

Witness Name: Charles Lister

Statement No: WITN4505001

Exhibits: None

Dated: 1 March 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF CHARLES LISTER OBE

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 3 November 2020.

I, Charles Lister, will say as follows:

Section 1: Introduction

Question 1: Please set out your name, address, date of birth and any relevant professional qualifications relevant to the duties you discharged while working with the Department of Health and the Alliance House Organisations (AHO).

1. My full name is Charles Edward Lister. My date of birth and home address are known to the Inquiry. I have no professional qualifications of relevance.

Question 2: Please describe your employment history including the various roles and responsibilities that you have held throughout your career, as well as the dates.

2. I was employed by the Department of Health (“DH”) and its predecessor department from 1971 to 2011, excluding a period between 2003 and 2009 when I worked for the Human Fertilisation and Embryology Authority.

3. I had a range of roles at the DH throughout my career. These are too numerous to list in full but included:

- 1991-1995 – Responsibility for various aspects of microbiological food safety policy and the emerging public health issues relating to Bovine Spongiform Encephalopathy
- 1995-1998 – Team Leader on HIV/AIDS sexual health promotion
- 1998-2003 – Head of Blood Policy – for more detail see my response to question 4
- 2003-2008 – Head of Policy, Human Fertilisation and Embryology Authority (HFEA)
- 2008-2009 - Programme Management for the HFEA's change programme
- 2009-2011- Senior Business Manager for the Director General NHS Workforce and Head of NHS Leadership

4. Since leaving the DH I have taken on a number of roles in addition to my role on the Caxton Foundation:

- 2012-present: Associate with Dods Training, delivering a range of workshops on core civil service skills. Dods Training is a business providing many training courses for the Civil Service in areas such as drafting, policy and negotiating skills. As an Associate I am a self-employed trainer.
- 2014-present: Chair of the Sperm, Egg and Embryo Donation (SEED) Trust (a charity)
- 2015-2019: Trustee/Director of Age UK Sutton
- 2019-present: Chair of the Caldecott Foundation (a charity)
- 2019-present: Chair of Warlingham Parish Council

Question 3: Please set out the positions you have held at the Department of Health and the Caxton Foundation including with any committees, working parties or groups relevant to the Inquiry's Terms of Reference, and describe how you came to be appointed to those positions.

5. The only positions I held relevant to the Inquiry's Terms of Reference were:
- Head of Blood Policy at the DH from October 1998 to May 2003. This was a lateral move within the DH. I applied for the role as part of career progression and was successful at interview. The role is described in more detail in my response to question 4.
 - Trustee/Director, and later Deputy Chair, at the Caxton Foundation ("**Caxton**") from August 2011 to April 2015. I applied to be a Trustee when these roles were advertised in mid-2011. As a Trustee, as well as being a Board member, I served on the following committees:
 - The National Welfare Committee ("**NWC**") as member and then chair between September 2011 and March 2014. I also attended one further meeting, in December 2014, as a stand-in.
 - The Audit Committee from September 2011 to April 2015
 - The Caxton/Macfarlane Trust Liaison Committee
 - The Partnership Group. This was a group for talking to beneficiaries and their representatives.
6. Appointments to the various sub-committees were made at the Trustee Board meeting on 1 September 2011 alongside consideration of their terms of reference. Trustees had already provided their expressions of interest in the various roles and appointments were made on personal preferences and individual skill sets. I was particularly pleased to join the NWC as this felt like the committee most central to Caxton's role.

Question 4: Please describe your roles and responsibilities in the above positions.

7. From **May 1995 to October 1998** I was the team leader responsible for HIV/AIDS health promotion. The focus was entirely on sexual health promotion. This involved working with the then Health Education Authority, local authorities and charities and community groups such as the Terrence Higgins Trust, Gay Men Fighting AIDS, and the Ugandan AIDS Action Group. In particular, I developed new national

HIV/AIDS prevention work for sub-Saharan African communities in England, working closely with community groups. I was also the UK representative on the EC Management Committee for the Programme on AIDS.

8. I then made a lateral move to Head of Blood Policy - **from October 1998 to May 2003**. This involved a wide range of responsibilities which increased during my time in the role, including:

- Development of government policy on the safety and supply of blood and blood products to the NHS
- Sponsorship of the National Blood Service (NBS) including business planning, ensuring Ministerial objectives were met, appointments to the Board, negotiations with the NHS on blood pricing etc
- The Better Blood Transfusion initiative
- Development of measures to reduce the risk of vCJD and Hepatitis C transmission through blood, including funding of measures introduced by NBS and the provision of recombinant clotting factors for people with haemophilia
- Ensuring supplies of key blood products for UK patients, including sourcing of blood plasma supply from the US
- Negotiating and implementing a new EU Blood Directive on standards and quality of blood
- Drafting responses for Ministers on calls for compensation and a public inquiry into the contamination of blood with Hepatitis C
- Sponsorship of the Alliance House charities. This meant that I was the liaison between the AHOs and the Department, making sure that the funding got delivered and dealing with any policy issues. This was of course long before I became involved with the Caxton Foundation.

9. During my time at DH, I had no involvement with the issues that led to the contamination of blood with Hepatitis C or with the setting up of the Alliance House charities

Question 5: Please explain the involvement you had with the AHOs in your various roles at the Department of Health.

10. The only DH role in which I had involvement with the AHO was as Head of Blood Policy when I had sponsorship responsibility for the Alliance House charities, as set out above. I will say more about this in my written evidence relating to my DH role at questions 16-49.

Question 6: What induction, training and information did you receive from the Caxton Foundation as to its functions, aims and objectives?

11. I was already familiar with the Macfarlane and Eileen Trusts and the history behind them before becoming a Trustee, from the period when I was Head of Blood Policy at DH. After leaving that role, I retained a personal interest in this area so was aware of the establishment of the Skipton Fund and the developments that led to the establishment of the Caxton Foundation. I met people affected directly on several occasions (including those who were involved in campaigning), and while Ministers' policy was no compensation and no public inquiry and I was maintaining that line, I always thought it was a great pity that we couldn't do more for them. I had natural sympathy for the people affected, whose lives had been changed so dramatically, or who had been bereaved, or had found themselves unable to work, and I wanted to help them and improve their lives. I was 58 when I left DH and saw becoming a charity Trustee as one way of making use of my skills and experience and giving back something. Given my keen interest in the issue, the Caxton role felt ideal for me to be involved in.

12. The first two Caxton board meetings were focused on ensuring that I and my fellow Trustees had a clear understanding of, and opportunity to discuss, the background to the establishment of Caxton, the duties of the charity as set out in the Trust Deed, the role and responsibility of Trustees, the governance of the charity and, very importantly, the experience of living with Hepatitis C as a result of contaminated blood. The latter included a presentation by a representative of Tainted Blood. In addition to this, all Trustees received an induction pack prepared by Caxton's legal adviser. I cannot remember what this included exactly but I expect it included the trust deed, with any amendments made at that stage, and the Charity Commission's guide 'The Essential Trustee'. Professor Howard

Thomas also kept the Trustee board up to date on an ongoing basis on developments such as new treatments for Hepatitis C and the impact on the individual.

Question 7: How much time did you devote to the positions you held at the Caxton Foundation? Please describe how your time was generally spent when discharging your role as Trustee and director of the Caxton Foundation.

13. This is hard to recall with any certainty but the amount of time spent grew considerably as I took on more responsibilities. There were times when it probably amounted to at least 2 days a week and occasionally more. Time was spent in activities such as:

- a. Chairing and attending meetings
- b. Considering grant applications in advance of NWC meetings (including dealing with round robin emails, see question 120 below).
- c. Working on the Caxton regular payments scheme
- d. Working with the CEO and staff on a range of day-to-day issues
- e. Managing recruitment of various roles, including an interim CEO, permanent CEO, the Chair of Trustees.

Question 8: Please set out your membership, past or present, of any other committees, associations, parties, societies or groups relevant to the Inquiry's Terms of Reference, including the dates of your membership and the nature of your involvement.

14. I have none.

Question 9: 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.

15. I have not provided evidence to any of the above, or been involved in them as a litigant. As part of my DH role, I was tangentially involved in 2000 when the National Blood Authority was sued in a class action by over 100 people infected with Hepatitis C after 1988 through blood transfusion. The case was brought under the Consumer Credit Act 1988. I was involved simply in monitoring its development on behalf of the DH and considering any policy implications from the outcome. I wasn't giving instructions to lawyers, and nor did I write a witness statement. I think I went to at least one meeting between NBA and their legal advisers, on behalf of the DH.
16. I was also a witness called by the BSE Inquiry about my DH role then, but this was focused on transmission through beef. There was no evidence on transmission through blood at that stage.

Section 2: Establishment of the Trusts and Schemes

Question 10: Please describe your involvement with and/or recollection of the circumstances in which the following trusts and schemes were established:

- a. Macfarlane Trust***
- b. Eileen Trust***
- c. Skipton Fund***
- d. Macfarlane & Eileen Trust (MFET).***

17. I had no involvement in the establishment of any of the AHO entities.
18. The Macfarlane and Eileen Trusts were established while I was in the DH but before I worked in HIV/AIDS health promotion (May 1995- October 1998) or in my blood policy role (October 1998-May 2003). As to the Skipton Fund, the announcement of the in-principle decision to have a payment scheme for those infected with HCV was made by the Secretary of State John Reid in late August 2003, some months after I had left the blood policy role. There had been calls for HCV payments or compensation for many years and it was considered by successive Ministers. To the extent that I was involved in that issue, I will include it in my separate statement dealing with my time in the DH.

19. I may have attended meetings at which the broad subject matter was discussed although I didn't attend any direct discussions of the creation of the Skipton Fund.

Question 11: Please describe your involvement with and/or recollection of the circumstances in which the Caxton Foundation was established.

20. I had no involvement in the establishment of the Caxton Foundation. However, I did take a personal interest in issues around contaminated blood because of my DH role, and was therefore aware from colleagues and from things I'd read in the media, of the events leading up to the government's decision to establish the Caxton Foundation.

Question 12: What did you understand the aims and objectives of the Caxton Foundation to be? What principles or philosophy underpinned its establishment?

21. I understood that Caxton was the government's response to the increasing pressure in Parliament to provide further recompense for people who caught Hepatitis C through contaminated blood. That response, as I understood it, was the extension of the Skipton Fund (including regular payments for people on Skipton Stage 2, the most severely affected) and alongside that the idea of having a charity – Caxton – that would provide discretionary payments to those on Skipton Stage 1, who had particular charitable need. That was set out in Andrew Lansley's statement of January 2011 (ARCH0001703).

22. Caxton's trust deed describes its objective as meeting "charitable need". The implication is that it would be dealing with people living in some degree of financial hardship. That meant that Caxton would have to determine whether somebody's need was "charitable", which in turn meant enquiring about their financial position and making an assessment based on the information they gave us about themselves.

Question 13: Please set out how, as a charity, the Caxton Foundation was regulated.

23. The Caxton Foundation was established as an independent charity and was therefore regulated by charity law.

24. There was also an accountability relationship between Caxton and the DH. The sole funder of Caxton was the DH, and the Secretary of State was the founder. Although there was absolutely no day-to-day interference, they did control the purse-strings. There was also a cap on staff numbers for all the AHOs as set in the Statement of Financial Controls. The accountability relationship was managed through the DH/Caxton Liaison Group. We also had occasional meetings with the Minister. I discuss this in more detail at question 70.

Question 14: What involvement did the Department of Health or any other Government department have in the setting up of the Caxton Foundation? In answering this question please address the following matters:

- a. **Were you involved in any consultation by the Department of Health or any other Government department about the establishment of the Caxton Foundation, its functions, aims and objectives?**
- b. **If so, please describe that process and set out the contribution you made to the consultation.**
- c. **Was there any discussion as to why the Government chose to distribute monies via the AHOs rather than directly? What, if anything, were said to be the risks and benefits of this scheme?**
- d. **Was there any discussion as to why the Government chose to exclude those who contracted Hepatitis B from the schemes?**

25. I had no involvement in the process and the policy decision leading to the establishment of the Caxton Foundation by the Department. Although I was still in the DH when Caxton was set up, I was in a completely different role. I was working on changes to NHS leadership and workforce issues at the time, in a completely different area of the DH. I cannot therefore offer any answers to these questions.

Section 4: Discrepancies between Caxton Foundation and the Macfarlane Trust

Question 50: On establishment of the Caxton Foundation, was there any discussion about:

- a. the discrepancies between support for those infected with HIV and for those infected with Hepatitis C?**
- b. the discrepancies in the schemes' treatment of those 'infected' with HIV and/or Hepatitis, and those 'affected' such as widows and dependents?**

If so, please detail them.

26. On establishment of the Caxton Foundation, there was a good deal of discussion among the Trustee Board about, among other things:

- the background to the establishment of the Caxton Foundation, including the establishment and work of the other Alliance House bodies
- our roles and responsibilities as Trustees of a charity
- what we had been set up to do (our charitable objects)
- the meaning of "charitable need" within our objects
- Hepatitis C and what it means to live with the virus
- the governance of the charity and the development of policies to deliver our charitable objects.

27. I don't recall these early discussions in detail but we would have discussed the intentions of Ministers that Caxton would provide similar discretionary payments to those provided by the Macfarlane Trust ("**MFT**") in respect of those with Hepatitis C. I was aware for example that in his statement to the House of Commons on 10 January 2011, the Secretary of State for Health had said:

"We know that some of those infected with HIV or hepatitis C from NHS blood and blood products face particular hardship and poverty. Those infected with HIV can already apply for additional discretionary payments from the Eileen Trust and the Macfarlane Trust, but no equivalent arrangements are in place for those infected with hepatitis C, so we will now establish a new charitable

trust to make similar payments to those with hepatitis C who are in serious financial need. These payments will be available for those at all stages of their illness, based on individual circumstances.” (ARCH0001703).

28. In line with this statement, our focus as a Board was very much on how to provide similar discretionary payments to those infected with HIV taking account of the individual circumstances of people with Hepatitis C, their widows/widowers and dependents. At this early stage, we weren't talking about 'discrepancies' because we didn't yet have a complete understanding of people's individual circumstances and what they might expect from Caxton. Instead we established a set of policies or principles that enabled us to begin work quickly in meeting the charitable objects in the Trust Deed. These principles are summarised in the minutes of the Board meeting held on 1 September 2011 [CAXT0000108_039-5].

29. Administratively, the starting point was to build on the system established by MFT, which we did. Our CEO and staff had worked for MFT for a number of years. It was therefore straightforward to adopt the grant application processes and Office Guidelines on grants that had been developed by MFT. But, as time went on and our understanding of the beneficiary community grew, it was important to adapt these to the needs of our beneficiaries. Similarly, we adapted our own policies to ensure that we were meeting need. This was anticipated in early discussions with DH on the setting up Caxton (in which I was not involved) which recognised that:

“...there was much greater diversity of associated ill health attributable to Hep C.....that as there was a large grey area where situations were not clear cut, we [i.e. Caxton] could implement case law as we go along”.
[CAXT0000095_016-10]

There are several examples of this approach in the rest of this evidence.

30. One early policy that was different from MFT was an assumption that Caxton would need to give priority to requests for help from households with an annual income below £14,000 a year (in line with the Government's definition of poverty of 60% of median income). People were therefore asked to declare full details of their

financial circumstances at the time of registration. In practice, it never proved necessary to apply this benchmark. But it is a good example of how as a new charity, with cash-limited funded and uncertainty of how many people would come forward for support, we needed to take decisions which sometimes differed from the well-established MFT.

Question 51: Please see the minutes of the Caxton Trustee Limited Board of Directors meeting held 2 August 2012 [CAXT0000109_082] in which you report the request from the DoH for there to be ‘read-across’ between the Macfarlane Trust and the Caxton Foundation. As to this:

- a. You appear to have got this DoH message via the Macfarlane Trust. Was this request ever made directly to you or to anyone at the Caxton Foundation (in so far as you know)?**
- b. What did you understand was meant by the DoH?**
- c. What if anything did the Caxton Foundation do in response to this request?**

31. The minutes of the Caxton Board of 2 August 2012 record that:

“Mr Lister advised the Board of a meeting he had had with Mrs Boyd regarding “read across between the two charities. He stated that where possible this had been achieved although due to the differing nature of the grant requests it was not entirely possible”

32. Mrs Boyd was a Trustee of MFT who chaired the NSSC, the MFT’s equivalent of the National Welfare Committee. As discussed in my response to question 50 above, the Caxton Board was aware from the outset that the intention of DH Ministers was for Caxton to provide similar discretionary payments to MFT. The issue of whether we were achieving “read across” was also being raised by beneficiaries directly with us and with DH Ministers.

33. My recollection is that by this time “read across” had been achieved to a large extent, as the Board minutes indicate, but there were always going to be

differences because of the different needs of Caxton's and MFT's beneficiaries. A good example is Caxton's early decision to make payments to beneficiaries who had either undertaken treatment to clear the virus or who were currently being treated, because the side effects of treatment for Hepatitis C could severely impair people's ability to work. It therefore made sense for the chairs of the two committees to stay in touch periodically so that we could discuss current issues and the scope for greater consistency and alignment.

34. This issue was discussed at the Caxton/MFT Liaison Committee meeting on 19 December 2012, and throws further light on the issue:

"It was noted that "read across" issues continued to be raised. Caxton had decided to make a winter fuel payment to all qualifying registrants this year, as MFT had done for several years, but in the light of the unclear funding position MFT had not yet reached a decision for the coming winter. Caxton had also adopted the MFT practice of excluding non-means tested benefits such as DLA from computation of household income. Both charities needed to avoid encouraging dependency, and there would be considerable benefit in liaison between the NSSC and NWC".

Question 52: The minutes of the Macfarlane Trust/Caxton Foundation Liaison Committee meeting held 31 August 2012 [CAXT0000068_008] notes a request from the Department of Health on the "differing payments to MFT and CF beneficiaries". Please explain:

- a. What you understand the DoH were requesting.**
- b. Whether a response was prepared by you and Mr Evans to the DoH and if so the content of the response.**
- c. How payments between the Caxton Foundation and Macfarlane Trust differed, and why.**

35. At the time this was happening, I was dealing with a number of other matters (including the imminent departure of the Chief Executive ("CEO"), a set of negotiations about his severance package, recruiting an interim CEO, and looking

for new Trustees and a new Chair). So I was busy with those things and don't recall this particular request. I can't remember what "differing payments" referred to specifically. It was perhaps to do with MFT's ability to make regular payments (which Caxton didn't at that stage), because for discretionary grants to buy goods, we used exactly the same method as the MFT.

36. Upon checking my old records, this appears to be a letter that had come to the Minister from an MP asking for information. So it was not something that DH were requesting for themselves. As a Minister's letter back to an MP, DH would certainly have ensured that a reply was sent.

37. The paper 'HCV/HIV Anomalies' (AHOH0000065-1) is undated but was clearly written around the same time so may have been connected to this enquiry. This shows that the main differences at this point in time were:

- **Regular/Top-up Payments:** MFT had a discretionary top-up payments scheme in place. Caxton introduced its regular payments scheme in 2014/15 using a different formula from MFT (see responses to Qs 153-163).
- **Loans:** MFT provided short-term loans to be paid back from the individual's discretionary top-up payments. Caxton did not have the same mechanism as MFT for paying back loans and preferred to focus instead on helping people out of debt and developing a regular payments scheme to lift beneficiaries out of poverty (see response to Qs 142 and 143).
- **One-off Fuel Payments:** Both Caxton and MFT offered one-off fuel payments of £500, but Caxton chose to focus initially on households with the lowest income and later awarded it annually to all registrants as a non means-tested payment (see also my response to Q133).
- **Calculation of Household Income:** Caxton initially included Disability Living Allowance (DLA) and Child Benefit in calculating household income when beneficiary numbers were unknown. We later took the decision to disregard means tested benefits in determining household income, moving more into line with MFT (see my response to Q76).
- **Grants for Household Goods, Repairs etc:** These started off identical to MFT but changes were made by the NWC in response to applications. For

example, we later added televisions and microwaves which were not included in the range of grants inherited from MFT. We also took a decision not to fund assisted conception as explained at Q140.

- **Vouchers:** Caxton initially adopted MFT's practice of issuing vouchers, or payments to the supplier, instead of giving the money direct to beneficiaries. This was to ensure that grant money was spent on the items specified in the beneficiaries' grant application – a requirement of our auditors. Caxton later stopped issuing vouchers following strong representations from many beneficiaries who found this practice demeaning. Instead, we simply asked grant recipients to sign an undertaking that the grant had been spent for the purpose issued. I do not recall whether MFT followed our lead on this.

