

Witness Name: JAN BARLOW

Statement No: WITN3108003

Exhibits: WITN3108004 - WITN3108007

Dated: 22 December 2020

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF JAN BARLOW

I provide this statement in response to a notice under subsection 21(2)(b) of the Inquiries Act 2005, dated 15 October 2020.

I, Jan Barlow, will say as follows:

I have done my best to answer the very detailed questions posed in the section 21 notice. I left my post in 2018 and no longer have access to the AHO's documents, so this statement is inevitably based on my incomplete recollection of events which took place some years ago. In relation to some questions, I have either no recollection or only a vague recollection of the matters raised. The details of applicable policies and procedure should be evident from the documents available to the Inquiry. The Inquiry team have provided me with some documents which they have identified as potentially relevant. However, I cannot rule out that there may be other documents in the AHOs' archives (to which the Inquiry has access) which demonstrate that my recollection is incorrect.

I would also like to state for the record that I never received two Rule 9 requests referred to in this s. 21 notice: one the Inquiry states was sent to me on 2 July 2019, and one the Inquiry states was dated 21 October 2019. As I never received these, I could not respond to them.

Section 1: Introduction

1. Prior to the commencement of my employment at the Macfarlane Trust (MFT) and the Caxton Foundation (CF) on 3 January 2013, I had worked in the charity sector since

1997, and as a charity Chief Executive since 2001. Prior to that I had worked as a manager in the NHS.

2. I was appointed as Chief Executive of MFT and CF via an open recruitment process, which included an open advertisement. I did not know, or know of, Roger Evans, prior to my appointment.
3. I was Company Secretary for MFET.
4. As a Charity Chief Executive, one attends board meetings and other committees/subcommittees "in attendance" only; one has no voting rights. In this capacity I attended the MFT Grants Committee and the CF National Welfare Committee. I also attended the CF Audit Committee, a CF Employment Committee which ran during the early part of my tenure, and a Liaison Committee between CF and the other Alliance House organisations which met infrequently.
5. None.
6. None.

Section 2: Operation of Macfarlane Trust and Caxton Foundation

Macfarlane Trust

7. I understood the aims and objectives of MFT to be to provide financial and other support to the beneficiaries of the charity. I cannot comment on the principles or philosophy which underpinned the charity's establishment as I was not involved in its establishment.
8. I understood that MFT had been set up by the then Secretary of State for Health and that DHSC was the sole funder of the organisation.
9. As a charity, the Charity Commission was the regulator for MFT. During my time at MFT, I do not recall any communication with the Charity Commission outside of the annual returns process, where charities are required to make annual submissions of their annual accounts.

10. Charity trustees are not allowed to be remunerated for acting as trustees. However, they are permitted to claim travel and accommodation expenses related to attending meetings, and some incidental expenses (eg postage, telephone calls etc) related to their duties as trustees. My recollection is that some MFT trustees (my recollection is those who travelled from outside London) claimed travel expenses during my time at MFT.

Caxton Foundation

11. I understood the aims and objectives of CF to be to provide financial and other support to the beneficiaries of the charity. I cannot comment on the principles or philosophy which underpinned the charity's establishment as I was not involved in its establishment.
12. I understood that CF had been set up by the then Secretary of State for Health and that DHSC was the sole funder of the organisation.
13. As a charity, the Charity Commission was the regulator for CF. During my time at CF, I do not recall any communication with the Charity Commission outside of the annual returns process, where charities are required to make annual submissions of their annual accounts. CF also had a corporate trustee and was therefore also regulated by Companies House. I do not recall any communication with Companies House outside of the filing of annual accounts and changes to directors, which as I recall were all submitted by CF's auditors.
14. Charity trustees are not allowed to be remunerated for acting as trustees. However, they are permitted to claim travel and accommodation expenses related to attending meetings, and some incidental expenses (eg postage, telephone calls etc) related to their duties as trustees. My recollection is that some CF trustees (my recollection is those who travelled from outside London) claimed travel and accommodation expenses during my time at CF.

Appointments of Trustees/Directors

15. The process for electing/re-electing trustees at MFT and CF was set down in the respective organisations' Trust Deeds.

16. My recollection is that the MFT board could comprised up to 9 trustees. I recollect that initially, 3 trustees were appointed by DHSC, 3 by the Haemophilia Society, and 3 by the board itself. During my tenure I recall there being 2 beneficiary trustees.

I cannot recall how many board members the CF board could have. The appointment of all CF board members had to be approved by the Health Minister. During my tenure there was one board member who had experience of living with Hepatitis C as a result of contaminated blood.

- 16(a) I can no longer recall why the Haemophilia Society stopped making nominations to the MFT board in 2013.

- 16(b) I can no longer recall the discussion at the CF board meeting on 7 February 2013. A board member who had experience of living with Hepatitis C as a result of contaminated blood was appointed following an interview process, which the board led, during my tenure.

- 16(c) I recall 2 beneficiary trustees of MFT during my tenure. I do not recall any board discussions regarding conflicts in relation to having user trustees.

17. I cannot recall whether there were formal policies regarding trustees/directors being able to sit on more than one board, but any prohibitions would have been set out in the organisations' governing documents. There were some trustees/directors who sat on more than one board and I recall that the two directors of MFET were required to be the Chairs of MFT and of the Eileen Trust. I was not aware of any negative impact of trustees/directors being on more than one board, and it did mean that those trustees/directors had an understanding of more than one organisation.

Departure of Trustees/Directors

18. I can no longer recall the length of time trustees/directors of MFT and CF could serve, but I do recall that they could serve more than one term.
19. My recollection is that the CF directors who left between 2013 and 2015 either left at the end of their term of office or due to a change of personal circumstances which

meant that they could no longer continue to fulfil their role as board member. As turnover was for these reasons, I would not consider this unusual.

20. I can no longer recall why Alan Burgess stepped down. However, I do recall that he was already a trustee when I was appointed, so it is possible that his term of office came to an end.

Relationship between directors and senior management

- 21 (a) I was not aware of any difficulties in the working relationship between the trustees of the MFT and CF and the senior management team.

21 (b) N/A

21 (c) N/A

- 21 (d) I worked most closely with the Chairs of the respective boards, which in my experience is usual, as the Chief Executive reports to the Chair. I also worked closely with the Chairs of the respective board subcommittees.

Appointments/departure of staff

22. The restructuring of the support team across CF and MFT was undertaken because since CF had become operational, there had been no review of the staffing in the team which supported beneficiaries across the two organisations.

22(a) The more senior Director of Operations role was created to replace the Support Services Manager role, as the organisations required someone who could deliver a greater focus on, and improvements to, customer care (such as grant turnaround times) and who had greater awareness of the changes in external policy which would impact upon beneficiaries (such as changes to welfare benefits) and could ensure the organisations were aware of, and able to respond to, these. I do not know what is meant by “financial advisor” in this context; no “financial advisor” role formed part of the restructuring of the team.

22(b) Each year MFT received an allocation from DHSC, and under the arrangements DHSC had set out with the organisations before I joined, a portion of the allocation was “top sliced” and allocated to CF, which acted as employer and leaseholder on behalf of all

5 AHOs, to meet staffing and premises costs. To my knowledge MFT had never received a s.64 grant, as the organisation was 100% funded by DHSC. There was no separate “beneficiary pot”. As I recall, there was an increase in costs in appointing a Director of Operations compared with the former Support Services Manager role, but the boards considered this an important investment to improve the standards of service delivery.

22(c) An Assistant Chief Executive was appointed following the departure of the Support Services Manager to cover the workload across CF and MFT prior to the appointment of the Director of Operations.

23 My recollection is that the changes in personnel were due to the restructuring.

23(a) Turnover was therefore not high; and

23(b) As the changes were due to restructuring, exit interviews were not required, as the reasons were already known.

