of widows that needed bereavement support.

With respect to the Macfarlane Trust and the Eileen Trust Partnership groups:

- **a. What was the purpose of the groups/meetings?**
- **b. How often did they take place?**
- **c. Who set the agenda?**
- **d. Who attended the meetings and how were the beneficiaries selected for these meetings?**
- **e. What impact, if any, did these have on the way each Trust operated?**
- **f. Were there any problems encountered in the running of the group/meeting and how were they handled?**
- **g. In answering the above, please refer to the following enclosed documents:**
  - **a. Terms of Reference for the new Partnership Group dated 25 September 2000 (MACF0000006_069).**
  - **b. Terms of Reference for the new Partnership Group (undated) (MACF0000006_112).**
  - **c. Bereavement Project Support Group meeting minutes from 12 March 2003 (HSOC0027948).**

302. I would say that the primary purpose of the Partnership Group in the case of the MFT would have been to give the registrants a voice, so that they felt that they could share with each other and with those of us who were supporting the group, their concerns and questions. This was in 2001 I believe, following the Strategic Review in 1999.

303. The Terms of Reference advise who was part of the Partnership Group. There would have been representation from THS, very likely the HIV worker. There was probably one of the haemophilia centre social workers involved too, together with the Trust social worker, the Chairman and myself. Then there would have been a whole range of registrants that would have been drawn from different cohorts. There would have been younger people under 21, single registrants, married registrants, and those with families. The representative group was wide and I seem to remember that people joined, and then they stood down after a period, after which someone else from that cohort would be nominated to replace them.

304. Later, when HCV became a much more active issue, there would have been a HCV worker who would have joined us, and representatives from the HCV community also, as opposed to just the HIV community.

305. Partnership Group meetings took place every couple of months I think, using a standardised agenda which had matters added as issues arose. I believe it was usually my secretary that kept on top of the agenda and minutes of these meetings. I recall I attended almost every meeting. The number of attendees at each meeting changed depending upon the issues being discussed.

306. I think the meetings had a huge impact on how the Trust operated, particularly once we had User Trustees on board. The way the Trust was run had to be much more registrant-oriented, and less business-oriented. Certainly, in my time the new Chairman helped greatly to facilitate these meetings. He was very interested in meeting beneficiaries, and this subtle organic change permeated throughout the organisation. I believe there was much more consideration given to the changing needs of the beneficiaries of the Trust during my tenure there.

307. I recall that we did try to hold some meetings in London and some in the regions to make sure everyone could get to them at some point. Travel expenses were paid and although most of the registrants had cars, they would not have driven into Central London. I do remember that holding meetings in London was a problem.

308. I do not recall the ELT having a similar structure, I believe members were invited to meetings with us from time to time, but there was no separate registrant community group. A number of registrants understandably did not want anything to do with the ELT or the HIV community once they had received payment. I recall a number of registrants telling us that they did not want anything to tie them to what had happened. In many cases they would have kept completely quiet about their HIV status throughout their lives.

309. The Bereavement Project was another way in which we worked to engage with the registrant community, as evident in the meeting minutes in document **HSOC0027948**. We did not specifically provide reports to the Trustee Board in this regard, however general developments and new factions of the Project as it expanded would be referred to in an update as and when necessary.

What was the relationship between the senior management and board of the Macfarlane Trust and the Eileen Trust and the beneficiary community? Could this have been improved in your view? What steps did you take to improve the relationships?

310. The senior management team serviced the registrant community in supporting everything that I have spoken about in this response, to improve our understanding and improve our services to them, in the case of both Trusts. Both the Trustees and staff members formed a group who were extremely familiar with the needs of the registrant community and were a community that engaged openly with us about what they perceived as being their changing

needs. Neither Trust had a distant Trustee body. The Trustees were knowledgeable and deeply involved in trying to help people with HIV and haemophilia, and had a great understanding of the impact of these conditions.

311. There is always room for improvement, however, I do believe that the Trusts were managed by people that sincerely did their best to seek improvement in the lives of the registrants.

Section 10: Relationships with other organisations

Further to your previous witness statement dated 22 October 2019, please describe the working relationship between the Macfarlane Trust and the Eileen Trust and the Haemophilia Society. Were you aware of any difficulties? If so, what were they, how did they impact on the running of each Trust and how, if at all, were they resolved?

312. The MFT registrants would almost certainly all have been members of THS as well. They would have been part of the cause for THS' campaigning for the establishment of the MFT, and later for support for people with HCV. It is possible that there were sometimes members of THS that might have felt that beneficiaries of the MFT were far luckier than they were, in that at that early stage, they did not receive any financial or other support for HCV, which MFT members did for HIV.

313. I believe staff members of all of the AHO's and THS co-operated well in respect of information exchange. Personally, I feel I had a good working relationship with THS representatives. After leaving MFT, I became a Trustee at THS a year later.

Please provide any key examples of the AHOs and the Haemophilia Society working together during your tenure at the Macfarlane Trust and Eileen Trust. Please consider the following enclosed documents:

a. Letter to Karin Pappenheim dated 7 January 2002 (HSOC0016840).

b. Draft Macfarlane Trust meeting minutes from 20 January 2003, heading "Chief Executive's Report and Statistics" (MACF0000009_012).