Question 53: In the meeting held 2 August 2012 [CAXT0000109_082] the “provisions MFT made for the recently bereaved” and the suggestion of “whether the Foundation could adopt the same policy” was discussed. It is noted that “there was concern that many more potential beneficiaries may come forward than expected resulting in a steep increase in the anticipated cost”:

- a. Did the Caxton Foundation take into account Macfarlane Trust policy, when setting its own policy?***
- b. If so how? Please give examples. You may wish to refer to the minutes of the Liaison meeting held between Caxton Foundation and the Macfarlane Trust on 31 August 2012 [CAXT0000068_010].***
- c. If not, why not?***
- d. Please give any examples of when the Caxton Foundation adopted a different policy and the reasons for it.***

38. We did try to apply the same standards as MFT wherever possible. An example would be using the same method and calculations to fund discretionary grants to buy goods. If MFT introduced something new it did not necessarily mean that we would adopt it, but we were not operating in a vacuum and we would take it into account and consider it.

39. There were times when Caxton felt that MFT's way was not right for our beneficiaries (such as the use of vouchers, which after beneficiary objections we ultimately agreed were demeaning), and then we diverged.

40. From the outset, Caxton provided a one-off Bereavement Grant of £3000 to the next of kin of a deceased primary beneficiary [CAXT0000062_076-15], from memory, this was the same grant provided by MFT when Caxton started. Later on, after we had received a few requests to fund funeral plans, we changed this to:

- A grant of £3,500 towards funeral costs when a beneficiary has passed away
- A grant of £3,500 towards a funeral plan for a beneficiary who had received a Skipton 2 payment.

41. In the minutes above, it sounds as if MFT had introduced a new policy of "continuing payments of 9 months for a beneficiary's widow". For Caxton, coming towards the end of its first year and conscious that many more beneficiaries might register, it would have been high risk to simply adopt this policy. It seems from the minutes that no figures were provided to be discussed at the next meeting of NWC so I cannot comment in further detail on this. However, in November 2012, the Caxton Board had its first discussion about introducing a regular payment scheme for primary beneficiaries and widows, although at that stage the concern was similarly that "any top up scheme can only be looked at realistically once a defined number of beneficiaries is known".

Section 5: The AHOs

Your appointment at the Caxton Foundation

Question 54: Please explain how you came to be a Trustee/Director of the Caxton Foundation.

42. In 2011, I arranged to leave the DH on an early severance scheme in response to the DH having one of their periodic reductions in staff and giving people an

opportunity to volunteer to retire. One of my aims for 'early retirement' was to look for opportunities as a charity Trustee. I was aware that the Caxton Foundation was being established. Given my previous experience in the Blood Policy Unit and my DH experience in general, this felt like an area where I could offer a substantial contribution. I therefore applied when Trustee vacancies were advertised in The Guardian and was successful at interview.

43. I applied to be a Trustee while I was still at the DH, but at the very end of my time there knowing that I was retiring six months later. I did take up the position while I was working in the DH, but I was looking ahead to when I would be retired. I then left the DH at the end of December 2011.

Question 55: How many Trustees/directors were appointed by the Government and how many by the Haemophilia Society during your tenure at the Caxton Foundation.

44. Schedule 2 of the Trust Deed establishing the Caxton Foundation set out the process for appointing Trustees (CAXT0000095_006). All Caxton Trustees/directors were appointed by the Trustees with consent sought from the Founder, i.e. the Secretary of State for Health. The Secretary of State must have appointed the first Trustees and I don't know what the process was for that. All the initial discussions about the foundation of Caxton took place between the DH and the First Trustees and I was not involved in any of those discussions.

45. There were no provisions for Trustees to be appointed by the Haemophilia Society.

Question 56: How long did each Trustee/director serve on the board? Could a Trustee/director be re-elected? If so, how many times?

46. Provision for this was set out in paragraph 7 of Schedule 2 to the Caxton Trust Deed. This stated that "Trustees shall be appointed for a term of up to three years and may be reappointed for a further term. A Trustee shall not then be eligible for

reappointment as a Trustee unless either:

- At least 75% of the Trustees vote in favour of his reappointment for a further term or
- He has ceased to be a Trustee for a period of at least one year after the end of his last term of office”

47. A decision was taken at the first Caxton Board meeting on 4 August 2011 to stagger the reappointment date for Trustees to avoid all appointment periods ending in three years. This was decided by ballot. [CAXT0000108_17-4]

Question 57: Were Trustees/directors remunerated for their work? Please include details of any policies on this, including policies for allowances/expenses.

48. Trustees/directors were not remunerated. As is usual with charities, Trustees could claim reasonable expenses, e.g. for travel to meetings. I do not think I ever claimed personally, as I was frequently in central London, so do not recall the specific policies. I did not claim for coming to meetings in London.

Question 58: Was there an overlap of Trustees/directors between the AHOs? Please explain how this worked.

49. There was limited overlap. This is explained on pages 9 and 10 of the Caxton Annual Financial Report for the year ending 31st March 2012 [CAXT0000034_010] in the section on Associated Organisations. The changes that occurred in 2012/13 are reflected in the section on Governance and Administration in the Caxton Annual Financial Report for the year ending 31 March 2013 [CAXT0000034_008-1]. Specifically:

- **The Eileen Trust:** Of five Trustees, three were Trustees of MFT and one – the chair - of Caxton. Peter Stevens continued to chair the Eileen Trust after retiring from Caxton, at which point there was no overlap between ET and CT.

- **The Skipton Fund:** There were four directors initially – 2 MFT Trustees, one Caxton Trustee (who from memory was Prof Howard Thomas). Martin Harvey was also a Director until he retired. His successor as Chief Executive did not continue in this role.
- **MFET Ltd:** The Chairs of MFT and the Eileen Trust were the sole Directors.

50. There was no overlap between Caxton and MFT apart from the first five months when Roger Evans was a Trustee of both charities. When Roger Evans became Chair of MFT he resigned from Caxton in February 2012. Caxton's annual report for the period ending March 2012 reports that the Trustees of MFT felt there would be a conflict of interest if Mr Evans remained a Caxton Trustee. However, there was a Joint Liaison Committee comprising members of both Boards which oversaw the Service Level Agreement between the two organisations. Later on, a MFT Trustee attended Caxton's Employment Affairs Committee as an observer.

User Trustees

Question 59: Please explain any reservations you held about appointing beneficiaries or user Trustees to the Caxton Foundation board. You may wish to refer to the following documents:

- the minutes of the Caxton Foundation Founding Trustees and others meeting 4 August 2011 [CAXT0000108_017]***
- the paper you authored with Peter Stevens 'The possible recruitment of a director with experience of living with Hepatitis C, 25 January 2013 [CAXT0000109_122]***

Question 60: In particular:

- Please explain your statement that "it was important for the Trustees not to be seen as 'Ivory Tower' residents" [CAXT0000108_017]. Do you believe the Caxton Foundation Trustees achieved this?***
- Please provide further information about the statement that "anybody with the infection from a non-iatrogenic source could provide exactly the same information about the challenges, costs***

and so on of living with the infection” [CAXT0000109_122]

- c. How did you and/or the Caxton Foundation become aware that the DoH did not wish the Secretary of State to be asked to approve the appointment of a Trustee whose main activity was campaigning against Government Policy?**
- d. Did you or the Caxton Foundation have any concerns that in voicing this, the Department of Health was interfering with the independence of the Caxton Foundation, as a registered charity?**
- e. Why did you consider that the appointment of a Trustee from one of the campaign groups would give the appearance of the Caxton Foundation supporting or sympathising with the campaigners? Why was that considered to be a problem?**

51. I have taken these two questions together. Looking back, there were two major concerns, both of which I shared. The first was that creating a user or beneficiary Trustee role would risk attracting candidates involved in campaigning who generally felt that Caxton should not exist, so I was concerned that such an appointment might disrupt our key aim of supporting beneficiaries (and was not necessarily representative of Caxton’s beneficiary community). The second concern was about the inherent conflicts in appointing people who might be recipients of grants themselves to a grant making body. A key role for Trustees was to agree policy on grants in which a beneficiary Trustee could not play a disinterested role. The board also discussed individual cases on which a beneficiary Trustee might also have to declare an interest.

52. This consideration is well summed up in the Charity Commission’s Guide, *The Essential Trustee*:

“It’s important to listen to the views and perspectives of members, beneficiaries and other bodies with an interest in your charity. Having people as Trustees is one way of obtaining these views. But all Trustees, regardless of how they are appointed, must act solely in the interests of the charity; it’s not their role to act on behalf of any particular group. They must also manage conflicts of interest,

including conflicts of loyalty to their appointing body.”

53. That said, I was concerned from the outset that Caxton should be in touch with and actively listening and responding to its beneficiaries. That explains my ‘ivory tower’ comment at the August 2011 board meeting. My approach to this issue was to think in terms of the skills and experience needed on the Trustee board to best deliver our charitable objects. Among other things, we needed to better understand the additional costs and other challenges of living with the virus. What we lacked was anyone with the experience of living with Hepatitis C who could add to the Board’s understanding of these challenges.

54. As to the remark quoted in CAXT0000109_122: the expert advice we received was that the experience of living with Hepatitis C was the same regardless of how it had been transmitted. I therefore felt that by adding a non-beneficiary to the board who had lived with Hepatitis C, we could add this important first-hand knowledge to improve our decision making whilst avoiding the conflicts of interest described above. At the same time, I was keen to strengthen our contact with Caxton beneficiaries through the Partnership Group and use that to genuinely listen to, and act where we could, on beneficiary concerns. So we advertised for someone with experience of living with Hepatitis C and went through the Haemophilia Society and Hepatitis C trust in order to do that.

55. I think that this twin track approach – a board member with experience of living with the disease and an active partnership group – did work and did address most of my early ‘ivory tower’ concerns. However, this is an area where I now question whether we took the right decision. I do wonder whether, with the benefit of hindsight, we might have found other ways of involving beneficiaries more directly, but the atmosphere at the time and the strength of feeling from some of the campaigning beneficiaries as to the very existence/purpose of Caxton did make this less straightforward at the time.

56. I think the statement that “DH would not wish the Secretary of State to be asked to approve the appointment as Trustee of somebody whose main activity is campaigning against government policy” was probably a supposition. I did not

attend the liaison meetings with DH but I think it unlikely that DH would have sought to influence Trustee appointments. My recollection, however, is that DH did not intend the Caxton Foundation to be a campaigning body. This is in the context of an active campaign for full compensation and a public inquiry and a strong feeling that victims should not have to ask for charitable aid. I think the statement that “the appointment of a Trustee from one of the campaign groups would give the appearance of the Caxton Foundation supporting or sympathising with the campaigners” has to be seen in that context. I should stress that all of us at Caxton had very strong sympathy for our beneficiaries and a desire to deliver the best we could for people who were seriously struggling with personal tragedy and financial hardship.

Structure of the AHOs

Question 61: 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 Caxton Foundation? Was information shared across the AHOs? If so, were registrants aware of this?

57. There was a single Chief Executive for Caxton and MFT. From memory, the Skipton Fund had a Scheme Administrator who was also assistant to the Chief Executive. The Eileen Trust had a part-time administrator. MFT and Caxton shared staff and resources and had a service level agreement to cover this. Some staff were employed solely to work for one AHO, others were shared such as finance and IT functions. Caxton inherited the CEO and staff previously employed by MFT along with their pay rates and terms and conditions. All were located in the same office in Alliance House except for the part-time Eileen Trust administrator who I believe worked from home.

58. Very strict rules were introduced on data sharing and confidentiality though I do not recall these in any detail. No data on individuals was shared across the AHOs. For example Caxton was not able to access the details of Skipton registrants unless

individuals had expressly given Caxton permission to do so, even though this would have been then best way to alert people to Caxton's existence. That's why we were so pleased when DH initiated the "Skipton Look Back" exercise in 2014. See also my answer to question 99. So data confidentiality was taken seriously.

59. Regarding storing documents and information: initially they were stored on site as paper files. Later on they were moved off-site to secure premises. I can't now remember whether there was a programme to digitise them. Basically, we didn't have enough space in AH for the existing charities when we moved in. In the end the solution was that we moved a lot of the file storage off-site (I discuss this more in my answer to question 65 – the interim CE after Martin Harvey left convinced us quickly that we could resolve our problem of space by simply moving documents off-site, with no need to move to the 5th floor as had been planned).

Question 62: Why did the Caxton Foundation act as employer for all five AHOs?

60. This decision was taken by DH in discussion with the chairs of MFT and Caxton (see MACF0000023_022-1). New Trustees were informed at the first Caxton board meeting on 4 August 2011 that the original intention had been for MFT to provide the staff and resources to enable Caxton to operate but this could not be done for legal reasons. (See CAXT0000108_017).

Question 63: Please set out your recollection of the relationship between the different AHOs.

61. The key relationship was between Caxton and MFT, as the two charities dispensing the most money and employing the staff. Most activity in AH was either to do with Caxton or MFT: Eileen and MFET were very small and Skipton had its own governance arrangements. The relationship between MFT and Caxton was managed through the Liaison Committee and regular one-to-one contact between Chairs – and for a period between me as Deputy Chair of Caxton and Roger Evans as Chair of MFT. Overall my recollection is of a broadly cooperative relationship, although as might be expected there was an initial period of managing trust and some areas of active disagreement (such as on whether we should appoint an

interim CE after Martin Harvey left – which in the end Caxton did without agreement from MFT, since we had identified a clear need for the role and recruitment was ultimately our responsibility).

62. Relationships between MFT and Caxton improved as time went on and greater trust became established. At the Caxton/MFT Liaison Committee held on 7 October 2013, Roger Evans commented that:

“the Liaison Committee had been set up to discuss matters affecting both organisations and said he felt it was a testament to how well they were going that the Committee hadn’t met since December 2012” [MACF0000026_032-1]

63. By this stage, a MFT Trustee was sitting as an observer on Caxton’s Employment Affairs Committee and regular meetings were taking place between the chairs of MFT and Caxton and with Jan Barlow as CEO. As ever, relationships were improved by frequent, open communication.

Question 64: Please describe the working relationship between the Trustees/directors of the Caxton Foundation and the senior management. Were you aware of any difficulties? If so, what were they, how did they impact on the running of the relevant AHO and how, if at all, were they resolved?

64. The staffing for the AHOs was lean. Senior management was therefore the CEO – which was Martin Harvey, then an interim CEO and then Jan Barlow. As with all charities, the main working relationship was between the Chair of the Trustee board and the CEO. The committee chairs, particularly the National Welfare Committee chair and Audit Committee chair, also had a regular working relationship with the CEO and key staff.

65. The working relationship between Caxton Trustees and Martin Harvey was fine, although because of his unavoidable personal circumstances he was not always available when we needed him and was perhaps not very receptive to new ideas. Martin was very ill when Caxton was set up, and there was pressure on him and his staff to get Caxton going on top of their usual role. He had been at MFT for

around ten years, was hugely experienced and had been able to get to know many MFT beneficiaries personally. His instinct was naturally to do with Caxton whatever had been done with MFT. But any downside of his having slightly fixed ideas inherited from MFT was counterbalanced by his experience and expertise.

66. I worked closely with Jan Barlow on a number of initiatives, in particular on the regular payments scheme, and had a very good working relationship. As a Board, we had some frustrations, for example, it seemed to take a long time to receive good performance indicators. But generally the things we wanted done got done and the performance of the staff team improved markedly e.g. on the turnround time for processing grants (see CAXT0000101_004-1).

Question 65: Please explain the circumstances which led to the establishment of the MFT/Caxton Foundation Liaison Committee. In addition, please explain:

- a. what your role on this Committee entailed**
- b. the purpose of this Committee**
- c. if this Committee was successful in achieving its purpose, and if not why**
- d. if there was a similar Committee for working with the other Alliance House Organisations, and if not, why**
- e. if there were MFT/Caxton Foundation Liaison Committee meetings from 2014, if not, why**
- f. if there was an arrangement that replaced these meetings from 2014.**

67. A Liaison Committee was on the cards right from the start, because of Caxton's role as provider of operational resources for MFT and the other AHOs. Also we didn't have Trustees in common (apart from Roger Evans initially) but we were sharing the same staff and an SLA was in place: there were decisions that Caxton would have to take that would impact on MFT. Having a Liaison Committee was one way of addressing those issues.

The Service Level Agreement between Caxton and MFT described the role of the Committee as:

“the forum to which will be brought all issues either of the Charities may wish to raise regarding the management and delivery of the services described in this Agreement and of any other services agreed by the Liaison Committee to be required and in which all material decisions regarding the implementation of this Agreement will be discussed and actioned.” [CAXT0000095_080-1]

68. My role, as one of the Trustees from Caxton, was to explain anything that Caxton wanted to do and to negotiate any changes with MFT if they had problems with it, and vice versa – to receive their suggestions. Members of the Committee were also responsible for reporting back to their respective boards who had ultimate accountability for decisions affecting their charities.
69. To take an example, in the early days of the Liaison Committee, there was a proposal to move all the offices to the fifth floor of AH where there was more space. There was negotiation over a draft agreement that Martin Harvey had drawn up with the landlords. It was quite a protracted discussion. Then our interim CE demonstrated that there was no need to move and we could save money by simply moving our paperwork off site. So, once the Caxton Board decided not to move, we went to the Liaison Committee to discuss our current thinking with MFT colleagues (see CAXT0000109_105-1).
70. I don't recall why and when the meetings stopped but I think the two chairs (Roger Evans and Ann Lloyd) began to manage all key issues between them without the need for the committee. I don't think a specific decision was taken. I was completely neutral about it – if the issues were managed between the two chairs then that seemed efficient.
71. There was not a similar committee for the other AHOs, simply because they were smaller so there was no need for it.
72. I do think the Committee was successful. For example, MFT agreed that we did not need to move to the fifth floor having listened to Caxton's reasoning.

Section 6: Caxton Foundation's relationship with Government

The following questions are in regards to your role at the Caxton Foundation:

Question 66: To what extent was the Caxton Foundation independent from the Government? How much oversight did the Department of Health (or any other Government department) have over the Caxton Foundation? In particular, did the Department of Health have any involvement with and/or give any direction/guidance to the Caxton Foundation (and if so, what?) as to:

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

73. The Caxton Foundation was set up as an independent charity. Although the charity was established by the government and reliant on funding from DH, we were completely independent in how we exercised our charitable functions. This independence is made clear in the Trust Deed establishing the Caxton Foundation which sets out the powers of the Trustees among other things. Our first meetings as a Trustee board were concerned with understanding our role and obligations as a charity and making decisions on how these should be exercised.

74. There was a requirement in the Trust Deed for Trustee appointments to be subject to the consent of the Secretary of State. In my time as a Trustee, no proposed appointment was refused. As Deputy Chair, I led work on Trustee recruitment, including the recruitment of a new Chair and a CEO. DH did not seek to influence our specification for the role or the recruitment process. We did a skills audit and tried to find people with those skills. I certainly never thought that we had to recruit people that DH would find acceptable. I thought we had to find people that we needed on the Board, and since we met that objective there was nothing for DH to object to.

75. All Caxton's policies were decided by the Board with no involvement or oversight by DH. DH also had no involvement in decisions on the kind of applications Caxton should grant or the quantum of grants/payments. We were set up by DH to do a job and their concern was that we did that job, not how we did it. I certainly did not feel that we did things because the DH wanted us to, or that we had to "toe the line". I didn't give DH a moment's thought when it came to thinking about how we fulfilled our trust deed. I have been on three different charity boards since leaving Caxton and the feel of being on Caxton was no different from the others.

76. Meetings were held periodically between the Minister and Caxton. This is also dealt with at question 69 below. I would be able to provide more details on the content of these meetings if I were provided with the minutes.

77. I was, of course, still in contact with, and in some cases closely connected to, former colleagues in the DH despite my departure. I recognised that this could be (wrongly) perceived to be a conflict of interest. In order to avoid any such conflict I ensured that I was not involved in the DH Liaison Panel (whose contact at the Department for Health was Ailsa Wright) and did not put myself forward to become the Chair of Caxton on Peter Steven's departure.

Question 67: Did you, or others within the Caxton Foundation, 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?