24. Staff salaries were based on a pay and grading system which already existed when I took up post. I have no knowledge of whether steps had been taken to ensure parity with the charitable/other sectors when it was introduced.

25. The minutes of the Board meeting on 25 April 2016 (minute 830.16) set out why it was thought that NHS pay rates were not an appropriate guide. The minutes state, “The board felt that it was not appropriate to benchmark Alliance House staff against the NHS/public sector, as Alliance House staff did not benefit from the more generous terms and conditions of NHS/public sector staff, eg pension”.

26. CF did not move away from incremental pay scales and pay salary increases based on performance.

27. Incremental salary progression was a contractual term for staff, which entitled staff to move up one incremental point each year until they reached the top of the scale for their grade. I do not recall whether and for how long any pay rise was put on hold, but once the matter had been clarified, the pay rise would have been backdated. It should

be noted that CF and not MFT was the employer of all staff who worked at Alliance House.

- 28. N/A – see 26 above.
- 29. N/A – see 26 above. CF and not MFT was the employer of all staff who worked at Alliance House.
- 30. My recollection is that the payment was conditional upon staff staying until the end of the financial year. My recollection is it achieved its aim of getting staff to stay.
- 31. Staff were not paid bonuses.

Use of external advisors

- 32. The money management advisors, Pennysmart, had been appointed prior to my joining CF/MFT. They were appointed to work with beneficiaries that CF/MFT referred to them and were paid for each case they worked on.
- 33. Pennysmart was appointed to work with beneficiaries on debt/money management advice. They were independent and regulated by their own industry regulator, and they made recommendations to CF/MFT on each case if appropriate. Sometimes outcomes for beneficiaries did not involve CF/MFT.
- 34. Beneficiaries were asked for their consent, and a referral then made by CF/MFT.
- 35. Pennysmart were independent advisors and worked to their own industry guidelines.
- 36. The board commissioned the proposal from Blackrook Media and I attended the board meeting at which the proposal was discussed, but the board decided not to engage Blackrook Media.

Running of CF and MFT

- 37. No communications strategy was developed for CF/MFT.

- 38. Strategy development was the responsibility of the board, and I was involved in the process which resulted in a strategy being developed. As CF had only been operational for a relatively short time, it was the organisation's first strategy.
- 39. Strategy development is the responsibility of the board, and as I recall, no financial strategy was developed.
- 40. I have no recollection of this discussion.

Section 3 – Relationship with Government

- 41. In general day to day contact between MFT and CF and DHSC was limited. Contact with DHSC could be with any one on the relevant DHSC team. I was not aware of any difficulties.
- 42. There was no regular pattern of meetings between MFT and DHSC outside of the annual review meetings. Ad hoc meetings were arranged either by email or telephone.
- 43. I attended the annual review meetings between CF and DHSC and the meetings were minuted. There was no regular pattern of meetings between CF and DHSC outside of the annual review meetings. Ad hoc meetings were arranged either by email or telephone.
- 44. Ad hoc meetings were to discuss issues such as policy changes. The meeting on 16 January 2014 was an annual review meeting. MFT would have used these meetings to discuss the need for increased funding, but due to the passage of time, I am unable to recall discussions at specific meetings.
- 45. My recollection is that ad hoc meetings were not minuted.
- 46. MFT and CF had been established by Trust Deeds which set out the nature of support that could be provided and to whom; my understanding is that DHSC had been involved in establishing the Trusts at the outset. The Trustees of the charities had discretion in deciding how this support should be delivered, taking into account the Trust Deed, charity law, and the funding available from year to year. Each year the charities received a letter from DHSC advising how much money had been allocated for that financial year.

- 46(a) As I understand it, since MFT's inception, 3 MFT trustees had been appointed by DHSC but DHSC ceased doing this during my time at MFT. The appointment of CF board members had to be approved by the Health Minister.
- 46(b) To my knowledge DHSC had no involvement in the content of any policies developed and adopted by MFT and CF.
- 46(c) To my knowledge DHSC had no involvement in how MFT and CF discharged their responsibilities to beneficiaries.
- 46(d) DHSC had no involvement in the applications MFT and CF received nor whether a grant should be approved or declined.
- 46(e) DHSC had no involvement with the quantum of grants/payments made by MFT and CF, apart from determining via the annual financial allocation how much money overall each charity had each year.
47. I recall that both MFT and CF at different points raised concerns with DHSC regarding funding levels in writing and in individual meetings - although due to the passage of time I am unable to recall specifics - but that no additional funding was forthcoming.
48. MFT/CF made representations to DHSC where the boards considered that DHSC proposals and decisions in relation to funding would negatively impact upon the level of financial support for beneficiaries. As I recall, during my time in the organisations, MFT made regular representations to DHSC regarding annual underfunding, and CF did so in relation to additional funding for running a regular payments system. The five Alliance House organisations also made a joint response to the January 2016 consultation document, "Infected blood: reform of financial and other support" where the organisations were concerned about the likely negative financial impact on beneficiaries of the proposed financial reforms.

With regard to the MFT board meeting of 21 January 2013 and the draft letter which one of the trustees tabled, as recorded in the minutes of that meeting, I believed that sending a letter to the Minister of the nature of the one tabled **in advance of any decision being made** would not be constructive, and would also remove any room for

further negotiation if an unfavourable answer was received. However, whether to send such a letter to the Minister was a decision for the trustees.

48(a) I do not have a copy of the email which Roger Evans sent to on 26 January 2013 which you refer to.

48(b) It was a matter for the trustees whether they considered it appropriate to challenge the DHSC and in what way. In my view, it was not a question of "showing loyalty" to DHSC, but rather one of negotiating possibilities, which the tabled draft letter would effectively have removed.

48(c) DHSC were already aware of the issue of underfunding, as, as I recall, a letter regarding underfunding had already been sent to DHSC prior to my joining the organisation in January 2013, and to which an answer was still awaited by the time of the meeting on 21 January 2013.

49(a) My previous statement, "Because of our day to day contact with beneficiaries it was important to give DHSC practical insights into the impact and practicality of proposed DHSC policy changes", refers in general terms to any potential policy changes the DHSC might have been considering making.

49(b) These insights would have been given either at meetings with DHSC officials or in writing.

49(c) The practical insights would have been in relation to the impact on beneficiaries of particularly proposed policy changes.

50(a) As stated previously, my recollection is that the organisations largely became involved in DHSC consultations and reforms either at the very last minute or after they had been announced.

50(b) Due to the passage of time, I cannot remember details of when DHSC did/did not take MFT/CF's input into account. However, I do remember the January 2016 consultation document, "Infected blood: reform of financial and other support" where the Alliance House organisations were so concerned about the likely negative financial impact on beneficiaries of proposed financial reforms that they submitted a joint response to the consultation document. The subsequent DHSC document was amended, and

although I cannot say whether this was as a result of our comments, or as a result of comments received from others as part of the consultation, or both, had DHSC involved us in the early stages of drafting their consultation document, we could have advised them that the proposals would have had a negative financial impact upon beneficiaries before they published the document.

51. My recollection is that during my time at MFT/CF there was very little involvement with DWP apart from in clarifying the status of payments beneficiaries received from the Alliance House organisations (ie these payments were disregarded by DWP when assessing eligibility for welfare benefits).
- 51(a) There were occasions where beneficiaries' benefits were stopped as a result of local DWP staff not understanding the status of the payments beneficiaries received from MFT/CF.
- 51(b) In these cases, we gave beneficiaries support via our expert external benefits adviser to get their benefits reinstated.
- 51(c) My recollection is that these cases were due to local DWP staff not understanding the status of the payments received from the AHOs, and this was raised with the respective local DWP department by the benefits adviser.