314. I recall very well the work that Karin and I did in preparation for establishing a means by which all people with haemophilia who had become infected with HCV should receive some form of financial support. I have referred to this in detail at paragraphs 21 and 22 of this response. Our discussions laid the groundwork for the Skipton Fund, and this came to fruition after I had left MFT. These discussions did not include registrants of the ELT at that time, as we had no way of knowing which of those registrants had HCV.

315. The draft minutes that I am directed to in the question above discussed the Bereavement Project because Chris Hodgson was standing down as Chairman of THS at that stage, and he was also not going to continue on the Trustee Board of the MFT. I believe we asked him to remain involved with the Bereavement Project. THS were not directly involved with this project but it certainly had an interest for the benefit of its members.

316. Another example of the AHO's working with THS was in relation to its HIV social worker, as a result of which we did not see a need for the MFT to appoint one directly. Of course, the MFT Board was also made up in part with THS members.

During your tenure with the Macfarlane Trust and Eileen Trust, were there any Trustees in addition to you who were also Trustees of the Haemophilia Society? If so, please give details. Did this have an impact on the relationship between the two organisations? Please give details.

317. First of all, my tenure at the MFT and ELT did not overlap with my time as a Trustee at THS. I joined THS early in 2004 and served two concurrent three-year terms, until 2010. I believe Chris Hodgson was the only Trustee for both MFT and THS at the same time. I do not think this had any negative impact on the working relationship between both organisations, in fact it was beneficial. Chris had dealt with haemophilia and HCV, he had attended Treloars, he had a lot of knowledge and experience about the matters directly affecting registrants of the MFT and THS.

What involvement or interactions did the Macfarlane Trust and Eileen Trust have with the UK Haemophilia Centre Directors Organisation?

318. The involvement between the MFT and UKHCDO would have been through the Centre Director who, for most of the time that I was director of the MFT, was Dr Mark Winter. He was the Centre Director for the Kent and Canterbury Haemophilia Centre, and was an active participant of the Haemophilia Centre Directors' Group. We met with a number of their members during my time at MFT, so that we could stay appraised of the changes going on at the time that would be relevant for our registrant community.

319. Dr Mark Winter would regularly report to the Trustees on medical matters that he felt were important to bring to their attention, development of fertility treatment and sperm washing being an example.

Please describe the working relationship between Macfarlane Trust and Eileen Trust and the UK Haemophilia Centre Directors Organisation. Were you aware of any difficulties? If so, what were they, how did they impact on the running of the Macfarlane Trust and Eileen Trust and how, if at all, were they resolved?

320. I do not recall there being any difficulties. We had a very positive working relationship that was valuable to the Trusts.

Please list any particular clinicians you were in regular contact with during your work with the Macfarlane Trust and Eileen Trust.

321. This would only have been Dr Winter. He was replaced by a successor towards the end of my tenure, however I cannot recall who this was.

Section 11: Reform of the Macfarlane Trust and Eileen Trust

Please provide details of any consultation or reform process you were involved in, in respect of the Macfarlane Trust and the Eileen Trust.

322. There was no formal reform process as such during my time at the Trusts. We conducted the reviews that I have spoken about and this led to changes. The Long Term Review certainly emphasised the role of the beneficiaries very much in the way that it was conducted. I know that reform took place after I left the Trusts, but I think that that happened as a result of the founding of the Skipton Fund. Once I joined THS, the brief was so much wider that the sort of intimate contact with members of the MFT was very significantly watered down.

What was your view of the changes made to the Macfarlane Trust and Eileen Trust as a result of the Archer Inquiry which reported in February 2009?

323. I had left the Trusts six years prior to this report. Anything that I heard was hearsay and I would not wish to comment on that.

What concerns, if any, did you have about the 2016/2017 reforms?

324. I was not aware that such reforms had taken place. This was almost 15 years after I had left the Trusts.

Section 12: Other

Do you consider that the Macfarlane Trust and the Eileen Trust were well run? Do you consider that they achieved their aims and objectives? Were there difficulties or shortcomings in the way in which each Trust operated or in their dealings with beneficiaries and applicants for assistance?

325. I believe that during my tenure both Trusts fulfilled their aims very well. I do not know what happened subsequently.

326. I am sure there were difficulties in the six years I was at the Trusts but I did my best to overcome them. The financial climate and the needs of beneficiaries changed during my tenure, and this came with its own challenges, however I do not recollect having to deal with any grave or insurmountable problems.

327. I am aware that later Trustees felt we had been too generous during my tenure but I was satisfied with how we had conducted ourselves.

Please provide any other information and or views you may have that is relevant to our Terms of Reference.

328. I have commented above that the ELT Trustees and I had always had concerns that the DoH had not reached out to as many registrants of that Trust as they could have. I feel that more work could have been done to identify many more people that could have benefited from the Trust.

329. The only additional comment I can make here is in relation to dental treatment. I recall this being a major issue because dentists on the whole would not treat people with HIV. That certainly was something that was raised at Trustee Board meetings and I know that the Haemophilia Centre Directors' Group tried to create a situation in which special provision could be made in hospitals for people with haemophilia and HIV to be treated, due to them having difficulty with sufficient clotting factor, and also the perceived significant risk to the dental surgeons treating them.

Statement of Truth

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

GRO-C

Signed: ....

Dated: ......11th Feb 2021......