78. We approached the DH in 2013 with a proposal for increased funding to allow for a regular payments scheme from 2014/15. This was ultimately refused. I discuss this further at question 153 onwards.

79. Any discussions that were had with the DH would have been fully minuted; I would be able to comment in more detail on this question if I were provided with those

minutes.

Question 68: Please describe the working relationship between the Caxton Foundation and the Department of Health. Was there a particular point of contact? If so, who was that? Were you aware of any difficulties? If so, what were they, how did they impact on the running of the Caxton Foundation and how, if at all, were they resolved?

80. I am confident that there was a good professional working relationship between Caxton and DH. This was managed through the Caxton/DH Liaison Committee which I did not attend. The main contact was Ailsa Wight. My contacts on a working level (such as when I managed the Trustee appointment process and needed Ministerial clearance) were with Rowena Jecock and Ben Coles.

81. There were occasional difficulties from a policy perspective, such as DH declining to fund our proposed regular payments scheme, but these did not affect the cordial nature of the relationship.

Question 69: What was the purpose of the Caxton Foundation/Department of Health Liaison panel? Why did you swap from membership of this panel to the Macfarlane Trust/Caxton Foundation Liaison Committee in November 2011 [CAXT0000108_070]?

82. The purpose of the Panel was to discuss any issues of common interest to Caxton and DH, primarily funding arrangements but also areas where DH could support Caxton such as publicity for the charity. The minutes at CAXT0000108_075-1 show the kind of issues discussed.

83. I swapped membership before the first meeting of the Panel to avoid any conflict or perceived conflict of interest. This was for the reason set out in answer to question 66 and also because it made more sense for Mary Leadbeater, as chair of the Caxton Audit Committee, to be involved in discussions with DH which would be predominantly about finance.

Question 70: Were there annual or other regular reviews between the Caxton Foundation and the Department of Health? If so, please provide details including the following:

a. Did the reviews take the form of meetings? If so:

- i. Who set the agenda for the meeting?**
- ii. Who would attend the meetings?**
- iii. Were any Trustees/Directors who did not attend able to contribute to the position to be put forward by the Caxton Foundation and, if so, how?**
- iv. What was discussed at the meetings?**
- v. Were formal minutes, or any other written record, taken at the meetings? If so, by whom and who would be provided with copies?**
- vi. If the reviews were conducted without meetings taking place, please provide full details of the process.**

84. The only meetings between Caxton and DH that I am aware of were the regular Liaison Panel meetings (which I did not attend) and occasional meetings with the Minister (I attended one of these with Ann Lloyd after she became chair). As usual with these kind of meetings, the key participants were the Chair and CEO of Caxton and the blood policy team at DH. Mary Leadbeater was also a member of the Liaison Panel as chair of the Caxton Audit Committee.

85. As I was not directly involved with the Liaison Panel, I cannot comment how the agenda was set or issues discussed, but I imagine that the agenda was jointly agreed in advance. I don't recall any discussion at Trustee board meetings about the meetings probably because the business would have been fairly routine. I do not recall seeing minutes of these meetings at the time.

86. As an independent charity, Caxton was responsible for producing an annual report and accounts and followed the relevant legal requirements in producing this.

Caxton's Statement of Financial Controls [CAXT000065_101-3] required that the annual report and certified accounts would be provided to DH within 5 months of the end of each financial year.

87. The meetings with the Minister were fairly ad hoc. There was one in November 2011 when the Minister met all trustees, then two in my time, maybe three. I attended at least one of the later ones (with Anna Soubry) in I think March 2013 after Ann Lloyd had been appointed as Chair of Caxton. The points to be raised at these meetings were discussed with all the other Trustees in advance and the outcome fed back to the Board. The Minister's private office would normally have taken a note of these meetings but I did not see them at the time. At the meeting I attended, I recall that the Minister fed back comments about Caxton that had been made by the campaign groups and we discussed these and Caxton's plans for performance improvement. This included concerns about the length of Caxton's forms for beneficiaries, the turnaround time for grant applications and the burden of justifying charitable need which some other applicants said left them feeling like beggars.

88. Ann Lloyd wrote to the Minister, then Jane Ellison, on 12 May 2014 with a progress update following the March 2013 meeting with Anna Soubry. This acknowledges that 12 months previously Caxton had not been working effectively and details the improvements made since then (AHOH0000053-1).

Question 71: Did the Caxton Foundation have ad hoc meetings with the Department of Health? If so:

a. How were these meetings arranged? Could Caxton Foundation call for such meetings?

b. Who set the agenda for these meetings?

c. Please describe any such meetings you know took place, including dates where possible.

e. Who would attend these meetings?

f. Were the Trustees/Directors who did not attend able to contribute to the position to be put forward by Caxton Foundation and, if so, how?

Were formal minutes, or any other written record, taken at the meetings? If so, by whom and who would be provided with copies?

89. Other than the meetings mentioned at Q69, I do not recall any ad hoc meetings.

Question 72: The Caxton Foundation Annual Financial Report for the year ended 31 March 2015 [CAXT0000035_078] notes that the APPG report on Haemophilia and Contaminated Blood had revealed that many felt that ‘the Alliance House organisations have what amounts to a “cosy” relationship with the Department of Health’. Do you consider this characterisation of the relationship to be fair?

90. I note that the perception of a cosy relationship with DH is strongly rebutted in the Annual Report, and I think quite rightly. Because Caxton was set up by the DH, some beneficiaries saw us as an extension of the Department, not as an independent charity trying to do the best for our beneficiaries. I can understand this perception from the outside but the relationship with the DH was one in which they expected us to deliver on the purpose for which we were established within set resources, but nothing else.

91. The fact that we made a business case for funds to run a regular payment scheme shows the relationship was one of independence – we were not afraid of asking for more funding. The ongoing discussions with DH were through the Liaison Group which I wasn't involved with, and I don't recall seeing notes of those meetings. I do not believe that we did not press our case more strongly because of some “cosy relationship” or indeed that we would have been awarded more money if we had only pressed harder: they were pretty definitive in their decision that they would not provide additional funding. Further argument from us would not have led to any change of mind.

Question 73: The minutes of the Caxton Foundation Board of Trustees meeting held 6 October 2011 [CAXT0000108_038] note that the board felt “the DH’s approach to management funding was increasingly difficult in procedural terms”. Please explain:

- a. what was difficult about Department of Health approach**
- b. if the board raised this issue with the Department of Health.**

92. My recollection of this is that it related to the procedures to be put in place following the decision to make Caxton responsible for management of all the Alliance House entities. Some of the difficulties are explained in the paragraphs that follow in the minutes (on p.6).

Question 74: In email correspondence between a beneficiary and the Caxton Foundation, copied into a number of parliamentarians, the Haemophilia Society and the Hepatitis Trust on 24 January 2014, the beneficiary states “there is a real conflict of interest having Charles Lister who is not only ex Department of Health but also ex Blood Policy Unit, make decisions” [CAXT0000113_009]. As to this:

- a. Is this a view that was expressed by other beneficiaries?**
- b. Did you consider a conflict of interest arose? If not, why not?**

93. I was aware of this view which, to the best of my knowledge, was not widely expressed. The view was expressed to me directly, possibly by the same beneficiary, at the meeting with Partnership Group on 6 November 2014. My DH background was well known, including on my biographical note on the website.

94. In my view my background was an advantage in that I was already familiar with the Macfarlane and Eileen Trusts. I also developed an understanding of Hepatitis C and the issues facing sufferers and had met a number of people who had contracted the disease through contaminated blood. I also brought a range of practical skills and experience from my various roles in developing policy and working with ministers.

95. I was careful to avoid any actual or perceived conflicts of interest, which is why I decided not to be a member of the Caxton/DH Liaison Panel at a point when I was still professionally and socially connected to DH. I certainly did not feel any loyalty to DH or feel that I would not want to do anything that would be awkward for DH.

96. In the light of this, I am confident that I was able to avoid any conflict between my DH links and my responsibilities as a Trustee helping to deliver the Caxton Foundation's charitable objects.

Question 75: What if any contact did the Caxton Foundation have with the Department of Work and Pensions ('DWP') in relation to welfare benefits? In particular:

- a. Why was the benefits disregard not in place for the first few months of the charity's existence [CAXT0000108_017]? What impact did this have on the Caxton Foundation and/or its beneficiaries?**
- b. Were you aware of any beneficiaries having their benefits stopped as a result of the assistance they received from the AHOs?**
- c. Did the Caxton Foundation take any steps to prevent this happening? If so, what? If not, why not?**
- d. Did the Caxton Foundation raise this issue with the DWP and if so what was the response?**

97. The first meeting of the National Welfare Committee was held on 21 September 2011. This meeting discussed the principles for providing support agreed at the Board meeting of 1 September 2011 and set the process in motion for receiving applications from beneficiaries. The Social Security (Miscellaneous Amendments) (No 3) Regulations 2011 were introduced on 4 October 2011. Decisions on the first applications for support were taken at the next NWC meeting on 17 November by which time the regulations implementing the benefit disregard had come into force. I am not aware of any contact that the Caxton Foundation had with DWP directly over the timing of the regulations. Any concerns expressed by the Founder Trustees would probably have been raised with DH.

98. A DH Press Statement was issued on 26 October 2011 stating that the Caxton Foundation will begin to initiate payments in November 2011. Given this timeline, I am not aware of any beneficiaries having their benefits stopped as a result of receiving support from the Caxton Foundation. Had there been any such instances,

I feel confident that the office would have raised this directly with DWP.

Question 76: The minutes of the Caxton Foundation NWC meeting held 18 April 2013 include, in relation to Bedroom Tax and Council Tax, that you raised “concerns about setting a precedent and stated that the Foundation should not be used to replace benefits” [CAXT0000082_001]. Please explain:

a. the concerns that you held

b. if you discussed these with DWP or the Department of Health

99. My point was that if the government reduced benefits, there shouldn't be an automatic assumption that the Caxton Foundation would replace them. Caxton was not a proxy for the benefits system. Firstly, Caxton could not commit to any type of ongoing regular payment at the time, and secondly, it could be argued that if the government had reduced or abolished a particular publicly-funded benefit it was not for another publicly-funded charity to replace them automatically. We would however need to consider the impact on our beneficiaries particularly if any changes introduced by the government led to increased hardship for our beneficiaries.

100. We did not discuss this issue with DWP or, to the best of my knowledge, with DH. With our agreement, Neil Bateman produced a briefing note for Caxton's website which explained the upcoming changes, including the introduction of universal credit.

101. It should be noted that Caxton took the decision in November 2012 to disregard means tested benefits such as DLA, Child Benefit, Carer's Allowance and Council Tax Benefit, in determining household income. This brought Caxton more into line with MFT's practice.

Section 7: Funding/finances of the AHO

The following questions are in regards to your role at the Caxton Foundation

When answering the below questions, you may wish to refer to the relevant

financial reports published during your time with the Caxton Foundation:

- I. Annual Financial Report for 2011/2012 [CAXT0000034_010]**
- II. Annual Financial Report for 2012/2013 [CAXT0000034_008]**
- III. Annual Financial Report for 2013/2014 [CAXT0000004_026]**
- IV. Annual Financial Report for 2014/2015 [CAXT0000035_078]**
- V. Annual Financial Report for 2015/2016 [CAXT0000002_056]**

Question 77: Please set out the process by which the Caxton Foundation 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?

102. I was not hugely involved with this aspect of Caxton's work. The process is set out in the Statement of Financial Controls. I have seen the copy at CAXT0000065_010-3 but I am not sure if this is the final version. These state that:

"The Caxton Foundation will receive funding from the Department of Health (DH) on a quarterly basis, which it will use to meet the objects of the charity.....The Trustees will be accountable to the Charity Commission for ensuring that the Foundation operates within the terms of its Trust Deed.

Decisions on the level of payments to the beneficiaries are a matter for the Trustees to decide in accordance with Charity Commission guidelines. However, these decisions must be made taking affordability into account based on the agreed funding."

103. DH provided total funding on behalf of all the UK countries and took responsibility for recovering contributions from the devolved administrations.

104. The process was that:

- Caxton provided a first budget estimate to DH by 1st September for the following financial year
- A revised and more detailed estimate was provided by the following February

105. There is more detail in the Statement of Financial Controls about the type of information required by DH. This process is fairly standard for all bodies funded by DH to fit with their annual budget setting cycle. As I remember, DH funding would provide first for the NHS and then the remaining DH budget would be distributed to projects. Once an allocation is agreed there is no flexibility about it. From the Caxton end, most of the work will have been done by the CEO and Head of Finance with involvement from the Chair of Caxton and the Chair of the Audit Committee.

106. I am not aware of any problems with the process. If I remember correctly, there was a frustration that DH was being quite prescriptive in what they demanded to see and what they wanted justified before the funding was paid. We were also subject to the usual government spending rules on annuality, meaning that we couldn't carry forward unspent money into the following financial year. These prescriptive requirements would have come from DH Finance wishing to account for spend rather than from the blood policy team. Caxton's relationship with DH finance is separate to the relationship with the DH Blood Policy Unit, and it's the Finance team who dealt with the money aspect. I don't think it changed over my time with CF in any significant way.

Question 78: What do you know about how the Government set the budget for the Caxton Foundation? What input did you/the Caxton Foundation 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?

107. As above, I was not very involved. The budget setting process was laid down in Statement of Financial Controls and was based on a budget provided by Caxton. To that extent, DH took account of the views of Caxton. At the end of this process, the Department will have written to the Caxton's CEO with the financial allocation for the following year. It will then have been for Caxton to manage within that allocation. I had no input into this – that was more of an operational issue, for which the Trustees were ultimately responsible but where the actual work was

carried out by staff.

108. I don't consider that I should have had any bigger role in it – operational roles in charities are normally for the Chief Executive.

109. Any further representations during the budget setting process will have been raised by Caxton at DH Liaison Committee. However, I was not a member of this so cannot comment on what happened in practice.

Question 79: What information, if any, did the Caxton Foundation 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?

110. Caxton started with beneficiaries who had registered with us, presumably following publicity around its inception. Only around 250 beneficiaries had registered at the time of Caxton's launch in October 2011. By 31 March 2012, this had risen to 405 but this was clearly far fewer than the likely beneficiary population. The difficulty of providing an accurate estimate of the beneficiary population was summarised in Caxton's Annual Report for the year ending 31 March 2012 [CAXT0000034_101-3]. We knew how many people had received Skipton 1 and Skipton 2 payments but "without records of treatment or mortality rates, accurate estimation of Caxton's potential total number of beneficiaries has not proved possible".

111. One of the first things that Caxton did was to write to the beneficiaries who had registered with Caxton with a "census form". That asked about people's income and expenditure in some detail so that we would understand a basic level of need, such as people with expenditure in excess of income.

112. The census forms were not provided to the government, they were confidential. The NWC provided an annual report to DH about the kind of support we were giving to beneficiaries, so the department was aware in general terms of the kind of support we were giving. We did not provide details to the DH about the degree

of need that the census suggested. I am not sure what the value of providing that level of detail would have been: Caxton was treated by the DH as an independent charity, we were left to meet our beneficiaries' needs as we saw fit.

113. I assume that information about Caxton's estimates of the funding needed to meet beneficiary need will have been included in the annual budget setting process described at Qs 77 & 78 above, but without sight of these documents, I don't know what level of detail will have been included.

Question 80: Were budgets/budget forecasts made by the Caxton Foundation prior to the start of the financial year? If so, how were the needs of the beneficiary population forecast? If not, why not?

114. This process is described in my answers to Q77 and 78 above. Budget forecasts were the responsibility of the CEO but I would have had some input to these. From my point of view as chair of the NWC, it took several months of receiving grant requests from a growing number of beneficiaries before we began to get a good understanding of the needs of the beneficiary population. This led to the development of plans for a regular payments scheme when we understood the extent of poverty among our registrants and had a better (though far from complete) idea of numbers.

115. Until we made the first payments under the regular payments scheme in 2014/15, we were spending less than the allocation available from DH. Lack of funding was therefore not an issue in awarding discretionary grants, although the lack of any guaranteed long-term income was an issue in making longer-term grants and planning (see my answer to question 85 and 153). We didn't know one year to the next what the allocation was going to be, which made long-term planning more difficult, an example being when we were told in 2014 that the 2015-2016 allocation might be reduced.

Question 81: What was the impact on the Caxton Foundation of spikes in applications?

116. I don't recall any particular spikes in applications, perhaps because until 2014-

2015 we were spending below our allocation so it wouldn't have mattered if we had spikes. There was a set of issues during 2014-2015 when we had the Skipton Look-Back exercise and Caxton beneficiaries almost doubled – that was the first year that we really had to think about how we'd balance the books. But I don't think we reduced the grants, rather we thought about how much to spend on regular payments and we initially reduced the winter fuel allowance by £150. Because we didn't in the end go over-budget, beneficiaries were in fact given the extra £150 later on.

117. I left Caxton in 2015 so cannot comment on any spikes after that.

Question 82: When the Caxton Foundation enquired about additional financial provisions in light of the increased number of beneficiaries, did the Department of Health provide any reasons why it did not intend to increase funding for the Trust? You may wish to refer to minutes of the Caxton Foundation Partnership Group meeting held 6 November 2014 [CAXT0000110_151] when providing your answer.

118. I believe Caxton was told by the DH that (in effect) it had to live within its means. I don't recall there being any other explanation from the DH. Generally the Department has limited ability to provide additional funding in-year once allocations are fixed. This was also the period of austerity when public spending was being severely curtailed and Caxton had at this point never spent its full allocation. Indeed, around the same time we were told that we might have a reduced allocation in 2015-2016 because of pressures on DH budgets. See also my response to Q83.

Question 83: As a result of increased beneficiaries, did the Caxton Foundation request additional funding from the Department of Health? If so, what was the outcome? You may wish to refer to the minutes of the board meeting on 22 October 2014 [CAXT0000110_166].

119. See Q82. The minutes of the board meeting on 22 October 2014 makes clear that the CEO had asked DH if additional funding would be available for an increase in beneficiaries as a result of the Skipton look back exercise requested

by DH. This was an enquiry rather than a formal bid. It did not come as a surprise to me that DH told us we had to live within our means. This was a typical DH finance response. Their argument was that Caxton had so far been funded on the basis of more beneficiaries than we had to date and that we had underspent in previous years. Also, as mentioned, austerity was putting increasing pressure on Government spending.

Question 84: Please set out as far as you can recall how much funding was provided at various times for the Caxton Foundation.

120. The only funding we had came from the DH and a small amount of bank deposit interest. I cannot recall now what the annual allocation from DH was annually. This would have been notified to the CEO each year in a letter from DH. Caxton would only have been able to draw down the amount of funding it needed each year, which until 2014/15 was less than the allocation.

121. The following table shows Caxton's expenditure over its first three full financial years, taken from the Annual Reports. This excludes AHO support costs. I have shown admin and governance costs as a proportion of total spend.

Year	Registered Beneficiaries at year end	Caxton Spend			
		Total	Support to Beneficiaries	Governance (% of total spend)	Admin (% of total spend)
2012/13	555	1,043,902	699,318	60,132 (6%)	284,452 (27%)
2013/14	695	1,257,887	954,458	51,940 (4%)	251,489 (20%)
2014/15	1080	2,022,708	1,730,619	42,169 (2%)	249,920 (12%)

Question 85: Do you consider that the funding provided to the Caxton Foundation by the Government was adequate? Please explain your reasoning.

122. On one view, the funding was perfectly adequate at first, because until 2014/15 we didn't spend the maximum allocation on discretionary payments.

123. From 2014/15, I was very disappointed not to have the additional funding needed to fund the regular payments scheme that we wanted to implement (to take our poorest beneficiaries up to 80% of median income). I discuss this scheme at question 153 onwards. That was the only time that I thought we could have done with more money.

124. Of course, it could be argued that the way we were funded on an annual basis rather than on a more long-term basis affected how we generally operated. It probably contributed to us underspending in the early years, as we were worried about not being able to meet demand if it increased, and as I mention above it held us back from offering regular payments. We couldn't carry money over from one year to the next, and there was always a level of uncertainty as to whether our budget would be cut the following year. One concern of ours was that people would adjust their lifestyles towards whatever new regular payment we might make, and if we didn't receive the same budget next year we might have to cut those payments.