Section 4: Funding/finances of the AHOs

52. The funding MFT/CF received was designed to provide additional financial support to beneficiaries in need, over and above the payments beneficiaries received from either MFET and/or the Skipton Fund. If the organisations had received greater funding from DHSC, clearly they could have provided additional levels of support. In relation to MFT, the main financial issue was that the annual allocation was not equal to the historical pattern of financial support that MFT had provided to beneficiaries, and in spite of regular representations to DHSC for additional funding, this was not forthcoming, and during my time in the organisation, each year MFT had to use a portion of its reserves to make up the shortfall. In relation to CF, a specific financial issue was that when the organisation wished to introduce a regular payments system, DHSC did not agree to increase the organisation's allocation, and therefore a lower level of regular payments which was affordable within the existing allocation had to be introduced.

53. DHSC was the organisation which CF and MFT had to invoice to draw down funds against the annual allocation. With regard to CF, the annual allocation was made up of allocations from each of the four UK countries apportioned according to the percentage of beneficiaries in each country, and CF knew each year how much was available to spend on beneficiaries in each country. With regard to MFT, I understand that the devolved administrations contributed, but that this was an internal mechanism at DHSC/devolved administration level, and MFT was never given separate allocation figures for each country.
54. MFT/CF received small amounts of money from bank interest. In addition, MFT received income from its investment portfolio.
55. CF was not able to accumulate reserves, and any funds drawn down from DHSC in one year and not used were carried forward and offset against any drawdown the following year. I understand that this was a stipulation from DHSC when CF had been set up (prior to my joining the organisation). This meant that the organisation had to budget and monitor spend carefully each year.
56. The MFT board decided on the level of reserves the organisation should maintain. During my time in the organisation, MFT used a proportion of its reserves each year to make up the financial shortfall in the DHSC allocation and thereby maintain the level of support that had previously been provided to beneficiaries.
57. DHSC would need to comment on whether the level of reserves had an impact on MFT's negotiations with DHSC for increased funding.
58. MFT used a proportion of its reserves each year to make up the financial shortfall, and in this way was able to maintain the level of support that had previously been provided to beneficiaries. MFT was aware of the fact that beneficiaries relied upon these payments from MFT, and therefore sought to protect these. Clearly, this could not have continued indefinitely as, without additional DHSC funding, the reserves would have run out. The focus on protecting existing payments meant that MFT could not increase existing payments to beneficiaries nor introduce new forms of support.
59. Budgets were drafted by MFT and CF prior to the start of each financial year, and confirmed once DHSC advised the organisations of their respective annual allocations.

- 59(a) By far the majority of funding received by MFT was used on regular payments, a long standing mechanism of providing support to MFT beneficiaries, and it was understood that beneficiaries relied on these payments. Given this and the annual shortfall, there was therefore no scope for assessing needs annually. See also 58 above. Similarly with CF, the majority of funding was used on regular payments and a grants programme, which it was understood beneficiaries relied on, leaving no scope for assessing needs annually.
- 59(b) As discussed above, the underfunding for MFT was addressed by MFT using its reserves to supplement the annual allocation, and CF implemented a lower level of regular payments.
- 60(a) DHSC set the **annual allocation**, as opposed to the **budget**, for CF and MFT. DHSC would need to comment on how it made its decisions regarding the annual allocations. As set out in 53 above, only CF reported on the number of beneficiaries in each of the 4 UK countries.
- 60(b) CF/MFT were not asked to provide draft budgets to feed into this process, and had to budget according to the allocation given each year. CF/MFT had no input into the DHSC annual allocation process and therefore had to make representations for additional funds.
61. See 53 above. I recall that CF did request additional funding from the devolved administrations. Because the proportion of beneficiaries in the devolved administrations was relatively small compared with the proportion in England, the actual monetary allocations for each country could also be relatively small, particularly for Northern Ireland, and demand for financial support could exceed the allocation received. My recollection is that when we requested additional funding directly from the devolved administrations, this was always forthcoming. My recollection is that the requests were made in writing but, as stated previously, I have not retained any documentation.
62. I recall that the Skipton lookback exercise caused a significant increase in Caxton beneficiary numbers.
- 62(a) There had been an underspend in previous years. I cannot recall the reasons for this.

- 62(b) CF was concerned that it would not be able to manage on its existing annual allocation as a result of the increase in new beneficiaries.
- 62(c) As I recall, representations were made to DHSC, but no additional funding was forthcoming. I cannot recall whether DHSC was advised that CF would need to reduce its winter fuel payments.
- 62(d) I can no longer recall the detail.
63. See 61 above. Due to the passage of time, I cannot recall how often CF made cases for additional funding to DHSC/the devolved administrations.
64. Due to the passage of time, I can no longer recall whether a business case was made in 2016/17.
65. I can no longer recall the reason DHSC gave for rejecting the business case to fund a regular payments scheme.
66. CF decided to proceed with a regular payments scheme, but the level of regular payments given to beneficiaries had to be reduced so that it was affordable within the annual allocation.
67. As I recall, the level of winter fuel payment was initially reduced in the autumn of 2014 due to the Skipton lookback exercise, the significant increase in CF beneficiary numbers, and concerns that the level of winter fuel payment given in previous years might be unaffordable. Once it was clear that it would be affordable, a second, top-up payment was made.
68. I cannot recall how often there was an underspend on the MFT budget. However, my recollection is that these underspends were against a deficit budget, ie a budget that included a shortfall made up by reserves. My recollection is that during my time in the organisation MFT never underspent to the extent that the reserves were not required to make up the shortfall against the annual allocation.
69. I cannot recall the detail of steps CF and MFT took to cut operational costs. However, the five AHOs operated from small shared offices and had a small staff, with the

majority of staff working for two or more of the five Alliance House organisations, so the scope for reducing costs further was limited.

Section 5: Eligibility for the Macfarlane Trust and Caxton Foundation

70. In relation to CF, in order to become a primary beneficiary of CF, there was a very specific requirement that individuals had to have received a payment from the Skipton Fund. In relation to MFT, during my time at MFT, I cannot recall any new MFT primary beneficiaries; if there were, DHSC would have made the decision regarding eligibility. I do not know the extent to which haemophilia centres/centre directors were involved in the DHSC process. DHSC would need to comment.
- 71(a) As I recall, the CF website and information documents for beneficiaries referenced the need for someone to have received a payment from the Skipton Fund in order to be eligible to be a primary beneficiary of CF. I do not recall any reference to eligibility criteria to become an MFT primary beneficiary, as the primary beneficiaries had been clearly identified in the early days of the organisation's establishment and the number of primary beneficiaries did not increase.
- 71(b) DHSC would need to answer whether the Government had a view as to the publication of policies about eligibility criteria. I do not recall DHSC expressing a view in this regard.
72. Please see 70 above. DHSC set these requirements.
73. Please see 70 above. DHSC would need to comment.
74. Please see 70 above. DHSC would need to comment.
75. Please see 70 above. DHSC would need to comment.
76. Please see 70 above. MFT/CF did not determine the eligibility requirements.
77. Please see 70 above.

Section 6: Decisions on substantive applications within the Macfarlane Trust and Caxton Foundation

The Macfarlane Trust

- 78 (a) Statistics were presented to the board on an ongoing basis regarding the number of beneficiaries registered with MFT at any one time, but were not collated over a number of years. I have no recollection of the specific numbers, but they will be in documents available to the Inquiry.
- 78 (b) I presume this question refers to the number of applications to become primary beneficiaries, in which case please see 70 above.
- 79 (a) Regular payments were made to beneficiaries based on an assessment of their annual household income.
- 79 (b) MFT did not make lump sum payments; these were made by MFET/the Skipton Fund.
- 79 (c) Grants were made according to the grants criteria in place at the time, and were assessed either under Office Guidelines or by the Grants Committee.
- 79 (d) Policies were in place in relation to the level of regular payments and grants.