125. It is fair to say though that our own principles were also one reason we did not spend more (on discretionary grants). We started off with a requirement that we provide charitable aid, and we interpreted that according to a definition of "poverty" – this meant that we turned down some grants from people who had substantial incomes. If we had given a grant to everyone who applied we would have set unsustainable precedents. Similarly, some people came to us with debt which we decided not to totally write off, but rather we worked with them to help them manage the debt (with some write-off from us). So there were ways in which we could have spent more that was not to do with the DH allocation but rather with the principles we established.

126. I left in early 2015 so I cannot comment on funding levels thereafter.

Question 86: The minutes of the Caxton Foundation Partnership Group meeting held on 6 November 2014 [CAXT0000110_151] note that you advised ‘funding was allocated by the Department of Health at the start of each financial year, and so additional funds would not be forthcoming’. What opportunities or procedures were there for the Caxton Foundation 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. Were such applications ever successful?

127. This comes back to the same point, that our budget was sufficient in the first few years. We didn't spend the maximum allocation until we sought to introduce the regular payments scheme, so there was no need to ask for more. Had we needed to, I think it would have been difficult to ask for top-up money, because money would only have been available for the DH to give us had there been underspends elsewhere in the DH. It wasn't like there was a freestanding pot of DH money waiting to be accessed. As stated in Caxton's Financial Controls document "DH has limited ability to provide additional resources once funding envelopes are set for the financial year".

Question 87: The minutes of the first Caxton Foundation Partnership Group meeting [CAXT0000110_151] note “it was suggested that Caxton could submit a business case requesting additional funding to pay for treatment for all beneficiaries”. Please explain whether a business case was put forward to the Department of Health for funding for the new treatment for Hepatitis C? If so, what was the outcome?

128. No such business case was produced. It was not in Caxton's remit to pay for treatments that would be provided by the NHS.

129. I note from the minutes that Jan Barlow explained at the time that:

“the Department of Health controlled the funding for both Caxton and the NHS.

It was therefore highly unlikely, if one part of the Department had decided that money was not being made available widely to the NHS for these treatments on cost-effectiveness grounds, that another part of the Department would agree that money be provided to Caxton for the same purpose”

Question 88: Did the Caxton Foundation have any other streams or sources of funding/income other than that provided by Government during your tenure? If so, where did this come from, how much was it, and how was it managed/spent by Caxton Foundation?

130. Government funding was Caxton’s only source of income during my tenure as far as I can recall. We had a very small amount of bank deposit income, which is shown in the annual account, but nothing else.

Question 89: Please refer to the Caxton Foundation Board Minutes dated 17 November 2011 [CAXT0000108_070] which note the Chair of the NWC was keen to “spend as much money as they could, within reason, to show that there is unmet need amongst the community”. You may also wish to consider the minutes of the CF/MFT Liaison Committee meeting 9 December 2012 [CAXT0000068_010].

- a. **Why was this approach taken?**
- b. **Was there unmet need? If so, how did the Caxton Foundation address this?**

131. I don’t remember this either as a quote or as a policy. The Chair of the NWC at that time was Roger Evans: he would be better placed to answer this question. Minutes of meetings do not indicate whether any particular comment was given lots of time in the meeting or made in passing. We assessed applications on their merits, there was no feeling that we had to spend for spending’s sake.

132. Obviously, there was a lot of unmet need: that was why we pushed for regular payments in the end. Lots of people were living on very modest incomes. One of the things I was personally shocked by when I started at Caxton was how little money some beneficiaries were living on. Some were living off the Disability

Living Allowance only, of around £6,000 per annum, to meet their expenses. We also found that an awful lot of people were in a lot of debt. Some were in the dreadful position of either having to go deeper into debt or go without essentials. We tried to address this by looking at applications and developing proposals for a regular payment scheme to lift people out of financial hardship, and out of the trap of debt.

Question 90: Who decided on the level of reserves the Caxton Foundation should maintain? You may wish to refer to the minutes of the Caxton Foundation Audit Committee meeting held 19 July 2012 [CAXT0000065_062].

- a. **What was your involvement in decisions on the level of reserves?**
- b. **Did you prepare a Reserves Policy?**
- c. **What was the justification for the level of reserves?**
- d. **Did the level of reserves impede or otherwise have an impact on the Caxton Foundation's negotiations with the Government for increased funding?**

133. There was an agreement with DH that Caxton did not need to maintain a reserve (see the 2013 Annual Report, which refers to an agreement with DH that no reserve will be held but that Caxton will work to an operating balance to ensure an appropriate level of cash flow). Reserves would usually be to ensure that an organisation had six months of operating costs in the bank to enable staff to be paid if funding dried up. But we didn't need reserves because funding came directly from DH – they wouldn't have wanted us to have substantial sums stored in the bank, not being spent.

Question 91: What, if any, steps did the Caxton Foundation take to cut its operational costs so as to maximise the monies available for beneficiaries?

134. This was an issue of concern to Trustees and we were keen to keep costs down. Some limits were placed by DH, i.e. a limit on staff head-count for the entire AH operation (staff fell under Caxton's responsibility and was part of the allocation we were given). Also, Caxton inherited a pay and staff contracts system from the MFT which we felt required modernisation. This included very lengthy spine

points which were more akin to an old fashioned public sector pay structure than a modern charity. During 2013/14 new contracts for new staff were brought in to address that and reduce costs alongside a restructuring of Caxton's welfare team.

135. At the point when the business case for a regular payment scheme was put to DH, the number of AHO staff working for Caxton was just 3.7 whole time equivalents. This included less than 50% of the CEO, less than 50% of a newly created role to replace the Welfare Manager, a full-time Welfare Assistant who ran the day to day administration of the Caxton grants programme, and percentages of time for other IT, finance and admin staff.

136. The table at Q84 shows that by 2014/15, governance costs (the costs to keep a charity legally compliant, including the Trustee board and internal and external audit) was 2% of total spend and admin costs amounted to 12% of total spend. Both of these I believe were at an acceptable level. I should of course acknowledge that, as well as the actions described above, the proportion of income spent on admin was always going to decrease as our beneficiary numbers and grants awarded increased.

Question 92: What, if any, steps did the Caxton Foundation take to ensure that the salaries it paid its staff were proportionate and/or commensurate with the charitable sector?

137. We inherited a pay structure from MFT which tied our hands initially. As to proportionality: I think the salaries paid were commensurate with the civil service and were therefore slightly higher than might be commonly found in the voluntary sector.

138. I don't believe we ever conducted any industry-wide review. Jan Barlow did a lot of work on revising the staff contract, and when we came to advertise new jobs I believe they were advertised at a rate commensurate with the sector. We didn't have an HR department, and had to rely on external advice to ensure that anything we did was compliant with employment law. I was not heavily involved with staffing or pay issues apart from reaching agreement on Jan Barlow's

contract.

Section 8: Identifying beneficiaries for the Caxton Foundation

Question 93: Whose responsibility was it to identify potential beneficiaries for the Caxton Foundation?

139. I don't think it was set down in black and white anywhere whose responsibility it was. My take is that the responsibility lay ultimately with the Board, but the Chief Executive would have had day-to-day responsibility for identifying beneficiaries. I also think that DH had some responsibility and certainly had more resources at their disposal.

140. This is something we talked about a lot as a board but were probably less successful than we should have been. One of the Trustees, Alan Rook, was recruited for his relevant expertise in communications and media, with the intention of using his expertise to run some kind of publicity campaign. But in the end that did not come to fruition.

Question 94: How were potential beneficiaries of the Caxton Foundation identified?

Question 95: Please explain your role in identifying potential beneficiaries for the Caxton Foundation. You may wish to refer to the minutes of the Caxton Foundation Board of Trustees meeting held 6 October 2011 [CAXT0000108_038].

141. I have taken these questions together. Initially the DH put out information about Caxton to clinicians and other professionals, and beneficiaries could then apply to be registered with us. There was also information on the websites of the Haemophilia Society, the Hepatitis C Trust, Tainted Blood and the Skipton Fund, which directed people to Caxton. There were attempts to give information to Haemophilia Centres so that if patients came through with Hepatitis C they could be told of Caxton's work.

142. I remember thinking that what we needed was more national publicity – it was such a human interest story that it would have been suitable for the national media. The issue of advertising through the media was discussed at one of the early set up meetings with DH [CAXT0000095_016-4) with a view from DH that *“if interest in the charity had not significantly increased by Christmas advertising should then be considered but, in the first instance, given the limited amount of money available, it could be better spent elsewhere.”*

143. There were multiple reasons why we were hesitant about running an advertising campaign. Firstly, it could potentially waste money. Secondly, it could backfire, because it could be turned into a negative story that would undermine its goals and discourage people from coming to Caxton (and be unfair on whichever beneficiary volunteered to tell their story as part of any media campaign). Thirdly, it may have been misinterpreted by those who had been refused money in a grant application. Lastly, perhaps it was just too soon to be thinking about a media campaign. With the benefit of hindsight I wonder if we were just too concerned about the possible pitfalls and could still have got some useful messages out even if that happened. I had just joined the Board and perhaps didn't feel I had enough clout and experience to push for such a campaign. With hindsight perhaps we should have written to people to ask them if they would be willing for their story to be featured in some kind of publicity push (although that is not to say that such requests would have succeeded given that there were undoubtedly privacy concerns expressed by many beneficiaries at the time).

144. I discuss my specific role in communications generally in my answer to question 174.

Question 96: A report to the Caxton Foundation NWC dated October 2012 [CAXT0000062_072] notes that “4.6% of the potential universe of 5000 Skipton Fund beneficiaries” had received support from the Caxton Foundation. This report also states that “the following months will see the creation and implementation of a communications strategy to bring the Caxton Foundation to the attention of the Skipton Community”. Please explain:

- a. *what, if any, steps were taken to advertise the existence of the Caxton Foundation to recipients of Skipton Fund payments*
- b. *if the communications strategy mentioned in this report was created*
- c. *any barriers to communicating with recipients of Skipton Fund payments*
- d. *how successful the Caxton Foundation was at raising awareness of its work with Skipton Fund beneficiaries.*

145. My honest recollection is that Caxton was not very successful at this, mostly because of data protection issues (see my answer to question 99). We brought in one Trustee - Alan Rook – who had media experience, as I describe in question 93 above, but it did not result in a successful communications strategy. It was not until the Skipton Look Back exercise in 2014 that beneficiary numbers really grew. Though it's fair to point out that beneficiary numbers were increasing year on year so the message was getting out, but perhaps not as quickly or successfully as it might have done.

Question 97: The minutes of the Caxton Trustee Limited Board of Directors meeting 1 November 2012 mention a suggested plan to “contact the 12-15 Haemophilia Clinical Specialists in the country to help ‘advertise’ Caxton to their patients” [CAXT0000109_105]. Did this occur?

146. I cannot remember whether this was done. The minutes state that it was Professor Thomas who suggested it and was to take it forward.

Question 98: It was stated in the Macfarlane Trust/Caxton Foundation Liaison Committee meeting held 19 December 2012 that the “difficulties of identifying the beneficiary community and their needs, together with the Board’s plans to attempt to overcome the consequent deficiency in their knowledge” [CAXT0000068_010]. Please explain:

- a. *the difficulties of identifying the beneficiary community*
- b. *the deficiencies in the Board’s knowledge*
- c. *any steps the Board took to overcome this deficiency.*

147. The main difficulty was that we didn't have access to the Skipton database (see below). The only way to identify beneficiaries would then be to advertise in one way or another, so we tried to put information about Caxton on relevant websites that people might access. A national publicity campaign may also have worked as I set out above, but we did not have the staff or expertise to run that. We tried to recruit that expertise through the trust Board but it did not come to fruition.

148. I do not know if we ran these problems past the DH. Arguably the DH would have been well-placed, with its resources, to do more to publicise Caxton. I don't know how much CF really pressed the DH to do that.

Question 99: The minutes of the Board of Directors of Caxton Trustee Limited meeting held 7 February 2013 [CAXT0000110_003] state that "direct contact with people who had received Skipton payments, in many cases years previously, was thought to carry a significant risk of data protection and confidentiality breaches, and was therefore ruled out". Please explain:

- a. if the Caxton Foundation sought legal advice on the risk of potential data protection and confidentiality breaches***
- b. any communication between the Caxton Foundation and Skipton in relation to identifying eligible beneficiaries***
- c. if consideration was given to asking the Skipton Fund to contact their beneficiaries to inform them of the existence of the Caxton Foundation, or to request permission for their data to be shared with the Caxton Foundation***
- d. if you agreed with this decision.***

149. The easy way to identify beneficiaries would have been to go to everybody who got a Skipton Stage 1 payment, and contact them to inform them of Caxton. We were told that we couldn't do this because it would be a breach of confidentiality. There was a very strict separation in the records of the different charities, as I discuss in my answer to question 61. Over and above a general concern about data protection, there was a concern that because Skipton 1 was a lump-sum payment, there was no ongoing contact with recipients until the recipients happened to have been in touch with Skipton themselves. Skipton was set up in

2003; there was concern that if we wrote to people at the address Skipton held for them, given the passage of time we would be in danger of breaching confidentiality (for example, if a new home-owner opened a letter intended for the Skipton beneficiary).

150. I don't recall if we sought legal advice. I think the advice on confidentiality came from the Chief Executive Martin Harvey, who was also a Director of Skipton. I don't recall asking him if he took legal advice on the matter. There may have been communication between Caxton and Skipton, I can't remember. If the Inquiry wishes to draw to my attention to any particular communications I would be happy to comment on them. Caxton had a data protection policy which was agreed by the Board and reviewed periodically by the Audit Committee but I can no longer remember this in any detail.

151. I agreed that we could not pursue the Skipton database avenue, given all the concerns. This does beg the question of why the DH didn't undertake this exercise. Moreover, the DH later ordered the Skipton Look Back exercise, which was done by AHO staff, and it did lead to roughly 400-500 new beneficiaries coming forward. If it was done then, why couldn't it have been done sooner? I do not know the answer.

Question 100: The All-Party Parliamentary Group (APPG) on Haemophilia and Contaminated Blood report titled 'Inquiry into the current support for those affected by the contaminated blood scandal in the UK' [RLIT0000031] found "many people infected with HCV, in particular, reporting that they had never heard of the Caxton Foundation before completing the survey". Please explain:

- a. Were you surprised by this finding?***
- b. What if any steps the Caxton Foundation took to raise awareness in response to this finding.***

152. I was not surprised by this finding, because we clearly hadn't identified all the potential beneficiaries that were out there. I might be saying that with the benefit of hindsight, because I don't remember a reaction to it at the time. There would

have been a huge range of severity of symptoms of the virus, including people who may have been less badly affected and therefore not have done avid research into matters relating to Hepatitis C. They may simply not have seen details about us online.

153. By the time of the APPG survey the Skipton Look Back exercise had occurred so the problem was being addressed.

Question 101: The minutes of the Directors of Caxton Trustee limited meeting held 15 December 2014 [CAXT0000076_010] record that beneficiary numbers increased by 40% between 1 April 2014 and 11 December 2014. Please explain:

- a. the reason for this increase**
- b. if the APPG survey contributed to this increase**
- c. how the Caxton Foundation responded to this increase**
- d. if the Caxton Foundation approached the Department of Health for an increase in funding to correspond with the increase in the number of beneficiaries.**

154. The increase was mainly attributable to the Skipton Look Back exercise requested by DH. I don't know if the APPG survey contributed to the increase.

155. When DH advised Caxton that the Skipton Look Back exercise was going to be done Jan Barlow did ask DH what additional financial provision had been made for Caxton given the certainty that beneficiary numbers would increase. DH advised at that point that there would be no additional funding in that year. Later that year, DH raised the prospect of a possible decrease in Caxton's funding for 2015/16. See my answer to Q82.

Question 102: Do you consider that more should have been done (and, if so, what and by whom) to reach people who might have been eligible for assistance?

156. I am sure that more could have been done, particularly by DH given their resources. I think more could possibly have been done by Caxton through a

campaign to raise awareness, but Caxton itself was not resourced to do it. It might have been done in conjunction with the DH and I am not sure now why that didn't happen. It is fair to say though that the Board was alive to the issue of reaching our potential beneficiary community, but I just cannot remember now why exactly we did not, or were not able to do, anything more.

Section 9: Eligibility for registration with the Caxton Foundation

Question 103: Who set the eligibility requirements (i.e. what an applicant had to show in order to be accepted as eligible) for the Caxton Foundation?

157. I have answered all questions in this section referring to 'eligibility to register', rather than to the success of individual grant applicants.

158. The individuals potentially eligible for Caxton's support were listed in the Trust Deed of 28 March 2011 [CAXT0000095_006-4]. Setting eligibility requirements was a matter for the Trustee Board.

159. Support was defined in our trust deed as "financial assistance and other benefits to meet any charitable need". There was then a question of interpretation of what is "charitable need". The second meeting of the Trustee Board on 1st September 2011 considered a paper by the Chief Executive on Caxton's Welfare Strategy. The Board's key conclusions are set out in the minutes of that meeting (CAXT0000108_039). Caxton's purpose of meeting charitable need led to priority being given to the relief of poverty.

160. In addition, there were policy decisions taken at later stages about what we meant by for example "a dependent child", "a carer", "a widow", etc. We decided not to support children over the age of 18, or 21 if in full-time education (such that I remember we refused an application from the offspring of a primary beneficiary who was older and was living independently of their parents). Those kind of policy issues were taken through the NWC and the Board. In practice, they would be taken once we got a grant application from someone whose eligibility we doubted: we had to be clear why we were saying no, and be consistent in any future similar requests. The NWC would then formulate a

policy so that the office staff were clear about it and could update their Guidance, and that policy would be signed off by the Board.

Question 104: Were eligibility requirements written down? If so:

- a. Were any guidelines or policies publicly available or otherwise accessible to applicants? If not, why not?**
- b. Where or how could individuals access it?**

161. My recollection is that information about eligibility and a description of the application process were made available on Caxton's website. I also recall in 2012 being involved with the CEO and others in producing a Q&A document for the website [CAXT0000079_005-2]. There was a process document drawn up by staff to help them in processing applications to join [see CAXT000108_103-1]. I expect this was based on MFT registration as there appear to be some parts that have been copy-pasted.

162. Later on, Caxton produced a newsletter for its beneficiaries [example at CAXT000011_006-1].

Question 105: Were you, in your role, consulted about the eligibility requirements or otherwise involved in formulating them? If so, please provide details.

163. See my answers above. I was not consulted on how the Trust Deed was framed or on who was part of our community of care. As for eligibility requirements around matters such as who fell into the definition of dependent child, then yes I was involved in formulating policy as I describe above.

Question 106: The Inquiry understands eligibility to register as a primary beneficiary of the Caxton Foundation was registration with the Skipton Fund. Is this correct? Were there other eligibility requirements for primary beneficiaries, and if so, what were they?

164. That is correct. This is made clear in the Trust Deed of 28 March 2011. Eligibility for support from Caxton was then dependent on demonstrating charitable need.

Question 107: Did the eligibility requirements change over time and, if so, how? For example, were there periodic reviews of such requirements?

165. The Trust Deed was set in stone and did not change. But we did have to interpret the meaning of beneficiary (although not Primary Beneficiary) on occasions, as I have described above. I don't believe there were any periodic reviews, although we were always open to changing our minds. I guess if something had come up that made us change our mind, then we might have reviewed it, but I cannot think off-hand of an example.

Question 108: Please explain how eligibility and support for those who were not considered primary beneficiaries were assessed. In particular, please explain the eligibility requirements and support available to:

- a. partners**
- b. children and dependents**
- c. carers**
- d. bereaved.**

166. I find it hard to recall this in full detail. The first I would have seen of an application on the NWC was the paperwork with a cover-sheet from the office and the application itself. The cover sheet would include information about any previous grants given and a bit of information about income and expenditure. By the time it came to us the applicant had already been through the "eligibility" bit of it so we were not involved in that (unless it required a novel interpretation from us of something).

167. "Partners" was defined quite broadly in the Trust Deed, and appropriately so in my view. I can't remember whether partners applied in their own right. Mostly, applications for grants for partners or children came from primary beneficiaries. I do not know what evidence (if any) CF required to demonstrate that someone was a partner. For children, I believe a copy of a birth certificate was required.

168. There was always a question about what support we should provide to carers. I think we only ever provided for respite breaks.

169. As to what support was available: I believe the types of support were the same for everyone. For example, if you were a widow the kind of support you got might not have been very different from that given to a primary beneficiary – debts, bills to pay, funeral expenses, and so on. Both partners and primary beneficiaries received grants for clothing, and grants for household goods, repairs etc. would have benefitted everyone in the household.