The process

- 80 (a) Applications delegated to staff under Office Guidelines were for straightforward requests, generally lower cost items. Applications considered by the board subcommittee were more complex cases, requiring more detailed consideration and were generally of higher cost.
- 80 (b) The Support Services Officer (MFT)/Welfare Officer (CF) and the Director of Operations considered grant applications under Office Guidelines.
- 80 (c) Staff used the Office Guidelines to determine applications.
- 80 (d) The Support Services Officer/Welfare Officer made the initial assessment of applications based on the Office Guidelines, and the Director of Operations reviewed and ratified the decision.

- 80 (e) The Boards chose which board members became members of the grants subcommittees. During my time at MFT/CF, both grants subcommittees had user trustees on them.
- 80 (f) The subcommittees referred to the grants criteria.
81. My recollection is that the change of title from National Support Services Committee to Grants Committee related to the restructuring of the Welfare Team and the desire for a more modern term for the committee.
- 82 (a) As I recall, applicants were required to make a written application, which included information regarding why the item was required and how it would benefit the beneficiary, the cost of the item, two quotations, and information regarding the applicant's income and expenditure to enable the committee to assess financial need. For applications relating to eg health/mobility related support, a supporting letter from the beneficiary's clinician was also requested. The terms "burden of proof" and "standard of proof" were not used in this regard.
- 82 (b) The Grants Committee kept the requirements under constant review.
83. No, I did not introduce a practice of sending people to interview those who had made applications for grants, to photograph their homes in order to prove what the money was needed for. This practice was in place when I joined the organisation but was phased out during my tenure. This is due to the fact that we were made aware that some beneficiaries regarded this as intrusive. We were also aware of the fact that, as staff resources were so limited, undertaking this level of assessment for individual grant applications had a significant negative impact on the speed at which grants overall could be considered. We therefore standardised the information we required in support of grant applications and did not continue to send staff to interview beneficiaries in their homes.
84. I cannot recall the level of detail that was provided to applicants whose grant applications were declined, but as I recall, they were given reasons in writing. They were also able to appeal the decision.

85. A “round robin” process was used to enable Grants Committee members to make decisions by email and telephone regarding urgent grants in between the 6-weekly Grants Committee meetings.

Criteria and Policies

86. The Office Guidelines and other policies for MFT were already in place when I joined the organisation. These were updated and approved by the Grants Committee and board with input from staff.
87. My recollection is that Office Guidelines were updated when it was felt that particular changes were needed.
88. Due to the passage of time I am unable to recall precisely which version of the Office Guidelines were in use when I took up post at MFT, nor whether there were versions between the 2011 and 2014/15 versions.
89. Staff, not the Grants Committee, used the Office Guidelines when determining applications.
90. Staff used the Office Guidelines, and the Grants Committee used the grants criteria.
- 91 (a) Medical input was given by the Medical Trustee when the board was determining policies.
- 91 (b) The policies were largely established when I came into post. I have no knowledge of whether the beneficiary community had been involved originally.
- 91 (c) DHSC had no input into the policies during my tenure.
92. The criteria “charitable need” and “exceptional circumstances” were being used by the NSSC when I took up post, but as I recall the latter criterion was subsequently not used by the Grants Committee.
- 93 (a) I cannot recall the definition of “exceptional circumstances” that the NSSC used nor whether there was any guidance.

- 93 (b) This definition was developed prior to my joining the organisation.
- 93 (c) I cannot recall whether the definition was publicly available.
- 93 (d) I cannot recall whether this definition was provided to all office staff and the NSSC when NSSC was using this criterion. As stated above, I recall that this criterion was not used by the Grants Committee when it replaced NSSC.
- 93 (e) This information was not included in the 2014 Grants Guidelines because it was no longer used as a criterion.
94. I cannot recall how NSCC assessed "exceptional circumstances".
- 95 (a) In this context, my understanding is that charitable need meant that some applying for a grant did not have the ability to fund it from their own resources.
- 95 (b) An income and expenditure statement was required as part of the grant application process.
96. I do not know who originally drafted the "Income and Expenditure" form. It would have been amended during my tenure to reflect changes, eg in state benefits terminology.
- 96 (a) Information regarding earnings/contributions from partners/other household members were required to get a complete picture of household income and disposable income.
- 96 (b) The decision to include Skipton Stage 2 regular payments had been made prior to my appointment; I cannot recall the reason for this decision.
- 96 (c) An increase in earnings of a member of the household could potentially lead to a reduction in the level of regular payments made by MFT, if this increase in earnings meant that the household income increased to a point where it moved the beneficiary into a lower regular payments bracket.
- 96 (d) A breakdown of household expenditure was required in relation to grants so that an assessment of disposable income could be made.

- 96 (e) An explanation of the need to assess charitable need and the criteria being applied would be given.
97. In relation to income and expenditure and thus disposable income, staff and the Grants Committee took a view in relation to the level of disposable income compared with the cost of the grant being applied for, and whether charitable need could be determined. For example, in the case of someone with a high disposable income asking for a very small grant for an item which could easily be afforded from their disposable income, it is unlikely that charitable need could be determined.
98. MFT was not in a financial position to be a substitute for other financial support such as welfare benefits that beneficiaries were entitled to.
99. As I recall, trustees decided in October 2013 to stop backdating payments to May 2009 for non-infected beneficiaries because it was felt that by October 2013, there had been a significant amount of time for non-infected beneficiaries to come forward, and also that MFT could not continue to run with what would amount to an open-ended financial liability.
100. Grants guidelines were published and circulated to beneficiaries.
101. This is correct. The grants guidelines that were updated were published for beneficiaries.
- 102 (a) Maximum amounts and frequency of payments applied to Office Guidelines only. My recollection is that the Office Guidelines were not circulated to beneficiaries as they were guidelines, and in certain circumstances, a beneficiary might be able to receive a repeat grant, or a larger grant for something covered under Office Guidelines, through the Grants Committee.
- 102 (b) Unfortunately I do not understand the question and therefore am unable to respond.
- 103 (a) I was not in post at the time of Archer, so cannot comment.
- 103 (b) The 2014/15 Grant Guidelines were developed later.
- 103 (c) I am unable to comment as I was not in post.

Decisions on applications

104. I attended NSCC/Grants Committee meetings in a support role, to ensure the Committee members had all the paperwork and information they needed, and to assist with reference to the criteria and precedents.
105. I do not recall MFT refusing a grant application due to lack of funds.
106. As I recall, the success or otherwise of an application did not depend on the number of applications made to MFT each year and each application was considered on its own merits.
107. Each application was considered on its own merits.
108. A beneficiary's income and expenditure, including benefits, was considered as part of an application to establish a clear picture of disposable income and therefore be able to determine charitable need.
109. MFT beneficiaries were expected to apply for benefits they were entitled to.
110. As I recall, due to financial constraints, financial support with assisted conception was only available to those without any other children.
111. As I recall, a referral to the external money management adviser was a condition for beneficiaries seeking financial support with debt. This was to ensure there was an understanding of, and access to, all the options available to the beneficiary for dealing with the debt.
112. I do not recall this case. However, as an agency working directly with MFT, Pennysmart were bound not to disclose a beneficiary's infected status to anyone else, and as they were independent, if they were liaising with other organisations on a beneficiary's behalf, there would have been no apparent connection to MFT.
- 112 (a) We were aware of beneficiaries not willing to divulge their infected status to creditors. See 112 above.

112 (b) See 112 above.

113. I do not recall the details of this case.

113 (a) As I recall, there was a standard timeframe for accepting an offer from MFT and that beneficiaries were advised of this in writing.

113 (b) As I cannot recall the details of this case, I cannot comment on what the beneficiary would have been told when they were offered the grant and loan.

114. I believe that the use of Office Guidelines and clear criteria for grants used by the Grants Committee, and the requirement for all beneficiaries to provide the same level/categories of supporting information for grant applications, resulted in a high degree of consistency and fairness when assessing grant applications.

115. The board meeting on 26 March 2018 was to consider grant applications to a one off programme funded by reserves. As I recall, the criteria for this one off grants programme was for mobility equipment and health- and mobility-related repairs and improvements to property.

Loans made by the Macfarlane Trust

116. The practice of making loans pre-dated my time at MFT. My recollection is that we did not make loans during my time at MFT; if we did, there were very few. As I recall, advances were given where the Grants Committee did not feel it was appropriate to give a grant. Advances were an advance on a beneficiary's regular monthly payment, and as I recall, these were limited to repayment over 2 years, repayment meaning that they either received no or reduced regular payments during the period of the advance.

117. See 116 above.

118. As I recall advances were not typically made in relation to debt issues and therefore would not have been made contingent on beneficiaries accepting the services of the money management adviser. As stated above, I do not specifically recall any loans being made during my time at MFT.

119. The NSSC/Grants Committee made the decisions regarding loans and advances.

120. The practice of making loans was one which had been introduced into the organisation many years before I joined. I am therefore unable to comment on the criteria used at that time and who was involved in drafting the criteria.
121. As stated above, I do not recall loans being made during my time at MFT.
122. The practice of securing loans against a beneficiary's property had been discontinued before I joined the organisation. I am therefore unable to comment on when and why this decision was taken.
123. As stated above, my recollection is that loans were not made during my time at MFT.
124. See 123 above.
125. As I recall, during my tenure the case you refer to in this question was the only case where MFT proactively entered into discussions regarding the sale of a beneficiary's property. In this particular case, this was done because the beneficiary had not been able to afford the leasehold costs associated with the property and MFT had been asked to meet these, the beneficiary was not able to maintain the property, and had not been living at the property. I recall there had also been issues with keeping the property insured. As I recall, the decision to enter into discussion with the beneficiary to sell the property was to release the beneficiary from the burden of a property they were unable to afford, unable to maintain, and were no longer living at.
126. During my time at MFT I do not recall any loans to beneficiaries secured against property being cancelled with no repayment needed.
127. As I recall, there was only one unsecured loan, and the repayment conditions specified at the time the loan was made, which pre-dated my time at MFT, were very unspecific and open to interpretation. There was a recognition that it would be difficult to enforce repayment and therefore the board decided to write off the loan.
128. I do not recall any cases where MFT agreed to remove charges secured against beneficiaries' properties.

129. I cannot recall the details of this case or any other similar cases and am therefore unable to comment.

Non-financial support

130. In relation to non-financial support, MFT beneficiaries were able to access support from a specialist benefits adviser and a money management adviser. As I recall information about this was on the MFT website.

Caxton Foundation

Identifying potential beneficiaries

131. There was a very specific criterion for an individual to become a CF beneficiary, namely they must have received a payment from the Skipton Fund.

131 (a) For data protection reasons, CF was not able to have direct contact with Skipton Fund registrants without their consent. It would have been a large undertaking for the Skipton Fund to contact all those who had ever received a Skipton Fund payment, and the resources were not available to do this. As I recall, when the DHSC commissioned a Skipton look-back exercise, the opportunity was taken at that stage to make everyone who had ever received a payment from the Skipton Fund aware of CF and the support available. As I recall, it also became standard practice prior to the look-back exercise to advise all new Skipton Fund registrants, ie those who received new Stage 1 and Stage 2 payments, of CF and the support available.

131 (b) The media campaign referred to at the February 2013 board meeting was never launched, as I recall due to the costs involved.

131 (c) As I recall, it was almost exclusively those who had received Skipton Fund payments who did not decide to register with CF (as opposed to individuals who did not register with MFT/ET). As I recall, this was because these individuals advised us that they did not feel they required additional charitable support.

132. There was an increase in new CF beneficiaries as a result of the Skipton Fund look-back exercise. This increase in beneficiary numbers increased the workload for the small CF staff team and increased the demand on the annual allocation. The year that

the significant increase in new CF registrants occurred, I recall that the board decided to stage the winter fuel payment as DHSC had advised that it would not be increasing the annual allocation, and CF had to ensure that it did not overspend. As I recall, the balance of the winter fuel payment was paid at the year end when it became clear that it was affordable. (See paragraph 67 above.)

Policies

133 (a) Regular payments were made to CF beneficiaries on low incomes. As I recall, household incomes were assessed, and those on low incomes were given regular payments, the size of which depended on the level of their household income, where those on the lowest incomes received a higher level of regular payment. There was an overall policy for regular payments and decisions were not made on an ad hoc basis. As I recall, it was the tariff scheme referred to in the August 2013 board paper that was developed further and later implemented.

133 (b) The only "lump sum" payments made were winter fuel payments and grants, the latter of which were assessed either by the National Welfare Committee or by staff working to Office Guidelines. The case referred to in the question was where the NWC declined a request for £20,000 towards the purchase of a second property. I do not recall this specific case, but CF took the view that it needed to be able to offer equitable support to beneficiaries, and its annual allocation would not enable it to make multiple payments of this size to numerous beneficiaries. MFT and CF were legally separate entities with different histories and were not required to refer to each other's practices when making decisions.

133 (c) Grants were made for a wide range of items including financial support for those undergoing treatment for Hepatitis C, respite breaks, and household items, all of which varied in size financially. Grants were approved either by NWC or by staff under Office Guidelines.

134 (a) The policies were largely established when I came into post. Updates to the policies were determined by the board and NWC, with input from staff.

134 (b) DHSC did not have input into the policies during my tenure.

- 134 (c) Medical input was given by the Medical Trustee when the board was determining policies.
- 134 (d) The policies were largely established when I came into post. I cannot comment on whether the beneficiary community had been involved originally. I recall that we did discuss proposals with the CF Partnership Group and take on board their feedback where possible.
135. Charitable need meant that some applying for a grant did not have the ability to fund it from their own resources.
136. Applicants were not required to show exceptional circumstances.
137. My recollection is that Office Guidelines were updated when it was felt that particular changes were needed. They were updated and approved by NWC and the board with input from staff.
138. NWC referred to the grant guidelines when assessing applications.
139. Grants guidelines were published and circulated to beneficiaries both in paper form and on the CF website.
- 139 (a) This document was finalised and circulated to beneficiaries both in paper form and on the CF website.
- 139 (b) It was distributed to beneficiaries in paper form and was permanently on the CF website.
- 139 (c) As I recall, a leaflet had been developed and circulated prior to my joining CF.
140. As I recall, beneficiaries were aware of the existence of Office Guidelines. The maximum amounts available under Office Guidelines were not published, as these related to the level of delegated authority of staff rather than limits on the amounts available to beneficiaries. The NWC could consider applications for items covered under Office Guidelines which exceeded the Office Guidelines limits.

141. Pennysmart and Neil Bateman were appointed to work with beneficiaries on debt/money management advice and benefits advice respectively. They were independent and worked to their own industry guidelines to provide expert advice that CF was not able to provide in-house.
142. A "round robin" process was used to enable NWC members to make decisions by email and telephone regarding urgent grants in between the 6-weekly NWC meetings. It was used whenever it was required.
- 143 (a) The level of regular payments was determined with the level of the annual allocation and affordability. The level of grant payments was made in relation to the amount being requested and each case was considered on its own merits.
- 143 (b) See 143 (a) above.
- 143 (c) The board and NWC decided upon the level of payments.
- 143 (d) As I recall the level of regular payments was reviewed annually. The level of grant payments was made in relation to the amount being requested and each case was considered on its own merits.
144. The "round robin" process was the mechanism used to enable NWC members to make decisions by email and telephone regarding urgent grants in between the 6-weekly NWC meetings.
145. As I recall, grant applicants were required to submit a completed application form giving details of the applicant's income and expenditure, two quotations for items they wished to purchase, and a supporting letter from clinicians with regard to applications such as for financial support whilst undergoing treatment and respite breaks.
- 145 (a) I have no specific recollection of this application. As far as I can tell from the paperwork provided, the information requested was consistent with what was required. It appears that this particular beneficiary chose to send pictures of the items being requested, but this was not a specific requirement.
- 145 (b) The provision of two quotes was a standard requirement in relation to grant applications for items a beneficiary wished to purchase.