Question 109: 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?

170. I don't remember any of significance, or if there were any at all. If you took the MFT trust deed and the Caxton trust deed side by side, you would see that the Caxton objects were modelled very much on MFT's. As time went on and we made decisions in Caxton about (for example) whether a child of a primary beneficiary qualified for support – it may be that the two positions diverged. If I remember correctly, the position on the eligibility of widows did diverge between the two charities as a result of a decision we took. I'm sure we would have taken account of what the MFT position was but that didn't stop us doing something differently. If the Inquiry would like to highlight any discrepancies then I would be happy to comment on them.

Question 110: 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?

171. There were occasions where a medical opinion was required to determine whether a particular grant should be paid. For example, for payments to people undergoing treatment, we would need confirmation of start and finish dates from the treating clinician. However, to decide whether someone was a Primary Beneficiary we didn't need medical evidence because that would have already been provided to get them the Skipton Fund money.

172. For the other categories of beneficiary, I'm not aware that we asked for any medical evidence or opinion. Their eligibility would have flowed from their relationship to a Primary Beneficiary.

Question 111: Who set the procedural requirements an applicant needed to satisfy before being accepted as eligible as a beneficiary for the Caxton Foundation? You may wish to refer to the Caxton Foundation Registration Procedures and Grant Processing Procedures [CAXT0000108_103]

173. The process of registering with Caxton (i.e. checking that the applicant fell within the definition of the Trust Deed), would have been managed by staff. I don't believe the Trustees had any role in setting that policy. The document mentioned is an internal document drawn up by the staff team, based on MFT documentation. It was not the job of a Trustee to ensure that the staff were doing basic operational work. This draft is clearly based on the process for MFT (and indeed one line even refers to MFT where it says NSSC). It's very much a process document drawn up by staff for use by staff.

Question 112: Why did the Caxton Foundation require beneficiaries to complete a census form? How was the information collected from the census used?

174. From recollection, the census data was used firstly to assess how many beneficiaries would qualify for support from Caxton on the basis of charitable need (so for more overarching purposes, enabling Caxton to plan and to understand its beneficiary base), and secondly to provide information to support individual grant applications. Again, I believe this was based on what was done in the MFT. If someone was on a very low income it made it easier for them to demonstrate charitable need.

175. When Jan Barlow became CEO, she questioned why Caxton needed detailed financial information from everyone if some payments, such as winter fuel, were not means tested. Caxton therefore moved away from an annual census and only requested detailed income and expenditure information from people submitting grant applications.

176. Although we moved away from an annual census, the value of having detailed information about a beneficiaries' income and expenditure situation remained. Caxton's annual report for 2014/15 makes the point that:

"Often the item for which support is being requested is symptomatic of a deeper, underlying problem, particularly in relation to debt, money management and accessing benefits. We have been able to offer people far more holistic support as a result of having information about household finances and therefore, even though we don't request this from everyone on registration, we continue to request this information as part of the grant application process".

Question 113: Were there discrepancies or differences in the procedural criteria between the different AHOs? If so, what were they and were these justified in your view? If not, did you raise this with anyone and, if so, who and when? What was the response?

177. I do not recall specific differences that I was concerned about. The registration procedure was based on MFT so I don't think there were any substantial differences. It is worth remembering that it was the same staff working on both MFT and Caxton processes, so they naturally adapted the processes from MFT to Caxton.

178. When we introduced the regular payments scheme, we decided to adopt a different scheme from MFT partly because we wanted to peg it to officially recognised poverty levels. A detailed assessment of the reasons we didn't follow the MFT approach is discussed in a paper Jan Barlow and I wrote for the Caxton board in August 2013 [CAXT0000110_047-4]

Question 114: Were the substantive eligibility and procedural requirements written down and publicly available? If so, where were they available and how could they be accessed by applicants? If not, why not? When answering this question please refer to the comments you made at the Board Meeting on 2 August 2012 [CAXT0000109_082] as to a view having to be taken as to what was appropriate to publish. What did you mean? What view was taken?

179. See my answer to question 104. My recollection is that eligibility and procedural requirements were available on the website.

180. As to my comments: I did not support the publication of the Office Guidelines as these were a reference manual for staff which set out, for example, a guide to the delegated amounts available for particular household goods. During my chairmanship of NWC, we gradually increased the level of delegated authority to staff to authorise payments without referral to NWC and the Office Guidelines were used by staff in these circumstances. Releasing the Office Guidelines may have been misleading as the amounts in the Guidelines were a guide for staff, not upper limits for grants that had to be rigidly adhered to.

181. I recall reviewing the website content following requests from some beneficiaries to publish the Office Guidelines and ensuring that the site included information on the types of grant available. I wanted to be sure that all beneficiaries understood the range of potential support available.

Question 115: As far as you are aware, did the Government have a view as to the publication of policies by the Caxton Foundation? If so, what was it?

182. I do not recall a view from Government on the publication of policies by Caxton. Our aim was to be as transparent as possible. If there was a view from the DH it is likely that it would have been “be transparent”, and we didn’t need to be told that as we already were.

Question 116: Were the eligibility requirements (both substantive and procedural) kept under review by the board of the Caxton Foundation? If so, how often? If not, why not?

183. This part of the Trust Deed was not changed and not kept under review. Those were the categories of people we were set up to support. Procedural requirements were dealt with as I have explained above (for example, abandoning the requirement to complete a census form).

184. What did change was the definition of things like when a widow would qualify,

when a child would qualify. These changes in policy were case-based as I have explained elsewhere.

Question 117: Were you aware of any concerns about or dissatisfaction with either the substantive or the procedural eligibility requirements for the Caxton Foundation? If so, what were these and what did you/the board do in response?

185. I was aware of concerns expressed by some beneficiaries about the perceived intrusiveness of questions about the financial status of beneficiaries, and the bureaucratic nature of the process. However, although this was unfortunate, these questions were necessary to establish charitable need. I am aware that staff would help people out if they found the forms burdensome.

186. I am not aware of any complaints about the substantive eligibility requirements. There were no categories of people who came forward and complained that they weren't eligible. The Trust Deed was pretty comprehensive there.

187. As to procedure: there were issues around delays in making a decision on individual grant applications. I am not aware of any complaints or delays about the procedure concerning eligibility to register.

Question 118: 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 for the Caxton Foundation. Relevant matters include:

- 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; and**
- f. Any time limits or fees for the bringing of a review or appeal.**

188. I do not recall any process relating to whether someone qualified as a primary beneficiary as this depended on whether they were in receipt of Skipton Fund payments. As for other beneficiaries, the Board took a view on (for example) the eligibility of dependent children but there was no appeals process against such policies nor was that put out for consultation. It was simply taken by the Board, usually when an individual grant application was received.

189. There was a route to appeal against refusals of a grant application (I discuss this at questions 166 and onwards below) – and if we had refused a grant on the grounds that the applicant was not even eligible to receive Caxton assistance in principle, the applicant could use that appeals route to explain why they in fact should be treated as eligible. We were willing to treat each case on its own merits – nothing was hard and fast, all things looked at on a case by case basis. We tried to avoid being overly bureaucratic.

Section 10: Decisions on substantive applications within the Caxton Foundation

The process

Question 119: Please explain who made decisions on applications for the Caxton Foundation and how this changed over the time you were involved. In particular please explain:

- a. When, if ever, staff employed by the Caxton Foundation 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) decisions on individual applications were made at board level and why?***

190. The Board decided that decisions on applications for grants to the Caxton Foundation would be determined either by the NWC using criteria/principles agreed by the Board, or delegated to staff following set principles.

191. Membership of the NWC was decided by the Board, initially at the Board meeting held on 1st September 2011. People volunteered for positions, and I volunteered to be on the NWC as I thought it was important work and central to our mission. For people in full time work it was not an easy committee to be on – it met frequently and generally during the working day, and the meetings could be quite lengthy, if we were going through say 30 grant applications. A lot of preparation time was also needed as well as being able to respond quickly to ‘round robin’ requests. Meetings of the NWC therefore were often just two of us for that reason.

192. I was a member of the NWC from September 2011 to March 2014 and Chair from March 2012 to March 2014. Mostly applications were sent around the NWC in advance so we would read them before the meeting. They were sent with a cover sheet completed by office staff (including what previous grants a person had received, income and expenditure, any other important information) and for each grant application the form that had been completed by the applicant. The applications were anonymous in that we were not provided with names, although there were people who made more than one application who became familiar to us by their circumstances. The cover sheet included details of previous grants so that we knew the history of support. For example, if we were supporting someone with debt relief it would be helpful to be reminded that we had provided them with £X amount 6 months ago, which might suggest that there was an ongoing problem. It might also illustrate dependency, so it enabled us to get a feel for them and their situation.

193. We would then determine the grant requests at the meeting. We also had grant requests tabled at the meeting. That might happen where the request had not been fully processed but was too urgent to wait for the following meeting

194. The NWC met initially every four weeks but this was changed in 2012 to six-weekly (see [CAXT0000109-82]). That was because of the turnaround time that the staff needed to process the requests and get them to us. For further explanation, see my response to question 120.

195. The NWC reported to the Board. There was a scheme of delegation agreed by the Board. This was clarified at the NWC meeting on 17 February 2012. At that date, NWC could agree up to £10K per case; over £10K and under £50K, the case had to be referred to the Chair of the Caxton Foundation for agreement; anything over £50K had to be referred to the full Board for agreement. We did revise the delegations from time to time.
196. Over the period of my involvement and beyond, the level of delegation to staff to make decisions on individual grant applications gradually increased as some types of request became more routine and Trustees were satisfied on consistency of approach. For example, initially all requests for support for people while they were undergoing treatment and couldn't work came to the NWC. Once we had seen a number of those cases, we determined that unless there were unusual circumstances such applications could be processed by the office. Respite breaks were another category of request that NWC agreed could be processed through the office without reference to NWC. The advantage of this was decisions on grants for which there was an established process could be taken much more quickly. Delegations were also agreed that enabled the CEO to agree urgent requests. For example at the NWC meeting on 23 May 2013, we agreed that in future bereavement grants could be authorised by the CEO (CAXT0000083_001-1).
197. The aim was to speed up the time taken to process applications, because it was far too long in the early days. By the end, we certainly managed to get a much quicker turnaround for all applications. By 31 March 2015, the average turnaround time for NWC grants was 10 days and the average turnaround time for grants approved by staff was 4 days.
198. Very occasionally, the Board was asked to take a decision on individual grant applications. These were usually individuals with a history of making (increasingly) contentious grant applications where NWC felt that a view from the full Board was merited (See also my answer to Q107). There are not many examples of this, they were few and far between. One example is of an applicant

who had a debt problem which they had received funds from us on a number of occasions to service, and then it became clear that they had a very large asset which, if sold, would solve their financial problems, and it seemed reasonable to us on the NWC that they sell it. So there came a point where we questioned whether we should continue giving money to this applicant. That was the kind of question we would put to the Board – often where we were minded not to grant money, rather than where we were minded to grant it.

Question 120: Please explain the use of 'round robins' to make decisions on grant applications. In particular:

- a. the circumstances under which a decision was made via round robin rather than in a NWC meeting;**
- b. how the authority to make decisions in this way was delegated;**
- c. if decisions were given the same level of consideration when taken via a round robin.**

199. The term 'round robins' referred to decisions on urgent grant applications taken by the NWC via email between meetings. These were essential to deal with urgent requests which could not wait for the next NWC meeting. The decision on what to ask the NWC to consider as a round robin was taken by Caxton staff using their initiative based on the urgency of the request. When the NWC moved from 4-weekly to 6-weekly meetings, the number of round robins increased. In a month we might receive 6 or 8 round robins. The authority to make decisions by round robin came from the NWC and ultimately the Board.

200. I am confident that decisions taken in this way were given the same level of consideration as in face-to-face meetings.

Question 121: In an email to Nicole Hornby dated 3 June 2016 you stated "If you need a more urgent decision, I am happy for you to go ahead with what Richard and Vijay have decided" [CAXT0000118_142]. How often were urgent decisions made without all NWC members reviewing the content of the cases?

201. I don't recall the circumstances of this case. However, as chair of the NWC, I

had confidence in the judgement of my colleagues on the committee. In this case, I clearly took a pragmatic decision that it was potentially more important for Caxton to respond to an urgent need than wait two days for my input.

202. I can't say how often urgent decisions were made without all NWC members reviewing the content of the case. The quorum for the NWC was two Trustees so that was the minimum. As the NWC minutes show and as I have explained at question 119 above decisions were often taken by two Trustees taking account of the criteria that had been agreed by the whole committee.

Question 122: You may wish to refer to the report by you to the Caxton Trustee Ltd Board meeting 1 August 2013 regarding NWC Case: Loan Taken Out by a Widow[CAXT0000110_167].

a. How regularly were the NWC unable to reach agreement on specific cases such as this?

203. This referral was not because the NWC were unable to reach agreement. Without going into detail on the specific case, this was a rare example of a beneficiary who NWC had supported over some months but required a view from the Board on continued support as it was felt that charitable need could no longer be demonstrated. Such cases were rare – I can think of only one other in my time. So, it was not about not being able to reach agreement, it was about the application raising bigger issues that required full Board approval.

204. In the early days we would sometimes feel that not enough information had been provided to decide the application, and so we deferred it. As a result of that, I worked with the staff team to improve what people were asked to supply, especially in applications that concerned debt. But I don't recall any occasion on which the NWC had all the requisite information but couldn't agree among itself.

Question 123: Please explain whether the Caxton Foundation developed written or unwritten policies for the determination of applications. If so:

- a. Who developed these?**
- b. Were they publicly available? If so, where were they available?**
- c. Was any expert (medical or other) advice sought to inform those policies? If so, what advice? Please give examples.**
- d. Were the views of the beneficiary community taken into account when setting the policies? If so, how was this achieved? Please give examples.**
- e. Please describe the policies.**

205. From the outset, Caxton established a set of principles in order to meet the needs of as many beneficiaries as possible. This developed over time but are well articulated in the document CAXT0000101_007-1. A later principle was that we would not offer funding for something to one person that we could not offer to everyone.

206. At its first meeting on 21st September 2011, the NWC agreed to recommend to the Board that “priority would be given to beneficiaries and families with an income not exceeding £14,000 per annum gross” (60% of median income, the official government property threshold). This was because it was not clear how many people would come forward for support and Caxton wished to focus its support on those most in need. However, in practice it was never necessary to apply this and was it was eventually dropped. Another example of a policy concerns the calculation of household income. On 1 November 2012, the Board decided to exclude means tested benefits, e.g. DLA, child benefit, carer’s allowance and Council Tax benefit, in determining household income.

207. As for other policies, the NWC developed policies in a case-law type fashion, as I have described above. Policies were formulated as we saw applications dealing with similar themes and wanted to treat them consistently. For example, the NWC meeting on 20 November 2014, reviewed the policy on support available for older children of beneficiaries and concluded that “those over 18, and those over 21 once they have finished full time education, are adults in their own right and that it is not the intention of Caxton to support adult children of primary beneficiaries.” (CAXT0000110_148-1). They were recorded in the

minutes and I think those policies would have made their way into the office guidelines. We also produced information for the website, which I was involved in, where we would say “these are the kind of things we can provide”. These policies would appear in the FAQs/helpful information; there was no option to “click here to download our policies”.

208. I can't think of any issue on which we ever sought expert medical advice, save for that if someone wanted something relating to medical care, one question might be: is this related to Hepatitis C? At first we were inclined to refuse grants where there was no medical connection to Hepatitis C, but later on we rethought it a little bit and decided that the need did not need to be connected to the disease.

209. We did not consult beneficiaries in setting these policies. The Partnership Group was obviously established to allow them to contribute to Caxton overall.

210. It was not a policy per se, but we had a broad test of reasonableness in assessing “charitable need”. When an application came in, there would be a judgement on each one on whether it was something they could afford to buy themselves and whether it was a luxury. For example, if someone's income was £10,000 more than their expenditure, why would they need £200 to buy a piece of household equipment? The item requested needed to be broadly a necessity (or at least not frivolous or a luxury), and secondly broadly something that they'd struggle to pay for themselves, generously interpreted. For example, if someone asked for say £1500 to buy a sofa, we might think that was expensive even for a decent sofa, so we'd award £500. This was not a written policy as such, just a view taken case by case.

211. Policies on other things were developed as I have described elsewhere in this statement. For example, we developed a policy that we would provide financial support when people were undergoing treatment and thus unable to work. We developed a policy that the need did not need to be connected to Hepatitis C, etc.

Question 124: Please explain your role in drafting guidance on the information required before a case would be considered by the NWC. You may like to refer to the minutes of the Caxton Foundation NWC meeting held 19 April 2012 [CAXT0000072_001].

212. As mentioned previously, I was concerned to ensure that beneficiaries were given guidance on the information needed by NWC in order to consider a grant application. There were, I recall, too many instances in the early days of decisions being deferred pending requests for further information. That was frustrating for both the beneficiary and for us, so it was important that beneficiaries understood what NWC wanted to see. I think these minutes refer to work I did with Caxton staff to improve the guidance given to beneficiaries to improve the quality of grant applications. That guidance would have gone on the website and may also have been sent to people directly, I'm not sure.

213. To illustrate this, there are examples at CAXT0000069_004-1 and AHOH0000071-1 of guidance issued on the grant application process and how we expanded it to assist beneficiaries. The first looks like it dates from the start of Caxton, the second is from August 2012,

Question 125: 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 the procedural requirements reviewed? If so, by whom and how often? What were the outcomes of those reviews?**
- c. Were you aware of beneficiaries who were unable to satisfy the procedural requirements such as providing supporting documentation? What if any adjustments or provision were made for determining such applications?**

214. Without having a copy of what we sent out it's hard to answer the question and I am having to do so from memory. There was a form that applicants had to fill in. That was set by the staff team, initially based on what was done for the MFT.

215. There was no formal burden and standard of proof. What we required of an application would vary according to what was asked for and whether, for example, we already had the census data on people's financial circumstances. If an applicant wanted money for a service then there was a requirement for them to come back with two or three quotes, or if they wanted something like white goods then they should send examples of things they would like, in the form of a catalogue photo or similar. For applications on debt, we would want to know a lot more about the debt they had incurred, how much was owed and what the payments were. The burden of proof was essentially on the applicant – they had to show what they wanted, why they needed it, why they couldn't afford it and what it costed. Obviously the same standards had to be applied to everyone.

216. There was no formal or recurring review of these requirements. However, in early 2013, we did take a fresh look at the way in which Caxton issued grants and the type and frequency of information we requested. As part of this, I contacted other grant giving organisations focusing on the relief of poverty among their beneficiaries, including the RCN Foundation and the Royal Medical Benevolent Fund. One of the outcomes was the decision, mentioned earlier, that we didn't need the annual census and could use an application form instead.

217. As for people who couldn't satisfy the procedural requirements: I can't remember individual cases. I expect there were some. I think if people came to us and said "I can't provide this because I'm too ill to obtain the information" then we would have taken account of that. We would have looked at this on a case by case basis and I hope we would have given people some leeway. There were perhaps some beneficiaries who saw a matter of principle in this and felt that they shouldn't have to provide estimates of something. Again, if the Inquiry wishes to draw my attention to specific documents then I can comment further.

Question 126: The minutes of the NWC meeting held 12 July 2012 record that "the Committee have reservations with regards to publishing the office

guidelines for distribution to Caxton beneficiaries” [CAXT0000089_002]. It is also noted in the minutes of the Caxton Trustee Limited Board of Directors meeting held 2 August 2012 [CAXT0000109_082] that “Mr Lister explained that there needed to be a prior clear decision as to what was appropriate to publish”. Please explain:

- a. the reservations the Committee held about publishing the Office Guidelines***
- b. the “major editing” required before publication [CAXT0000089_002] that would refer to the maximum amounts of money***
- c. if the Board shared the NWC reservations.***

218. Please see my response to question 114.

219. The editing would have been to remove the guide on maximum sums of money available for items such as household goods. We wanted people to apply for what they felt they needed, not be influenced by sums which were a guide for staff. NWC also had discretion to award higher grants than those in the guidelines, so for that reason as well, I was concerned that publication could be misleading. There was also a concern that if we published that, some people would see it as a “shopping list”. We wanted to be fair to everyone and for people to apply only for what they felt they needed.

220. The Board did share these reservations.

Question 127: What proportion of applications were granted (wholly or in part) and what proportion were refused?