145 (c) In order to be able to determine charitable need, a certain level of information in support of applications was always required. The staff team often assisted by, for example, filling in forms with beneficiaries over the telephone, using income and expenditure information from previous applications (where applicable) if this had not changed, and assisting beneficiaries with sourcing quotes.

145 (d) I am not able to answer this question as I do not know which “p.30” is being referred to.

146. We were aware of dissatisfaction amongst some beneficiaries regarding the application process, but in order to be able to determine charitable need, a certain level of information in support of applications was required.

146(a) I am unable to recall how many complaints CF received about the application process.

146 (b) As I recall, during the early part of my tenure, we carried out a review of the level of information similar grant making organisations required, and it was felt that our requirements were moderate given the need for the charity to be able to demonstrate that it was evidencing charitable need. We were aware that, for example, other grant making organisations held detailed telephone interviews in relation to each grant application.

147. The “round robin” process was a **mechanism** for being able to consider urgent grant requests outside of the 6-weekly NWC meetings and NWC members referred to the same criteria as the ones used at full NWC.

148. The length of time it took to process grants was significantly improved during my time at CF, and statistics regarding grant turnaround times was reported to the NWC and board at each meeting. Improving grant turnaround times was one of the reasons for the Welfare Team restructuring discussed in 22 (a) above.

149. NWC did consider the amount of money previously given to an applicant and a list of all previous grants received formed part of the paperwork NWC received for each application. Information on previous grants received was used to enable NWC to understand the level of requests an applicant was making to the organisation and whether the applicant might have deeper underlying financial issues. Awareness of

the frequency of grant requests being made by some beneficiaries was one of the factors that led to the introduction of the regular payments scheme which gave regular payments to those on the lowest incomes.

150. As I recall, the success or otherwise of a grant application did not depend on the number of applications made to CF each year and each application was considered on its own merits.
151. As I recall, CF accepted retrospective applications when it first began to operate, but once the organisation had been operational for a period of time and mechanisms were in place to consider applications quickly through Office Guidelines and to consider urgent applications via the round robin mechanism, it was considered that applicants should not need to make retrospective applications. In budgetary terms, CF could not continue to run with what would amount to an open-ended financial liability relating to previous financial years.
152. NWC considered applications on a case by case basis. Ensuring applicants provided the same level of supporting information and reference to the criteria were the ways in which consistency was ensured.
- 153 (a) Each application was considered on its own merits, and the particular circumstances of individual cases which, whilst on the surface might be similar, were often quite different in the detail, leading to different decisions regarding what, on the face of it, might appear to be grant applications for the same thing. Ensuring applicants provided the same level of supporting information and reference to the criteria were the ways in which consistency was ensured.
- 153 (b) See 153 (a) above.
154. With regard to disposable income, staff and the NWC took a view in relation to the level of disposable income compared with the amount of the grant being applied for, and whether charitable need could be determined. For example, in the case of someone with a high disposable income asking for a very small grant for an item which could easily be afforded from their disposable income, it is unlikely that charitable need could be determined. There was no fixed criterion in relation to household income because each case was considered on its individual merits, and overall household income and expenditure levels and disposable income were reviewed in each case. In this

particular case, information regarding the frequency of grant applications may have been the trigger for considering whether the beneficiary was in financial difficulty, but I do not have a specific recollection of this case.

155. The concern regarding not wishing beneficiaries to build up a dependency on CF related to the fact that the organisation's financial situation might change in the future such that the organisation could not continue to support beneficiaries at the same level. The issue of dependency on the organisation for grants by beneficiaries on low incomes was a key driver for the development of a regular payments system.

156 (a) As I recall, a referral to the external debt and money management adviser was a condition for beneficiaries seeking financial support with debt. This was to ensure there was an understanding of, and access to, all the options available to the beneficiary for dealing with the debt, and that CF's contribution to the debt solution was as effective as possible.

156 (b) It would depend on the circumstances of the individual case.

156 (c) It would depend on the circumstances of the individual case.

157 (a) Pennysmart were independent and worked to their own industry guidelines. The advice they gave was quite specialised and it was for this reason that they were used; CF staff and trustees were not qualified in this area and would not have been in a position to review whether the advice given was correct.

157 (b) As I recall, Pennysmart sometimes provided a number of alternative solutions, and on occasion there might have been solutions which CF was not in a position to pursue as opposed to disagreeing with their specialist advice per se.

157 (c) I am unable to comment on whether Pennysmart's advice was appropriate in this particular case as I cannot recall the detailed circumstances.

157 (d) It was open to beneficiaries not to pursue a course of action recommended to them; therefore, appeals as such did not occur in this regard.

158. Due to the passage of time I am unable to recall whether CF received complaints about either the money management advisers or the benefits adviser. You have given me

access to two sets of documents where it is clear that two individuals were not happy with their interaction with Pennysmart, but I am unable to recall the background to either of these cases. But as stated above, it was open to beneficiaries not to pursue a course of action recommended to them by Pennysmart.

159. Without being able to recall specific examples, if a beneficiary had raised an issue with regard to Pennysmart, this would have been discussed with both the beneficiary and Pennysmart.
160. I cannot recall instances of grants being approved “in principle” by the NWC before an applicant sourced quotes.
161. CF was not set up to provide health services to beneficiaries, and any beneficiary we became aware of requiring urgent support from mental health services would have been signposted to their GP. As I recall, CF did on occasion provide grants for beneficiaries to receive counselling, but this was not in relation to urgent cases.

Non-financial Support

162. In relation to non-financial support, CF beneficiaries were able to access support from a specialist benefits adviser and a money management adviser, and beneficiaries were made aware of the support provided via the CF website and written information.

Section 7: Complaints and appeals

- 163 (a) This related to appeals against decisions on grant applications. The criteria for becoming a CF beneficiary was that the individual had to have received a payment from the Skipton Fund. This was a matter of fact and could not be appealed as such.
- 163 (b) The criteria for becoming a CF beneficiary was that the individual had to have received a payment from the Skipton Fund. This was a matter of fact and could not be appealed as such. In relation to whether someone was eligible to be an MFT beneficiary, as I recall there were no new MFT primary beneficiaries during my time at MFT. However, if there were, DHSC would have made the decision regarding eligibility.
- 163 (c) In relation to grant applications to CF/MFT:

- i) and ii) Grants were discretionary and there was no right for a beneficiary to give evidence or make representations in person with or without a representative
 - iii) In order to appeal a decision regarding a grant, the beneficiary was required to provide additional and/or new information in support of the appeal
 - iv). Additional/new information was required in support of the appeal
 - v) The first level of appeal was to the MFT Grants Committee or the CF NWC, with the provision of additional/new information, and the same committee members heard the appeal. If the beneficiary was unhappy with the appeal decision, the second level of appeal was to the board, and members of the Grants Committee/NWC were not part of the decision.
 - vi) As I recall, reasons were given for why grants were not awarded.
 - vii) There were no fees for bringing an appeal, but as I recall, there was a time limit of 3 months, but I cannot recall exactly due to the passage of time.
164. As I recall, the number of appeals was small in relation to the total number of grants awarded. The number of appeals was reported to the Grants Committee/NWC and respective MFT/CF board. I cannot recall the percentage of appeals that were successful, but this information was also reported to the board.
165. As charities, the awarding of grants was discretionary and subject to trustee discretion and I believe we would have needed to take advice from the Charity Commission/lawyers as to whether an independent adjudicator would even have been permitted in the context of a charity. In addition, given the relatively small number of appeals against grant decisions, setting up an independent adjudicator, if permitted, would most likely have been expensive compared with the number of cases considered.
166. I do not recall the detail of the one appeal which occurred during MFT's last, part-year of operation or how it was resolved, and I cannot recall the detail of any in previous years for either MFT or CF.
167. There were complaints procedures but I can no longer recall the detail.
168. I do not recall any complaints under the complaints procedure, only appeals against grant decisions, which were considered under the appeals process, described above.