221. I don’t have this information and of course cannot remember now given the passage of time. The minutes of the NWC will record decisions that we took as a Committee in meetings (although not round robin decisions or those taken by Office staff). To begin with I think we deferred more and sought more information. Once the guidance about what we needed was clearer, I believe we deferred fewer.

222. I did a quick analysis from the NWC minutes for the first two years to test my memory, and this clearly shows a trend towards more grants agreed and fewer decisions deferred. This does however exclude decisions taken by the Office which are not recorded in the minutes.

Question 128: Were reasons for refusing an application provided to an unsuccessful applicant?

223. To the best of my knowledge, reasons were given but as this process was managed by the staff team I cannot vouch for this on all occasions.

Question 129: Was there a procedure in place to consider applications made on an urgent basis? If so, what was that procedure? If not, why not?

224. The usual procedure was the 'round robin' where NWC members were asked by staff to make a decision via email. Staff sometimes contacted me by phone if a decision was needed especially quickly. The Chief Executive also had discretion to take decisions in an emergency. For example, the NWC minutes of 13 December 2013 (CAXT0000097_005) records payments made in this way to help a beneficiary awaiting benefits, as recommended by Jayne Bellis, and one to help a beneficiary with their gas and electricity meters as recommended by Neil Bateman.

Question 130: What practical support or assistance was given to applicants to help them in making applications?

225. This was the role of the staff team. I think the staff team were pretty good at this. In some instances, the staff went and did home visits, if people had real difficulty (for example, one applicant had had treatment and was suffering from brain fog – a common side effect of treatment – and that person needed a lot of support with an application and received a home visit). The staff were also available on the phone and fielded questions about applications (including procedural questions). As mentioned, I was concerned as a Trustee that applicants were given guidance to help them through the process.

Question 131: What evidence was each applicant expected to provide when making a grant application? Please refer to the report and supporting documentation for a request for clothing and financial assistance to the NWC dated 7 November 2013 [CAXT0000088_045]. Please explain:

- a. if the extent of the information requested here was usual for such an application**
- b. if you believed two quotes for a £75 razor were necessary**
- c. If the Caxton Foundation had a mechanism in place to reduce the administrative burden on applicants undergoing treatment for serious medical conditions. If not, why not?**
- d. why applicants were required to provide further details of their income for an application when they had already submitted a 'means tested' form and provided details of their income (see p.30)**
- e. if any changes were made to the level of supporting information required before the NWC would consider a grant application.**

226. I am obviously concerned to maintain the privacy of the individual concerned in [CAXT0000088_045] and my answer relates to the documents that have been provided by the Inquiry rather than from my recollection of the specifics of this particular case.

227. Yes, the level of information requested here was usual. It wouldn't have been intended to be onerous, but two quotes or copies of adverts or links showing the prices was generally required or as estimate of their cost. We would have just wanted to know what the applicant wanted and how much it was going to cost, and of course we had our own obligations to ensure that money was given out appropriately.

228. The anonymised case contained in the documentation appears to be somewhat complicated. The request was for various items of clothing for the applicant and his wife, but also a request for income support during treatment, but he had not provided any details of the income he was losing. The applicant was suffering from a medical problem that was unrelated to Hepatitis C, and we did initially

want a medical view on whether this condition was related to Hepatitis C. He was clearly reluctant to ask the doctor for the letter, so we said that he should send us a letter from hospital simply with dates of treatment. So it seems that we had already decided not to require that the illness be connected to Hepatitis C.

229. Unfortunately, from the documentation provided, it appears that he had not set out any justification for any of the material things he wanted, and he had already bought the razor (we did not ordinarily consider retrospective requests for things that were not urgent, since it would appear that the applicant was able to afford it from their own funds to have bought it). It seems that we paid for the razor notwithstanding, and we asked for evidence regarding the other aspects of the request. We applied the same rules to everyone and it didn't seem as if there was a particular reason not to with him. I cannot provide an outcome for the request as the reference number has been redacted in the documentation I have received.

230. We did not require anyone to make long round trips for the purpose of obtaining quotes – something from a website would have sufficed. I am not sure why in this case the applicant did not simply provide this.

231. We dealt with things case by case. We could take a pragmatic view if someone was struggling, or would struggle, with providing evidence. But we still needed basic information in order to take any decisions. A request that simply asked for support while undergoing treatment was not enough to make the decision. Other applicants were able to provide it with no difficulty.

232. As to (d), I don't know whether we were still receiving the census by this stage, I wonder if it had already stopped by then. For applications of this nature, we needed evidence of income likely to be lost during treatment, which is different from general evidence of earnings.

233. As to (e), I cannot remember in much detail. When I chaired the NWC we changed our approach to discretionary grants quite a lot. We introduced a

payment for people undergoing treatment, and initially we looked to see whether their poverty could be linked to Hepatitis C but we later dropped it because it seemed to me irrelevant and impossible to prove.

234. This case led to a policy change. At the Caxton Board meeting on 19 November 2013, it was agreed that. "Following review of a recent case where a client was receiving treatment for something that was not specifically hepatitis, it had been agreed that support could be given even when treatment was not as a direct consequence of hepatitis C".

Question 132: Was there a procedure in place to ensure consistent decision making on grant applications? You may wish to refer to the minutes of the Caxton Foundation National Welfare Committee meeting held 15 December 2011 [CAXT0000063_001]. In particular, please explain:

- a. your request for "obvious inconsistencies" to be emailed to the NWC for consideration**
- b. if many inconsistent decisions identified**
- c. how inconsistent decisions were remedied.**

235. These minutes reflect a concern of mine early on to ensure consistent application of the principles and procedures adopted by Caxton. NWC were best placed to monitor this and we did this routinely at meetings through the questions we put to staff. I cannot recall any specific inconsistencies but it might be if for example two different applicants were awarded different amounts by NWC or staff for a sofa when there was no real difference between the two.

236. When deciding applications, we Trustees would seek guidance from staff on what we had awarded other people in the past for similar items (although that did not preclude there being a specific reason to give someone more). Indeed, the trend was toward increased consistency, which gave NWC the confidence to delegate more decisions on grant applications to staff.

237. The Office Guidelines would be the first line against inconsistencies – it set out

maximum amounts and amounts over time (for example, a grant for moving house could only be given once every seven years, although that did not preclude the NWC stepping in and making a moving-house grant more frequently if the applicant explained why).

Question 133: Please describe:

- a. What regular payments were made to beneficiaries and how they were assessed/quantified.**
- b. What lump sum payments were made to beneficiaries and how they were assessed/quantified.**
- c. What payments or grants were made for specific expenses or items and how they were assessed/quantified.**

238. The first regular payments scheme for beneficiaries was introduced in 2014/15 after an initial business case for additional funding had been rejected by DH. Initially we wanted a scheme that took beneficiaries to 80% of median income taking account of the increased cost of living with Hepatitis C. However the DH turned that down. We then devised an affordable scheme, which still provided additional income for Caxton's poorest beneficiaries but was less generous than we would have liked. I have said more about this in my response to Qs 161 and 162. Because of the time needed to devise a new scheme, we were not ready to make payments until the end of the 2014-2015 financial year. Recipients therefore received a lump sum backdated to the previous April. We told beneficiaries that the decision would be taken year on year depending on Caxton's finances, but the intention was that it would be a monthly payment. I left Caxton shortly after.

239. We also made regular payments when people were receiving treatment, although they were time-limited (so they were regular but had an expiry date). Treatment for Hepatitis C was punishing and lengthy and would prevent beneficiaries from working. We were particularly keen to avoid situations where people were deterred from agreeing to treatment because of the financial implications. NWC therefore agreed time-limited monthly payment for people in

this situation. These might last four or six months for example depending on need and I recall occasionally agreeing to backdate payments. We would however need information from beneficiaries on loss of income and additional costs related to being on treatment such as travel costs and any special dietary requirements. We made a decision that we would not replace an unlimited amount of lost earnings since that did not seem to be charitable need or the best use of our funds.

240. In addition, a winter fuel payment was made as a lump sum to Caxton beneficiaries. This was initially given out by NWC to poorer beneficiaries but later to all of our registrants and not means tested. I cannot think of any other regular or lump sum payments.

241. A large number of grants were made for specific expenses or items. I cannot list all of these but the main ones were:

- financial support whilst beneficiaries had treatment for Hepatitis C to ensure that the prospect of loss of earnings and additional costs associated with the treatment, such as travel, did not deter them from opting for treatment
- respite breaks for those with Hepatitis C and their spouses/partners/carers
- support with debt and money management, including referrals to Caxton's specialist debt counsellor and benefits adviser
- health and mobility-related repairs and adaptations to beneficiaries' homes
- financial assistance with the purchase of essential household items and clothing
- support with vehicle maintenance costs to ensure beneficiaries could retain their mobility and independence
- support with the cost of re-training and essential equipment for setting up in business, to help beneficiaries recover their financial independence

242. By "how quantified", I assume this means "how did we decide how much to award": if things came to us it meant that they were beyond the Office Guidelines amount, or sufficiently novel, and so we considered things on a case by case basis. We would reach a view based on the person's financial circumstances,

the quotes/adverts showing the price of the item provided, what we had provided to others (for consistency) and a general catch-all of “reasonableness”. As discussed elsewhere, we did not award grants that we would not in principle have been able to award to all applicants (i.e. if the amount sought was simply too high).

Question 134: 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 fund?

243. Each grant application was considered on its merits. I cannot recall any occasion in my time where a grant was declined purely because of its impact on the fund. I cannot remember a circumstance where it felt like we couldn't provide a grant because we would go over-budget. See my answer below for more detail.

Question 135: Did concerns around beneficiary dependency, or the frequency of applications made by beneficiaries, impact on decision making on individual grant applications? You may wish to refer to email correspondence [CAXT0000125_060] re: Round Robin-Unit travel and living costs where you reference “the dependency issue”.

244. There were instances of people who applied for grants constantly where dependency was a concern. If someone was asking for things on a regular basis it might indicate that they had a bigger financial problem that we needed to be aware of. We might have been able to help further, such as with debt relief or by referring them to Jayne Bellis for financial advice to help them tackle the underlying problem. I explain more about dependency in my answer to question 157.

245. Repeated applications also raised a question of fairness. We were concerned that if people were constantly asking for things, they might think we were there to provide for every need of every level, whereas we were there to help them through bad times and not to supplement their everyday life. We also didn't want the levels of assistance provided to vary depending on how ambitious the

applicant was in their requests.

246. If the applicant had already had £3000 awarded through the office that year, then the application would be referred to the NWC. That was in the Office Guidelines. I don't know if that stipulation was known to beneficiaries; it was inherited from MFT.

247. From the outset, we decided not to fund ongoing costs, since they were effectively regular payments by default. For example, we didn't fund the cost of sending a car for an MOT, because that was an ongoing cost. We would however fund repairs arising from the MOT. We didn't want to create an expectation that beneficiaries would get money for ongoing costs every year.

248. One of the attractions for me of the regular payments scheme was that it would give people more choice about how they spent their money. Taking people above the poverty line would reduce their need to come to us. It would be less burdensome and uncomfortable for them and allow them a greater degree of control and choice.

Question 136: Who set the level of payments to beneficiaries? How was the level of payments set?

249. Applications from beneficiaries were looked at on a case by case basis. Requests for household items were looked at in relation to the Office Guidelines which we inherited from MFT. But other payments, such as for debt relief, were decided on their merits. Quite often, for debt relief requests we would provide what Jayne Bellis had proposed – she would say for example “I have negotiated the debt down to this level, if you provide X amount they should be able to manage the rest of the debt”. Jayne was helpful because she would come up with a plan for the beneficiary and the lender, as well as often reducing the debt, although of course the final decision of whether and what to award lay with us.

250. Before Jayne got involved it was perhaps a little more based on what felt reasonable to us, based on their income and level of debt, and what we thought they stood a chance of repaying. I think we were usually fairly generous on debt,

and it was rare that we didn't provide some debt relief when asked.

Question 137: Did the Caxton Foundation consider the amount of money previously given to an applicant when determining each application? If so, why?

251. The paperwork the NWC received would tell us what had previously been paid to an individual. It was helpful to know what they had received already, otherwise we would receive applications without any previous history and so this gave a more complete picture of their circumstances. Applications were determined on their merits, so receipt of money on previous occasions would not necessarily be relevant. However, occasionally we would take previous history into account if it was beginning to feel excessive. A series of grant requests might indicate that the applicant was struggling to live within their means. We might consider a referral to a debt specialist in such circumstances. For example, one beneficiary applied to carry out some minor work on his house, but the Committee noted from his application that his expenditure greatly exceeded his income, he was in credit-card debt and he was frequently applying for grants. We therefore felt that a referral to a debt counsellor would assist, although in his case we agreed the grant regardless.

Question 138: Why did the Caxton Foundation have to reduce its support to beneficiaries in 2014? What was the level of reduction? What caused this? How was the decision made? What if any representations were made to the Government to increase funding? What was the response?

252. In 2014, Caxton saw a large increase in beneficiary numbers due to the Skipton Look Back exercise. However, to the best of my knowledge, this did not lead to reduced support for beneficiaries. Because of concerns about rising beneficiaries, the Board initially awarded a reduced winter fuel payment of £350 (from £500 the previous year to all beneficiaries) but a further £150 was paid before the end of the financial year when it became apparent that we could afford it.

253. I'd be happy to review my answer if the Inquiry provides me with documentation

which makes clearer what reduction in support is referred to.

Question 139: Please explain the process followed when amending the Office Guidelines. In particular, please explain:

- a. any evidence used to support decisions**
- b. any consultation on potential amendments.**

254. The process for amending the Office Guidelines was through the NWC. Examples can be found in the NWC minutes. For example, on 6 March 2013, the NWC added grants for televisions and microwaves which were not in the Guidelines inherited from MFT. This followed receipt of applications asking for these, and our view that these were reasonable items to want in the home.

255. The only evidence we used was the understanding of beneficiary need that we had developed as a Committee, we certainly didn't commission external evidence. We didn't hold any consultations about potential amendments. However, we did review comments and suggestions made by the Partnership Group. For example, on 21 August 2014, NWC decided that requests for respite breaks for carers could be processed through the Office Guidelines without reference to NWC to speed things up. This was after the Partnership Group raised concerns about the time taken to process requests for respite breaks for carers.

Question 140: Please explain the decision to remove support for assisted conception in 2013. You may wish to refer to the minutes of the NWC meeting held 6 March 2013 [CAXT0000081_002].

256. I don't recall exactly. I think it was that assisted conception was in the MFT guidelines because that dealt with people who had contracted HIV as a result of infected blood, and conceiving naturally was too risky for their partner, so assisted conception was an appropriate thing to offer. However because Hepatitis C is not commonly sexually transmitted, that justification did not apply to our beneficiaries.

Retrospective grant policy

You may wish to refer to the following documents to respond to this section:

- I. Caxton Foundation Office Guidelines 2012 [CAXT0000062_076]**
- II. Caxton Foundation Office Guidelines 2014 [CAXT0000103_005]**
- III. Transcript of the Caxton Foundation Partnership Group meeting held 28 November 2013 [CAXT0000110_094]**
- IV. Minutes of the NWC meeting held 6 March 2013 [CAXT0000081_002].**
- V. Minutes of the Caxton Foundation NWC meeting held 13 December 2013 [CAXT0000097_005]**
- VI. Report from the Caxton Foundation Chief Executive and Director of Operations to the NWC 10 December 2015, re: retrospective policy in medical related cases [CAXT0000046_005]**

Question 141: Please describe the Caxton Foundation retrospective grant policy, in particular:

- a. the circumstances that led to a change in policy**
- b. if there was consultation on potential changes to the policy, and if so, with who**
- c. if there was an explanation provided to beneficiaries on the “exceptional circumstances” where retrospective grants may be agreed**
- d. how this policy was communicated to beneficiaries**
- e. if there was written guidance for the NWC to apply when exercising discretion in relation to retrospective grants.**

257. At the outset, Caxton gave retrospective grants in recognition that people had been expecting Caxton to start its work and it was not unreasonable that they might have made purchases and expected us to reimburse them. However, as time went on we did not think it was reasonable for people to buy something and expect us to pay for it (unless there was a specific urgency, such as emergency home repairs and grants for funerals). If expenses had already been met, it was hard to demonstrate charitable need, which was of course a legal

requirement on us. We were a grant-giving body; one wouldn't normally assume that a grant had been agreed and come in retrospect. In March 2013, as part of its review of Office Guidelines, the NWC decided that no retrospective grants should be paid for the period before October 2011. In November 2013, NWC observed that whilst retrospective grants had been appropriate in the early days of the Foundation, there was now no reason why people couldn't apply in advance. From then on, the Committee only considered retrospective requests in exceptional circumstances. We did not consult on this change in policy.

258. I don't recall how this was communicated to beneficiaries. Some objected so there was clearly awareness of it.

259. There was no written guidance that I can recall on exceptional circumstances for the NWC— that would be hard to do by its nature. As to explanations to beneficiaries – I am sure that it was on the website that we would not normally grant retrospective claims except in exceptional circumstances.

260. We did sometimes backdate payments to people undergoing treatment, as a broad exception to our policy against retrospective payments. We might do this because for example the applicant had only recently learnt that we offered such grants, as this was something we only offered part-way through my time in Caxton.

Loans policy and debt support

You may wish to refer to the following documents to respond to this section:

- i. Minutes of the Caxton Foundation National Welfare Committee meeting held 15 March 2012 [CAXT0000071_001]***
- ii. Report by Charles Lister to the Caxton Trustee Limited Board of Directors meeting 3 May 2012, re: addressing beneficiary debt [CAXT0000109_029]***
- iii. Minutes of the Board of Directors of Caxton Trustee Limited meeting 3 May 2012 [CAXT0000109_010]***
- iv. Report to the Caxton Trustee Ltd Board meeting 2 May 2013***

[CAXT0000110_015]

- v. ***Minutes of the NWC meeting held 23 May 2013 [CAXT0000083_001]***
- vi. ***Report by Charles Lister to the Caxton Trustee Ltd Board meeting 1 August 2013 regarding NWC Case: Loan Taken Out by a Widow [CAXT0000110_167]***

Question 142: Please explain any consideration given to the Caxton Foundation issuing loans to beneficiaries.

261. We did not get many requests for loans. From recollection, we did not want to go down the business of loans, which by their nature require arrangements for repayment, preferring to focus on grants and other support.

262. We were aware that MFT had issued loans and had difficulty obtaining repayment. We saw no point in putting this strain on beneficiaries or staff.

Question 143: It is noted in the NWC minutes 15 March 2012 [CAXT0000071_001] that the Macfarlane Trust Loans Policy was “not appropriate for the needs of the Caxton beneficiaries as beneficiaries were asking for assistance towards repaying their debts not asking for loans from Caxton”.

- a. ***Where did your information about the Macfarlane Trust’s policy of issuing loans to beneficiaries come from?***
- b. ***Did the Caxton Foundation issue loans for debt relief? If so, why in your view was it appropriate to grant loans for the relief of debt, and not otherwise?***
- c. ***Did the Caxton Foundation receive requests for loans from beneficiaries?***

263. Information on the MFT’s loans policy will have come from staff – the same staff team managed both Caxton and MFT.

264. Caxton’s focus on debt relief was to help people out of debt. We gave grants to help pay off debt. I don’t recall us making a loan for this purpose.

265. We did receive occasional requests for loans – for example a loan to purchase a property, a loan to start a business – but they were infrequent.

Question 144: Please explain how the NWC decided the general approach to debt relief as contained in the report dated 3 May 2012 [CAXT0000109_029]. In particular:

a. any consultation on this approach

b. if the approach was communicated to the beneficiary community.

266. In Caxton's first year around a third of grant applications were for relief of debt. Some levels of personal debt were substantial. From census data, it was clear that many people would have difficulty clearing debt and avoiding debt in future. Caxton staff had attempted to negotiate down debt in some cases. But the problem was such that NWC obtained Board approval to recruit an independent money management adviser to work with beneficiaries in managing debt. The role was advertised for both Caxton and MFT. Jayne Bellis was recruited, having among other things demonstrated her empathy with beneficiaries in this position.

267. Jayne was successful in working with beneficiaries and lenders to negotiate down or consolidate debt. This enabled Caxton to write off an element of debt having confidence that there was a plan in place for the beneficiary.