Section 8: Engagement with the beneficiary community

169. The issues which were noted in the January 2013 minutes related to the relationship between MFT beneficiaries and the organisation prior to my appointment. My understanding was that there had been an MFT Partnership Group with beneficiaries which had always been beneficiary led. I recall being told by colleagues and some beneficiaries that this Group had at various stages been formed, disbanded, and reformed by beneficiaries. During the early part of my time at MFT the Partnership Group was again reformed by beneficiaries with a new Chair and MFT saw this as the opportunity to engage with beneficiaries. In relation to concerns regarding clarity and transparency, my understanding was that this related largely to the support available to beneficiaries, in particular grants, and was one of the reasons that the Grants Committee was established, and clear criteria for grants were published.
170. The Partnership Group was the mechanism by which MFT engaged with beneficiaries, but this had always been beneficiary-led, and the group was disbanded again by beneficiaries during my time at MFT because the Chair of the group was unable to sign off agreed minutes with beneficiary attendees at the meeting.
171. The majority of contact between beneficiaries and MFT/CF was in the context of the support that MFT/CF offered via regular payments, grants, and referrals to the benefits and money management advisers, and the main point of contact was therefore the Support Services Officer/Welfare Officer, with support from the Director of Operations. There was little contact between the board and the beneficiary community, although there were two beneficiary trustees on the MFT board and one on the CF board who were able to provide a beneficiary perspective to board discussions. The pattern of financial support was well established by the time I took up post, and because of MFT's financial situation, there was no scope for altering the type of support offered without changing the system of regular payments, which the organisation knew would not be possible because beneficiaries had relied on these payments for many years. During my time at MFT, given that additional funding from DHSC was never forthcoming, the pattern of support remained one which was limited to that which had existed historically and therefore there was a status quo situation. During my time at CF a Partnership Group was set up, as I recall at the instigation of the CF board, which included CF board members as a mechanism for engaging with beneficiaries.
172. During my time in the organisations, I do not recall examples of either CF or MFT approaching DHSC jointly with beneficiaries regarding annual allocations.

173. Due to the passage of time I am unable to recall what the events and circumstances were as of June 2014 which gave rise to this decision.
- 174 (a) As I recall, the partnership groups were a mechanism for beneficiaries and board members/senior staff to meet to discuss developments in the organisations and seek feedback.
- 174 (b) The MFT partnership group was beneficiary led and beneficiaries chose who from amongst their number would be Chair etc, and as I recall, the meetings were open to all beneficiaries to attend. As I recall, the Caxton partnership group had representatives from the different sub-categories of Caxton beneficiaries and representatives from the different beneficiary campaign groups.
- 174 (c) As I recall the MFT partnership group was open to all beneficiaries and therefore representatives from campaign groups would have been invited to attend.
- 174 (d) The CF board Chair was Chair of the CF partnership group. In terms of the MFT partnership group, being beneficiary-led meant that the group was disbanded by beneficiaries when agreement could not be reached amongst beneficiaries themselves, such as when it was disbanded during my tenure because the Chair was unable to agree final minutes of a meeting with beneficiaries who had attended.
- 174 (e) Due to the passage of time I cannot recall how frequently the CF partnership group met.
- 174 (f) Discussions and feedback at the CF partnership group were taken into account in relation to the support that CF provided to beneficiaries where this was possible and did not conflict with the organisation's obligations under eg charity law and its governing document.
- 174 (g) In essence the CF partnership group seemed to function because it had representatives from the different sub-categories of CF beneficiaries and representatives from the different campaign groups, was chaired by the CF board Chair, and the administrative support was provided by the organisation. As stated above, the MFT partnership group, had always been beneficiary-led and had a history

of being disbanded by beneficiaries themselves when agreement could not be reached amongst beneficiaries themselves.

175. I do not recall any other groups being instituted when the MFT partnership group was disbanded by beneficiaries.
176. As I recall, the MFT online bulletin board was an online chat forum for beneficiaries which had been set up before I joined the organisation and which had always been moderated by a beneficiary. As I recall, MFT decided to close down the bulletin board because it became a forum where beneficiaries were hostile to each other, and MFT was concerned about the legal implications of hosting such a forum that was essentially outside of its control. The beneficiaries subsequently set up and moderated their own forum, and MFT supported this by confirming that individuals who wished to become members of that forum were MFT beneficiaries and therefore eligible to join it. As advised in the introduction to my response to this s. 21 notice, I never received the Rule 9 request dated 21 October 2019 referred to here, and could therefore not respond to it.
177. Due to the passage of time I can no longer recall what events and circumstances at April 2014 led to the discussion at the board meeting.
178. Due to the passage of time I cannot recall what this related to.
179. The organisations were aware that some beneficiaries were dissatisfied with the AHOs. As I recall, the APPG report was balanced, with a majority of responses being positive or neutral towards the organisations. The organisations were aware that a great deal of dissatisfaction stemmed from the fact that they had been set up by DHSC as charities, which meant that the organisations had to operate in accordance with their governing documents and charity law, and that their levels of funding were controlled by DHSC via the annual allocations, which were outside the organisations' control.
180. Due to the passage of time, I cannot recall what action MFT and CF took in response to the APPG report.

Section 9: Relationships with other organisations

181. As I recall there was very little contact between MFT and CF and the UK Haemophilia Centre Directors Organisation. However, MFT contributed to the UKHDCO's annual report each year at their request, and as I recall, Dr Vanessa Martlew was MFT's formal link with UKHDCO. I was not aware of any difficulties.
182. I do not recall being in regular contact with any Haemophilia Centre directors, although there may have been contact between staff directly supporting beneficiaries and some Haemophilia Centre directors in their capacity as lead clinicians for particular beneficiaries.
183. As I recall, the MFT beneficiary trustees were involved with the Haemophilia Society and in the early part of my tenure had been appointed by the Haemophilia Society. Due to the passage of time I can no longer recall whether any of the MFT beneficiary trustees were also trustees of the Haemophilia Society.
184. Due to the passage of time I can no longer recall the interactions of the working relationship between MFT and CF and the Haemophilia Society prior to 2015, but I cannot remember there being a significant amount of regular contact.
185. Historically, I had understood that the relationship between the AHOs and the Haemophilia Society had been cordial, and this was the impression I had in meetings with Chris James, Liz Carroll's predecessor, during my early months at Alliance House. I cannot recall whether we were aware of the Haemophilia Society's view of the AHOs prior to Liz Carroll's 10 February 2015 letter, but the AHOs did not agree with the view that they were not fit for purpose.
186. Roger Evans and I did not make the comments Liz Carroll alleged we made, and the Haemophilia Society subsequently issued a public retraction and apology to myself, Roger Evans, and the Trustees of MFT.
- 187 (a) This was a board decision.
- 187 (b) As I recall MFT took the same approach.
- 187 (c) Due to the passage of time I cannot recall how long relations with the Haemophilia Society were suspended.

187 (d) As stated in 184 above, I do not recall there being any significant regular contact with the Haemophilia Society prior to these events, and therefore I do not recall there being any impact on beneficiaries.

187 (e) See 187 (d) above.

188(a) Due to the passage of time I cannot recall whether this letter was sent.

188 (b) Due to the passage of time I cannot recall why or if the relationship had deteriorated prior to the publication of Liz Carroll's letter.

188 (c) I do not recall any negative impact on MFT as a result of communication being with Bernard Manson instead of Liz Carroll.

Section 10: Reform of the AHOs

189. Due the passage of time, I cannot recall other consultations or reform processes that we were involved in.

190. The AHOs submitted a joint response to proposals in the "Infected blood: reform of financial and other support" consultation, and as previously stated, the proposals in the consultation were subsequently amended. As I recall, Lord O'Shaughnessy was not the Health Minister at this time; his involvement related to the later decision to transfer responsibility for providing financial support to beneficiaries from the AHOs to NHSBSA.

191 (a) As I call, the DH Reference Group was set up by DH so that they could take advice on implementing their proposals. As I recall, there were representatives from the AHOs and other external organisations. I cannot recall how frequently the Group met.

191 (b) I cannot recall what this relates to, but as far as I can remember, members of the MFT board were part of the Reference Group.

191 (c) I cannot recall the reasons for Roger Evans' resignation.

191 (d) I cannot recall why this was the case.

191 (e) The Reference Group was set up by DHSC for DHSC purposes, so only they would be able to comment on its usefulness and whether it served the purposes they had established it for.

191 (f) I can no longer recall the detail.

192. As I recall, once the decision to transfer the responsibility for providing financial support to beneficiaries from the AHOs to NHSBSA was taken, meetings about this were to discuss the mechanisms for the transfer. As I recall, we were given no say in how NHSBSA would operate the service for the future. Before the decision to transfer the service to NHSBSA was made, DHSC announced that there would be an open procurement process to determine who would be the future service provider, and the AHOs intended to submit a bid. As I recall, this announcement was made in the summer of 2016. However, as I recall, the deadline for making submissions was delayed, and the next substantive announcement was that the service was being transferred to NHSBSA without a procurement exercise taking place. Therefore, the AHOs were unable to submit a bid as there was no procurement exercise.

193 (a) Following transfer, the relevant AHO was to be closed, so the question of subsequent information sharing did not arise.

193 (b) As I recall, we were advised to seek explicit consent from beneficiaries regarding transfer of their data to NHSBSA, which we did, and the agreed information which was required in order for NHSBSA to continue to provide support to beneficiaries of the AHOs was transferred.

193 (c) See 193 (b).

193 (d) As I recall, we asked beneficiaries to consent to the transfer of the specific data that was transferred.

193 (e) I cannot recall why beneficiaries were not asked whether they would consent to their records being transferred over. However, I do recall that some beneficiaries objected to even some of the basic information being transferred.

193 (f) I was not aware of any problems regarding the data transfer and do not recall there being any discussions with NHSBSA in this regard subsequently.

194. I left the organisations in October 2017 for personal reasons, after 4 out of the 5 AHOs had been wound up.

Data sharing and storage

195. To the best of my knowledge, no data was shared between the different AHOs on funds received by beneficiaries. If data was needed by one AHO from another AHO, the beneficiary's consent was sought. As the criteria for becoming a CF beneficiary was that an individual had to have received a payment from the Skipton Fund, CF would have needed to have this confirmed by the Skipton Fund, but this would have been with a beneficiary's consent.

196. The rules on data sharing were governed by data protection legislation.

197 (a) I cannot recall what provision was made for storing data from email servers. However, with regard to beneficiaries, copies of all emails were printed and kept on beneficiaries' files.

197 (b) I cannot recall whether advice was sought from Russell-Cooke in this regard.

198 (a) As I recall, advice regarding data storage came from Russell-Cooke.

198 (b) As I recall, the classes of records related to the subject matter of documents such as financial records which an organisation was required to keep for a specified number of years for the purposes of HMRC, HR records, and beneficiary records.

199 (a) As I recall, if we had invited all registrants/beneficiaries across the AHOs to make Subject Access Requests, that could have involved several thousand requests, which we did not have the resources to meet. During my time with the AHOs we did, however, respond to individual ad hoc Subject Access Requests from beneficiaries when we received them in accordance with the relevant AHO's obligations under data protection legislation.

199 (b) I cannot recall whether there was further communication on this subject with DH.

200 (a) I cannot recall which organisations other than THT were considered.

200 (b) As I recall, THT was selected because under the terms of the governing document, any residual funds at the time of winding up had to be transferred to an organisation with identical or similar objectives, and THT was felt to be a very close match, as it supported people with HIV.

200 (c) The MFT board would have made the final decision.

200 (d) I do not recall beneficiaries being consulted in the process. But as stated above, the governing document determined how any residual funds had to be used on winding up.

200 (e) I cannot recall how beneficiaries were informed of the decision; this may have taken place after my departure.

200 (f) I had already left the organisation by the time the final details of the transfer to THT were agreed.

Section 11: Other

201 (a) I refute this allegation. My recollection is that Mr Ward raised with us the issue that outdated wording was being used in some of our documentation which did not reflect the nature of modern relationships, including same-sex relationships. As a result, we reviewed the wording that had been carried forward in our documentation and amended it to be inclusive.

201 (b) I refute this allegation. During my time at Alliance House I, along with the boards, endeavoured to make the organisations efficient and responsive to beneficiaries within the confines of the organisations' governing documents and charity law, to provide clarity with regard to what support was available to beneficiaries and how to apply for it, and to ensure equality of access. In particular I sought to ensure that grant applications were considered and responded to as quickly as possible, and that payments were made as quickly as possible; the significant improvement in these turnaround times that resulted from these endeavours were reported to the boards regularly.

201 (c) I refute this allegation. As stated in paragraph 83 above, I did not introduce a practice of sending people to interview applicants and take photographs of their home. On the contrary, this practice, which was in place when I joined the organisation, was actually stopped during my tenure. I do not understand what the allegation regarding money being used on office space refers to, as during my tenure the AHOs continued to share the same small office space that they were already occupying when I joined the organisations. In addition to this, decisions regarding spend on accommodation would have had to be made by the board; this was not an area I had control over.

202. I do consider that the organisations were run well and in line with the Charity Commission's "Hallmarks of an effective charity" document, (superseded by the Charity Governance Code).

203. The main difficulty/shortcoming related to the fact that when the organisations were set up by DHSC, they were set up as charities. This meant that the organisations were bound by their governing documents and charity law in the way they could operate. Trustees therefore had to determine charitable need when making payments; money could not just be "given" to beneficiaries without an assessment of charitable need, and we knew some beneficiaries objected to this. We were aware of comments such as "having to go cap in hand to a charity", but as charities, the organisations could do nothing about this. The charities were also limited by the fact that they were 100% funded by DHSC and DHSC determined the level of funding each year. There was no negotiation about the level of funding, and the charity trustees had a duty to spend the funds in line with the various regulations they were governed by. As referred to in previous paragraphs, submissions to DHSC by the charities at various times for additional funding did not result in an increase in funds, and the charities had to operate within the funds available to them. During my time with the organisations, MFT used reserves it had built up in the past to supplement the annual allocation from DHSC so that it did not have to reduce the level of support to beneficiaries. However, the level of funds made available to the organisations left no room for innovation, and as I recall, the bulk of the funding both MFT and CF received was spent on regular payments, a grants programme, and winter fuel payments, with a difference in emphasis across the two organisations for historical reasons.

204. N/A

Statement of Truth

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

Signed

GRO-C

Dated 22 December 2020

Table of exhibits to Witness Statement of Jan Barlow, dated 22 December 2020:

Date	Notes/ Description	Exhibit number
02 August 2018	List of questions provided to Jan Barlow in first Rule 9 Request	WITN3108004
22 August 2018	Letter from Jan Barlow to Infected Blood Inquiry, responding to first Rule 9 Request	WITN3108005
21 September 2018	List of questions provided to Jan Barlow in second Rule 9 Request	WITN3108006
12 October 2018	Letter from Jan Barlow to Infected Blood Inquiry, in response to second Rule 9 Request	WITN3108007