268. In the majority of debt relief requests, it became a condition of Caxton that beneficiaries looking for relief from debt would need to work with Jayne Bellis or at least provide evidence that they had taken advice from a money management provider (see CAXT0000110_150-5). That was because we felt that there was a risk of recurrent debt. We recognised the helpfulness of Jayne's work – many beneficiaries needed help with managing their debt that went beyond simply paying off part of it. One could see from their level of income and expenditure that they would simply fall back into debt, and we wanted to get them out of that situation altogether. For some it seemed high-handed and some people refused it. There were one or two circumstances where we refused grants because of

that.

269. This approach was communicated to beneficiaries as I can see a reference in the minutes of the NWC of 17/5/12 that I had to revise guidance for beneficiaries. (CAXT0000073_001)

Question 145: The minutes of the Board of Directors meeting 3 May 2012 record the “NWC were also in the process of writing a policy to deal with debt as it was felt that they had been very cautious in the past and could do more going forward” [CAXT0000109_010]. Please explain:

- a. if, and when, this policy was created and communicated to beneficiaries**
- b. if, and when, a guidance note on presenting claims more efficiently was produced**
- c. how the NWC proposed to do “more going forward” for those in debt**
- d. if more applications for debt relief were successful following this process.**

270. The draft policy was tabled at the NWC meeting of 17/05/12. It would be helpful to see this document. I am pretty certain it was finalized. It would have been pointless producing it and not communicating it to beneficiaries so I assume we did, but I cannot recall or swear that we did. I don't recall dates and method of communication.

271. Regarding the guidance note: I worked with staff to produce something to go out to beneficiaries, along the lines of, “if you're putting in a request for debt, this is the information we need”. We got many applications for debt with insufficient information, and that delayed the decision. I wanted to make it easier for beneficiaries to put in a claim that didn't require us to go back to them for more details. I'm pretty certain that was produced, and I wonder whether the policy and the guidance note were the same thing. I assume that the Inquiry will have paperwork that would answer this definitely.

272. There was a paper called “Addressing Beneficiary Debt” which went to the

Board meeting on 3rd May 2012. I think this process did reduce the number of deferred applications (i.e. ones that we couldn't decide yet for lack of evidence). I am not sure of its effect on overall success rate, although from memory we did offer some relief on most debt applications.

273. Doing “more going forward” meant understanding more why people were in debt and how we could help them out of it permanently and avoid a recurrence. That was how our thinking led to engaging a debt manager to help people.

Question 146: Please comment on the circumstances that led to your report to the Caxton Trustee Ltd Board meeting 2 May 2013 seeking support for the NWC approach to decline mortgage/property requests [CAXT0000110_015].

274. I think this related to mortgage shortfalls caused by endowment mortgages and in one case interest-only mortgages. Applicants had taken out certain financial products to buy a house which were risky, and which left them with large shortfalls at the end of the mortgage term. We declined them because the amounts requested were high (such as £100K – and that would set a huge precedent had we accepted to do that) and because the applicant would have faced this difficulty even without Hepatitis C. Even though we didn't always require a link between the need and Hepatitis C, it didn't mean that we would always totally ignore it. Endowment and interest-only mortgages were a nationwide problem that could affect anyone. The problem was fundamentally with the financial product they had taken out and was not connected in any way – even indirectly – to the difficulties they faced with Hepatitis C.

Question 147: The 2 May 2013 report includes that requests to cover mortgage shortfalls had been declined “as the amounts are high and because such shortfalls would have presented the individuals with problems even if they had not been affected by Hepatitis C” [CAXT0000110_015]. Please explain the Caxton Foundation policy on requests that were considered not directly related to Hepatitis C. You may want to refer to what is said about charitable need in the minutes of the Board meeting on 11 September 2011 [CAXT0000108_039].

275. I have explained the context of that particular sentence in my answer above. In

general, and from memory, we initially took into consideration whether a particular need was related to Hepatitis C. We dropped this quite early on basis that a link could not always be made and that what mattered was that a primary beneficiary was in charitable need. There were however some rare cases where we did want to establish the connection with Hepatitis C. Someone's general poverty could fall within our remit but these financial products just had no connection at all to the illness or their financial situation at all. Thousands of people in the UK were affected by them. We were there to look at income and expenditure and help them with day to day needs, we were not there to buy a house for beneficiaries.

276. There was also a fairness question – why should only some beneficiaries have the difference between interest only/endowment shortfall paid, and not all of them? That would have quickly used up our funds. There was an unwritten principle that we wouldn't do for one person what we couldn't in principle do for everyone. Mortgage problems are a good example of something that we just couldn't have done for everyone. We used a benchmark of reasonableness and I think it was a reasonable position to adopt that we wouldn't do something for one person unless we could do it for everyone.

Question 148: The minutes of the Board of Directors meeting held 19 November 2013 note a change in NWC policy where “it had been agreed that support could be given even when treatment was not as a direct consequence of Hepatitis C” [CAXT0000110_074]. Were applications for support prior to this policy change revisited? If not, why not?

277. I don't think there had been previous cases. I think this is a good example of revisiting the rules on the basis of one case presented to NWC. In any event. I do not recall a review of past cases following this decision.

Question 149: The minutes of the NWC meeting held on 23 May 2013 record that “it was agreed that the NWC could be more flexible when considering mortgage assistance” and that “a document should be devised providing clearly defined processes on how a decision will be reached for each case and

the Committee would like to review all past cases relating to mortgages” [CAXT0000083_001]. Please explain:

- a. if you supported the change in approach towards mortgage assistance***
- b. if this process document was produced***
- c. if the NWC reviewed all past cases relating to mortgages, and if so, what the outcome of this review was.***

278. I don't honestly recall my position on mortgage assistance. I would probably have been concerned about managing an ongoing commitment – the dependency issue. My view by this point was that we should have a regular payments scheme which lifted beneficiaries out of poverty and would give them more disposable income to make spending choices.

279. This issue came back to the NWC on 8 July 2013 and the last reference I can find on it was 15th August 2013, which said that the issue would be picked up at a later date (CAXT0000085_001). I cannot remember and I cannot find in the documentation any record of how we resolved this. I think what probably happened was that all of this got subsumed into the “regular payments” question.

280. I don't know whether a process document was produced or whether we reviewed all past cases. From the documentation I have, all I can see is that all requests for mortgage assistance were declined on the basis that we did not support ongoing costs.

Question 150: You may wish to refer to the minutes of the NWC meeting 8 July 2013 [CAXT0000110_039] to respond to this question relating to mortgage assistance. Please explain:

- a. why it was “difficult to create criteria that would be fair to all requests”***
- b. the “worry about creating dependency”.***

281. See my answer to question 149. I really don't remember what was meant by it

being difficult to create criteria that would be fair to all requests. That was a point made in discussion and the minutes do not say which of the three of us made it. I think we would have been concerned that common criteria might hamstring us a bit from making case by case decisions. We decided to treat financial assistance towards mortgage arrears the same as any other debt (including referral to the financial counsellor as a first step).

282. I discuss dependency at question 157. If people can only afford their mortgage because Caxton are helping them out with it, then there was a dependency and that was not what Caxton was there to remedy. We were willing to help out if there was a path for the applicant to get back to affordability. There is a reference in the document to arranging a separate meeting to discuss this in more depth, I don't know if that meeting took place.

Question 151: Was the Caxton Foundation Board of Directors more sympathetic towards beneficiaries with debt issues than the NWC?

283. In my view, NWC was very sympathetic to debt issues, especially if people were willing to demonstrate attempts to get themselves out of debt. As I have mentioned, the majority of debt applications were indeed granted, as I recall. There was no difference in the attitude of the Board.

Question 152: The Inquiry understands that the Caxton Foundation's engaged Debt Counsellors and Benefits Advisors such as Jayne Bellis and Neil Bateman. As to this:

- a. What was the selection and appointment process for these individuals?***
- b. What were the terms on which they were engaged?***
- c. Was the provision of assistance for a beneficiary contingent on them accepting advice from such advisors?***
- d. What information was provided to the Advisors about the beneficiaries? What consent was obtained for this? Please see the letter from the Contaminated Blood Campaign to the Charity Commission dated 17 April 2013, which includes concerns on***

beneficiary confidentiality when referrals were made to the benefits advisor [CAXT0000110_010] on this issue.

- e. What were the provisions about the confidentiality of the information the beneficiary provided to the Advisor? For example, did the Caxton Foundation expect to be provided with all the financial information provided to the Advisor? You may find the correspondence at [CAXT0000097_017] and [CAXT0000107_001] of assistance.***

284. Neil Bateman was already engaged by MFT, and the NWC decided to use his services on 17/11/12. There were no concerns about the job he was doing so it seemed perfectly sensible just to use the same person who was already familiar with the kind of circumstances we were dealing with.

285. The money manager/debt counsellor role was advertised in 2012. The role was for an independent contractor working for both Caxton and MFT. Jayne Bellis was appointed following interview and started I think in November 2012. I was involved in drawing up the job specification for the debt counsellor, together with MFT trustees and the staff team (CAXT000078_005-1). We were looking for someone to help beneficiaries manage financial problems, primarily debt, who would be sympathetic, supportive and not judgmental. We may have looked at job specifications for similar roles elsewhere, I cannot remember to that level of detail.

286. I was on the interview panel for the debt counsellor role. My view of Jayne was that she was genuinely empathetic, would work well with people and not be judgmental.

287. Jayne and Neil both had contracts. I do not recall Neil's contract, but in Jayne's case it was a service level agreement with her company, PennysmartCIC Ltd (AHO0000067-1).

288. We agreed that Jayne's services would be shared with MFT on a 50/50 split.

289. There were a number of cases where support on debt was contingent on

beneficiaries accepting advice from a money manager. In the past, there were instances when Caxton staff had tried to negotiate someone's debt down with the lender. We saw Jayne's role as giving them free expert money-management advice, from someone who could help take off the pressure that they were under. Jayne would negotiate with the lenders, possibility consolidate debt into one payment rather than having several payments to make each month, and give us confidence that if we paid of a proportion of the debt that this would help them resolve the problem rather than just be a sticking plaster. For that reason we increasingly made grants contingent on using her services or the equivalent services of another debt adviser.

290. Neil Bateman's role was different and was focused on helping beneficiaries get their full benefit entitlement, including supporting beneficiaries at benefit tribunals. What Neil Bateman did was brilliant. During this period, disability claims were outsourced (I think to ATOS) and they refused very many. Neil went to Tribunals and argued the case to ensure that people got the benefits they were entitled to. My recollection is that there were a number of beneficiaries who were really pleased by the support that they got from Neil as well as from Jayne. A number of comments from beneficiaries about Caxton's services are quoted in a Trustee Board paper from 7 August 2014 following a survey sent out to primary beneficiaries and widows (CAXT0000110_132). These include:

"Mr Bateman has done wonders regarding our council tax and housing payments"

"I know that Caxton has received some bad press recently but all I can say is that you have been very helpful to us and the referrals to the benefits and financial advisors have been a god send"

291. Jayne obviously needed full information about the applicant's debt situation to do her job. Consent forms were in place from the outset for both her and Neil Bateman. Jan Barlow updated these after she became CEO as she felt the originals were not sufficiently robust. An example consent form has been provided to me but I cannot be sure if the original or the updated version (AHOH0000102-1)

292. Jayne would provide a report back to the NWC after her consultation with the applicant, containing a proposal; Caxton would not be given full details of the consultation. In the situation cited in these documents, the applicant was spending well in excess of his income but wished Caxton to pay to write off some of his debt. We declined to do so without him having a consultation to address the underlying issues of overspending. I think it was reasonable of us to insist in those kind of circumstances that people did see a money manager – to ensure the best use of Caxton's limited funds.

Regular Payment Scheme

Question 153: Please explain your role in the development of the Caxton Foundation regular payment scheme. You may wish to refer to the following documents:

- a. Report from the Welfare Committee Chair to the Caxton Trustee Ltd Board meeting 2 May 2013, re: emerging issues [CAXT0000110_015]**
- b. Report from Charles Lister and Jan Barlow to the Caxton Trustee Ltd Board meeting 1 August 2013 re: Options for a Caxton Top-Up Payment scheme [CAXT0000110_047]**
- c. Report from the Deputy Chair and Chief Executive of Caxton Trustee Ltd to the Board meeting 19 November 2013, re: Regular payments scheme [CAXT0000110_072]**
- d. Minutes Part B of the Board of Directors of Caxton Trustee Limited meeting held 19 November 2013 [CAXT0000110_087]**
- e. Business case for increased funding for the Caxton Foundation from 2014/15 for a regular payment scheme [AHOH0000001]**
- f. Report from Charles Lister and Jan Barlow to the Caxton Trustee Ltd Board meeting 26 February 2014, re: regular payments [CAXT0000110_088]**
- g. Report from the Chief Executive and Director of Operations to the Caxton Trustee Ltd Board meeting 15 December 2014, re: Regular Payment Scheme [CAXT0000110_145]**
- h. Report from the Chief Executive and Director of Operations to the**

Caxton Trustee Ltd Board meeting 26 February 2015 regarding regular payment scheme [CAXT0000111_024]

i. Minutes Part B of the Board of Directors of Caxton Trustee Limited meeting held 26 February 2015 [CAXT0000111_017]

293. I was dismayed by many beneficiaries' low level of income, with a large number living below the poverty line. I therefore became convinced that a regular payments scheme was needed with the object of lifting beneficiaries out of poverty, giving them more freedom to manage their money and reducing the number of times they needed to come to Caxton for grant requests.

294. We got agreement from the Board in principle to do this, and started investigations. I had a lot of discussion with the Rowntree Foundation about their calculations around poverty, as well as with DWP statisticians. We rejected the Rowntree approach because it would have been unaffordable. The "bag of goods" that Rowntree assumed that people would need would have needed a top-up scheme that was beyond our means and beyond any business case that we could have reasonably put to the DH.

295. Initially we wanted to put people at 80% of median income. That led to a business case which had a few iterations put to the Board. The DH refused the 80% scheme, so we decided to press ahead with a more limited scheme. Various options were considered during 2014 with final decisions taken at the February 2015 Board meeting, By the time we had agreed on this it was the end of the financial year so we gave it all out as a backdated lump sum.

Question 154: At the Caxton Foundation National Welfare Committee meeting held 17 November 2011 "it was suggested that primary beneficiaries with a household income of less than £14k should receive payments to bring them up to this level. The Committee did not want to commit to this suggestion but agreed to consider each case on its merit" [CAXT0000062_001]. Please explain:

- a. the reasons behind the Committees decision not to commit to a top up payment scheme in 2011, particularly given the principles agreed***

at the Board meeting 1 September 2011 [CAXT0000062_069] and discussed at the NWC meeting 21 September 2011 [CAXT0000062_003] included that “top priority will be the relief of poverty for primary and secondary beneficiaries, regardless of how they became poor”.

- b. any factors that led to a change in the principle not to make top up payments to beneficiaries.*
- c. any barriers to an earlier introduction of a regular payment/top-up scheme.*

296. We took a very cautious approach at the outset being cash-limited and unsure of beneficiary numbers and beneficiary need. With a clear focus on relief of poverty, we decided to focus on provision of grants. The decision not to make top up payments to beneficiaries was taken at the outset – see NWC minutes of 21st September 2011. I think that was reasonable – we didn't know how many beneficiaries we would have or what their needs would be.

297. As we came to know our beneficiaries and their needs better, we were able to adjust. I was personally a bit shocked by the low level of income some people were having to manage on. They were below the poverty line, and risked either going without or getting into debt. We felt that as a matter of principle none of our beneficiaries should be living below that poverty line. We also recognised that as we weren't giving out as much in grants as we had thought we might, there was money available.

298. There were no barriers per se to introducing the scheme earlier, just that we didn't have the information required to ensure that it was both needed and affordable. To begin with we had about 250 beneficiaries but we knew there were many more out there, and we didn't know what their financial situation might have been. As soon as we got a handle on that, we started the proposal for a regular payment scheme. My first paper to the Board about a regular payment scheme was dated 1st November 2012.

299. I doubt that DH would have ever funded anything higher than the allocation they

gave us every year. We would always have had a stiff response to a regular payment scheme that was outside the funding they were going to give us. That meant that initiating this scheme was always dependent on the extent to which it could be funded.

Question 155: The minutes of the Caxton Foundation NWC meeting held 18 April 2013 include that “Charles noted that there are a group of beneficiaries living on an income of less than £10k a year and he raised the question of whether we could do more for them.” [CAXT0000082_001]. Please explain:

- a. if the NWC shared your concerns**
- b. how the NWC responded to this.**

300. This was a shared concern. The response was the regular payments scheme, already under discussion by then.

Question 156: The report to the Caxton Trustee Ltd Board meeting 2 May 2013 notes that the issues of welfare reforms and a regular payment scheme were linked. This report includes that it “begs the question of whether Caxton should be using its funding to compensate for benefit cuts” [CAXT0000110_015]. Please explain the relationship between benefit cuts and a regular payment scheme.

301. The relationship was that compensating for benefit cuts would involve a regular payment.

302. Partly, we felt that if the government had decided that a publicly-funded benefit should be cut, it was uncomfortable for Caxton (which was publicly funded) to overrule that. We did recognise that benefit cuts might increase our beneficiaries’ need for support, but that does not mean it was appropriate simply to replace what the DWP had removed.

303. In the end, Neil Bateman put some advice on the website about what was happening in changes to benefits, so that our beneficiaries were aware.

Question 157: The minutes of the NWC meeting 8 July 2013 record that the Committee raised a top up payment scheme was a “big decision to make as regular payments can encourage dependency and create problems” [CAXT0000110_039]. Please explain:

- a. the problems that were anticipated**
- b. how concerns of dependency impacted the timing and implementation of a regular payment scheme**
- c. if these problems eventuated**
- d. why the Board came to the view that it would be appropriate at that stage to go forward with a regular payment scheme.**

304. I note that the point about dependency was made as part of a discussion, it was one of many things we discussed. The main concern about dependency was linked to the fact that Caxton was cash limited by the government. There was no guarantee of the same level of funding year on year: we did not even have a three- or five-year guarantee of funding from DH: it was decided each year. We did not want beneficiaries to manage their finances and take out regular financial commitments that they then would not be able to meet if Caxton was unable to fund them in future years. Even offering warnings to beneficiaries might not prevent a dependency: it is human nature for people to spend the money they have coming in.

305. In that context, agreeing to any kind of regular payment scheme was a big decision, and we had to make clear to beneficiaries that we could not guarantee the same amount every year

306. Concerns of dependency did not impact on the timing of the introduction of the regular payments scheme, which was delayed by other factors, such as DH refusing the business case, and increases in beneficiary numbers in 2014 creating uncertainty. From recollection, our message to beneficiaries on the payment scheme was that the same – or any – amount should not be expected for the following year. We were very aware of the need to manage expectations.

307. I am not aware of any dependency created in my time, because the first payment was only made a couple of months before I left. I left Caxton before there could be any assessment of the impact of the scheme.

308. The Board came to the view that a Regular Payment scheme was appropriate because the circumstances of some beneficiaries were so compelling. Our role was to relieve poverty, and the NWC provided evidence to the Board of people in that situation, so the dependency argument was outweighed by the recognition that we needed to do something to alleviate their poverty.

Question 158: What was the Department of Health's response to the business case for increased funding for the Caxton Foundation from 2014/15 for a regular payment scheme [AHOH0000001]? What justification was provided to the Caxton Foundation for declining the business case? In particular, given the Department of Health's desire for 'read across' between the Macfarlane Trust and the Caxton Foundation, what was said about the fact that the Macfarlane Trust had such a scheme?

309. I think the Department's response, dated 19 February 2014 (six weeks before the end of the financial year) and found at CAXT0000110_089, is worth quoting in full because it perfectly illustrates the level of uncertainty in which Caxton was operating:

"Ministers have decided that this is not the right time for an uplift in allocation, whilst they continue to consider how best to address a range of issues about the system of support available for those affected by contaminated blood, many of which were highlighted during the Westminster Hall debate on the topic on 29 October 2013.

I am also sorry that I am not yet able to confirm the Caxton Foundation allocation for 2014/15 as ministers are still considering the overall apportionment of spend across the whole of the health system. I will let you know as soon as I can once these decisions have been made.

I recognise that the decision not to increase funding will be disappointing news for the Foundation. However, I hope that it does not come as a surprise to you given our discussion on a number of occasions of the continuing downward pressure on Government spending.”

310. This was such a clear “no” that we did not seek further explanation; there was simply no point arguing as it was clear that it would not have been effective.

311. As to “Read Across” – the DH’s decision didn’t stop us having a regular payment scheme, it just stopped us having the scale of scheme that we wanted.

Question 159: Did the Caxton Foundation take any further steps to advocate for funding for a Regular Payment Scheme?

312. It was clear that there was no point pressing the case for more funding from DH. We therefore focused on developing a scaled-down scheme that was affordable.

Question 160: When did the Caxton Foundation introduce a regular payment scheme to support beneficiaries on lower incomes? How was this publicised?

313. The scheme was finally ready at the end of 2014/15. The payments were approved at the Board meeting on 26 February 2015 (my last board meeting). Those entitled therefore received a lump sum payment backdated to April 2014.

314. The decision to award payment will have been communicated to those who qualified based on individual/household income as reported in the survey we sent out that I describe in question 133. In brief, we wrote to all registered beneficiaries to set out the scheme and how to qualify for it. We invited those interested to come back to us with the required information. I’m confident it would have been on the website as well, and we also mentioned it to the Partnership Group.

Question 161: Did the Regular Payment Scheme achieve its objectives?

Please refer to the following documents in your response:

- a. Report to the Caxton Trustee Ltd Board meeting 26 February 2014 where it is noted that the revised proposal “would not achieve our original objective of raising all our clients above the poverty threshold but it would still provide some additional income” [CAXT0000110_088].**
- b. Minutes Part B of the Board of Directors of Caxton Trustee Limited meeting held 26 February 2015 which state “a number of beneficiaries would still have a household income below the 60% median income/poverty line after the payment for 2014/15” [CAXT0000111_017].**

Question 162: The minutes of the Board of Directors of Caxton Trustee Limited meeting held 19 November 2013 [CAXT0000110_087] record that the business case to the Department of Health was to “exclude Skipton Stage 2 regular payments from calculations of household income”. The report you co-authored for this meeting includes that “Stage 2 regular payments are made in recognition of advanced illness and are non means tested. It could be argued that including Skipton 2 payments in our calculation of household income would discriminate against this group of clients. MFT exclude MFET payments from their calculations of household income” [CAXT0000110_072]. Please explain:

- a. why the Regular Payment Scheme that was put in place included Skipton Stage 2 payments in the calculation of household income**
- b. if you agreed with the way household income was calculated for the Regular Payment Scheme.**

315. I am answering Qs 161 and 162 together. The objective of the Regular Payment Scheme changed after the DH’s decision not to provide additional funding in 2014/15. In developing a limited scheme, we had to abandon the objective of topping up all beneficiaries to a set income level above the poverty line and settle for one that provided additional income within the budget we had available

for 2014/15. This would still provide additional income for Caxton's poorest beneficiaries but nothing like the extent of the original scheme.

316. This involved a number of unfortunate but necessary compromises. One was that we had to take account of household income in its entirety including Skipton Stage 2 regular payments and child related benefits. We did however exclude Disabled Living Allowance so that we were not discriminating against those with non means tested disability costs.

317. In designing the revised scheme, we retained the Households Below Average Income (HBAI) 60% (and later 70%) income levels as the cut off point for those eligible for assistance. However, we were forced to make compromises here as well, by introducing a cut off of two children per family in our calculations, whereas the HBAI model had different levels for between one and five children.

318. None of us were happy with these compromises and imperfections but we had to accept that they were forced on us by the funding limitations.

319. In June 2014, the Board was presented with different models for the limited scheme all of which had pluses and minuses. The one we went with did best in trying to reflect the different composition of households without being too administratively complex.

320. We could not of course know exactly how the scheme would work until forms had been sent out and completed by eligible beneficiaries and the final modelling done. At the February 2015 Board meeting, we learnt that even the most generous payments we could make would leave 16 beneficiaries (out of the 181 eligible for support) below the 60% median income poverty line by no more than £1000. By contrast, 81 beneficiaries would be more than £3000 above the poverty line.

321. Many of those who would still be below the poverty line were people who were living at home with parents and other family members and just receiving Jobseekers Allowance or Employment and Support Allowance. Their outgoing

were therefore likely to be reduced. The Board therefore accepted the CEO's advice that we could not justify a more complex scheme of payments at this stage to take these people above the poverty line. The end of the financial year was approaching fast. Instead we awarded each of them an additional one-off payment of £750 and agreed that if the scheme continued in 2015/16 work would be done to model the cost of bringing these remaining people above the poverty line.

322. I left Caxton as a Trustee on 30 April 2015, so I cannot answer whether the scheme achieved its objectives beyond that point.

Question 163: After receiving a lower than predicted application rate for the regular payment scheme, were other avenues of communication utilised to raise awareness with beneficiaries who may have been living below the poverty line?

319. Any such actions will have been taken in 2015/16 after I ceased to be a Caxton Trustee.

Widows/Widowers

Question 164: It was suggested in the report to the Board 19 November 2013 with regards to widows/widowers that the Caxton Foundation "might like to consider having a policy where it would no longer support someone in this category once they had been living with a new partner for 1 or 2 years, or once they remarried" [CAXT0000110_072]. Please explain:

- a. why this was suggested***
- b. if this was adopted.***

320. Caxton's eligibility allowed for applications from spouses of those infected with Hepatitis C, since the financial hardships caused directly or indirectly by diagnosis would often be felt by the households rather than only by the one diagnosed. However, where a spouse had remarried and/or formed a new household, it was right to consider whether that justification remained.

321. I think we needed to put some limit on it. Either we could offer lifelong eligibility regardless of their new circumstances or we put a limitation on it. I think it was reasonable to take the latter approach.

322. I assume we would take a flexible approach to matters such as historic debt incurred in the previous marriage that was carried over to the new marriage.

323. I'm not sure if this policy was adopted.

Non-financial Support

Question 165: What if any non-financial support was available to eligible beneficiaries of the Caxton Foundation? Was the availability of non-financial support made known to the potential beneficiaries, and if so how?

324. The only non-financial support I can recall was the services of Neil Bateman and Jayne Bellis. Also, the Hepatitis C Trust had a counselling provision, and we had an arrangement with them for our beneficiaries to get free counselling if they wanted it. I think that was published on the website. Staff would have been aware of it and if they engaged in communications with beneficiaries would have been able to tell them about it.

Section 11: Complaints and appeals

When answering the below questions, you may wish to refer to the following documents:

I. Minutes of the NWC meeting 19 January 2012 [CAXT0000069_001] and attached Caxton Foundation Appeals Procedure [CAXT0000069_009]

II. Minutes of the NWC meeting 17 February 2012 [CAXT0000109_021]

III. Email correspondence to Jan Barlow and Rosamund Riley re: NWC - item 3 on the agenda [CAXT0000085_007]

Question 166: Please explain how the appeal procedure operated for the Caxton Foundation. Who determined the appeal at the NWC, and were they the same staff who made the original decision?

325. The appeal procedure was clarified at the NWC meeting on 17/2/2012 (CAXT0000109_021). If a grant was declined, the beneficiary had the right to appeal, and had to present additional information to support their case. That information might be either evidence, or a submission, explaining why they felt we had got the decision wrong. The appeal was then determined by the NWC, meaning (probably) the same Trustees who made the original decision. Grants refused by staff would also come to the NWC as an appeal. Staff never made appeal determinations, as far as I remember. I can't remember if in that situation, further information was required, I assume that it was.

326. If the NWC upheld the refusal, the beneficiary could appeal to the full Board. The rule originally was that the beneficiary would have to provide further supporting information to the Board, after which the decision of the Board was final. Later, in 2013, (see CAXT0000085_007-1) we decided that a second appeal did not require further information. We also clarified that NWC members would be available to answer questions but would abstain from the final decision.

Question 167: In an appeal either to the NWC or the full Board:

- a. Was there any right to give evidence or make representations in person;**
- b. Was a representative permitted to accompany the applicant;**
- c. What was the standard of review or appeal applied;**
- d. Were there requirements to provide "fresh evidence" at each stage of the appeal process;**
- e. Were written reasons for the decision provided; and**
- f. Were there any time limits or fees for the bringing of a review or appeal.**

327. There was no right to make representations in person and therefore also no right to be accompanied by a representative. We were not a tribunal.

328. We re-made the decision from scratch. We took a view on the case presented by the beneficiary both in their original application and what had been provided thereafter.

329. I have answered (d) in my answer to the question above (the first appeal required information, a second appeal to the full Board did not following a change in procedure).

330. As to written reasons: I believe they were provided to the beneficiary. I don't believe I ever drafted any written reasons (the staff would have drafted them), though I'm not sure.

331. After we clarified the rules, appeals were expected to be made within 3 months of the beneficiary being notified of the original rejection. I don't know how rigidly that was adhered to. I can't remember what the position was before the clarification (it was possibly the same – the clarification might just have been writing down what we were already doing in practice).

332. There were no fees. We didn't charge fees to beneficiaries for anything.

Question 168: 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?

333. It was not uncommon to have first appeals, but it was fairly uncommon to have second appeals. I have reviewed the documentation and can see that in 2012 and 2013 there were 12 appeals to the NWC. All but three were upheld.

Question 169: Was there a complaints process? If so how did it operate?

334. There was a formal complaints procedure which was made available on Caxton's website (AHOH0000069). There was an escalation process for complaints about the handling of grant applications, through the Support Services Manager initially and then to the CEO, the NWC Chair and finally the Chair of the Board of Trustees. Other complaints were to go to the CEO first and then to the Chair of the Board of Trustees. Contact details for all individuals

to whom complaints could be directed, including me, were provided. I do not recall whether this complaints procedure was revised later, apart from updating the contact details.

Question 170: How common was it for the Caxton Foundation to receive complaints? How many complaints were you aware of being made? How frequently were complaints upheld?

335. It was not common as I recall, but I cannot quantify it. Nor do I recall how frequently complaints were upheld. There will be a difference as well between formal complaints made through the complaints procedure, and people who complained about something in a more general sense without making a formal complaint. Until 2013, our turnaround time for processing grant applications was too slow, so I would expect there were a number of complaints about that.

336. Complaints about operational performance of the charity would have been addressed by the staff team. I cannot remember anyone complaining about the conduct of staff.

337. Complaints being upheld would suggest that there had been an unfair or inappropriate treatment of the beneficiary that was recognised and a remedy put in place. But I don't recall anything like that.

Question 171: What information was provided to beneficiaries about the appeal and complaints procedure?

338. I cannot remember. I expect any communication with a beneficiary declining a grant request would have included information on how to appeal. We had information about complaints and appeals on the website as well.

Question 172: Are you aware of any complaints being made to the Charity Commission or any outside agency in respect of the Caxton Foundation? If so, please give details.

339. I remember that one beneficiary wrote to the Charity Commission making complaints including that the release of information to Jayne Bellis was

inappropriate. From recollection, the complaint was not upheld by the Charity Commission. I cannot remember any other complaint being made to the Charity Commission.

Section 12: Engagement with the beneficiary community

To assist you with addressing the questions set out below you may wish to refer to:

I. 'Beneficiaries - Communication and Engagement' dated September 2011

[CAXT0000108_045]

II. Minutes of the Caxton Foundation Board of Trustees meeting held 6 October 2011 [CAXT0000108_038]

III. Minutes of the Macfarlane Trust/Caxton Foundation Liaison Committee meeting held 19 December 2012 [CAXT0000068_010]

IV. Email from Alan John Rook dated 17 March 2014 re: Caxton communications

[CAXT0000110_091]

V. Minutes of the Board of Directors of Caxton Trustee Limited meeting held 25 April 2014 [CAXT0000110_108]

VI. Minutes of the Caxton Foundation Partnership Group meeting held 11 June 2013 [CAXT0000110_048]

VII. Minutes of the Caxton Foundation Partnership Group meeting held 28 November 2013 [CAXT0000110_082]

VIII. Minutes of the Caxton Foundation Partnership Group meeting held 5 August 2014 [CAXT0000110_150]

IX. Minutes of the Caxton Foundation Partnership Group meeting held 6 November 2014 [CAXT0000110_151]

Question 173: What steps did the Caxton Foundation take to engage with and understand their beneficiary community?

340. Ongoing engagement did not really take place until we had the Partnership Group in June 2013. Before that we did not actually have any forum in which

beneficiaries could meet Trustees face to face and give views and opinions. Shortly after we instituted the Partnership Group we also created a newsletter for beneficiaries to keep them up to date with developments. We also continually improved the content of the website.

341. Other types of engagement included the census forms and the work we did before implementing the regular payments scheme. The grant application process also threw more light on the community's personal circumstances, needs and expectations and how the disease had affected them. We gained a huge understanding of people's circumstances simply through the grant application process.

342. As for understanding: at the first Caxton Board meeting Howard Thomas gave a presentation on Hepatitis C. We also had a representative from *Tainted Blood* who gave his experience of living with the condition and what he thought the expectations of the beneficiary community might be in seeking support from Caxton.

Question 174: Please explain your work with the Caxton Foundation on communication and engagement with the beneficiary community. In particular, please explain:

a. the Board's response to your paper 'Beneficiaries - Communication and Engagement' dated September 2011.

b. the statement "Trustees may need to face critical comment head on" as an argument against open sessions in Board meetings [CAXT0000108_045]

c. your involvement with the Caxton Foundation newsletter [CAXT0000108_038]

d. your role in establishing a forum [CAXT0000108_038].

343. The paper, "Beneficiaries - Communication and Engagement" dated September 2011 [CAXT0000108_045] was written by me for a Board meeting in September 2011. It was intended to consider the ways to engage with beneficiaries – such as occasional open Board meetings, etc – with pros and cons of each. Nobody was in favour of an open Board meeting. A lot of what we discussed was not

appropriate to discuss in an open meeting. I should stress that I was not fearful of the cons or suggesting that they were a reason not to adopt the idea, just that they had to be acknowledged and would need to be addressed if we did choose to do that action.

344. The Board's response to the paper is set out fully in the minutes of Caxton Board of 6th October 2011. This was still before Caxton had "gone live". Lots of things were discussed, some of which happened and some of which didn't – it was an exercise to generate ideas.

345. I don't think I was involved with the newsletter until Jan Barlow became CE. I did keep returning to the question of whether we could have a forum, and eventually we did.

346. As to communication and engagement generally: I did a bit of research with someone with a background in broadcasting who had been on the HFEA board about different things we might do, and I fed those ideas back internally. My main role then became improving the information on the website so that beneficiaries could submit the best possible applications.

347. I see from the email at AHOH0000105-1 that I raised the question of establishing a forum for beneficiaries as early as August 2011 and that I am quoted in a paper of April 2012 as suggesting a survey of the community as part of improving communications. However, neither of these happened until 2013 and 2014 respectively. The outcome of the survey is at CAXT0000110_132-1.

Question 175: The Inquiry understands that the Caxton Foundation set up a Partnership Group to engage with the beneficiary community.

a. What was the purpose of this group?

b. How often did meetings 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 the Caxton Foundation operated?

f. Were there any problems encountered in the running of the group/meeting and how were they handled?

348. The purpose of the Partnership Group was set out in the minutes of its first meeting. Ann Lloyd explained that it was a liaison group to help Caxton develop policy and strategy, to identify areas where better service could be provided to clients (beneficiaries) and because of a need to improve dialogue.
349. There were not many meetings. There were four in my time, with quite a long gap between them, in June 2013, November 2013, August 2014 (perhaps attributable to the fact that we changed the membership) and then one in November 2014. That was the last one that took place in my time.
350. I think Ann Lloyd, Jan Barlow and maybe I set the agenda and circulated it beforehand. There was no opportunity for beneficiaries not on the group to provide input into to agenda. Those on the group, to the best of my recollection, were sent a draft agenda with an opportunity to comment on it and add things to it (The Partnership Group Minutes of 6th Nov 2014 note that for future meetings, group members would have an opportunity to suggest agenda items. That had not happened on this occasion because of the “large number of items on the agenda”). Beneficiaries could also raise anything they wanted at the meeting.
351. I think the Partnership Group worked reasonably well. I remember that the second meeting of the group was organised by us in a venue in Vincent Square, Westminster and it turned out not to have disabled access, so that was unacceptable.
352. The membership changed over time. To begin with, members were from the patient and campaign groups along with the Haemophilia Society and the Hepatitis C Trust. I’m not sure we got quite the full range of views we were hoping for at the beginning, especially since those used to campaigning tended to dominate the meetings somewhat, as they were people who were used to speaking in a more public setting. Later on we felt that it would be more

representative if it had a broader membership (and also to include widows and carers as well as primary beneficiaries). We asked beneficiaries to volunteer to be on the group. To keep it to a reasonable size, a decision was taken (I cannot remember how) that there would be a separate meeting with other stakeholder charities, to focus on policy issues. That meeting for the separate group was in fact cancelled because of a dispute which I mentioned at questions 180-181.

353. There were things raised in the meeting that we went away and considered, for example about doing more for carers. One thing we changed as a result was to speed up the decision-making process on applications for respite care as mentioned in my response to Q139. The Group generally made Caxton more outward looking. It was good for Trustees to meet beneficiaries and, if they were angry, to hear that anger. If there were things we were doing that people disliked, we might want to continue doing them but it was an opportunity to explain why we did.

Question 176: What was the relationship between the senior management/board of the Caxton Foundation and the beneficiary community? Could this have been improved in your view? What steps did you take to improve the relationships?

354. We could have convened the Partnership Group earlier than we did. Clearly there were moments where things were difficult – from quite early on, staff were saying that some beneficiaries were abusive on the phone. Inevitably given the issues at stake, there were tensions and high emotions at times. At one point there was a demonstration by some campaigners outside the AHO office. I do not want to give the impression that it was all wonderful, but equally most beneficiaries had an unproblematic relationship with Caxton and many had a very positive relationship with us. I think the fact that we were set up as a charity made some beneficiaries unhappy and those people might perhaps never have been satisfied with us. Some people balked at the questions that we had to ask, as a charity.

355. The most vocal ones did not necessary reflect the majority. The majority were appreciative of what we did but some people refused to follow whatever procedures we set down as a matter of principle and were clearly genuinely

aggrieved. The best we could do was to try to make the application process as straightforward as possible within the limits that we had. Sometimes being fair and consistent meant insisting on a referral to a debt adviser or insisting on documentary evidence even if people didn't want to provide it.

356. I was very concerned to make sure that we were giving beneficiaries all the information that we needed to submit a good application. We wanted applications to succeed and recognised that failed or deferred applications (as a result of lacking information) might cause friction. That was my main contribution to improving the relationship.

Question 177: In the Macfarlane Trust/Caxton Foundation Liaison Committee meeting held 19 December 2012 it was noted that the Caxton Foundation “needed considerable improvements in its communications with beneficiaries, an issue that would benefit from the recruitment of a Trustee with professional experience in this area” [CAXT0000068_010]. Please explain:

a. The Inquiry understands that Alan Rook was recruited as a Director to meet this need. Is this correct?

b. The CF minutes dated 7 February 2013 [CAXT0000110_003] and 2 May 2013

[CAXT0000110_034] record that Mr Rook offered to input into options for trying to reach beneficiaries of the Caxton Foundation. The proposals for a communications strategy are set out in an email dated March 17 2014 [CAXT0000110_091] and discussed in the meeting on 25 April 2014 [CAXT0000110_108]. Were Blackrook Media engaged on this or any other basis? If so did you see any problem with a Trustee being engaged in this way?

c. Were any other steps taken to improve communications/relationships with the beneficiary community?

d. Did any of these steps lead to an improvement in communications?

357. Alan Rook was recruited for that purpose. We did not engage his firm for the communications strategy or anything else, precisely because we felt the

relationship would be against charity law. Trustees cannot make a profit from their role.

358. Shortly after these proposals, we had the Partnership Group up and running and that was the focus of attempts to improve communications. The group did indeed lead to an improvement.

Question 178: It was noted that “both charities required a change of “culture” in the office that would enable their websites to be kept up-to-date without prompting from Trustees” [CAXT0000068_010]. Please describe the concerns about the office culture and if change occurred to improve communications with beneficiaries.

359. This is a document of the Caxton Liaison committee, which I sat on. We had experience of staff who had taken on Caxton on top of MFT and perhaps needed a prod from time to time. It sounded like there needed to be better leadership, for the CE to make the staff aware that the website needed to be kept up to date. We had only just recruited Jan Barlow at this time.

360. Jan did a review of staffing and there was a mini “change programme” that took place, including one redundancy and the creation of a new post. It would have been the CEO’s job to make sure that communications were carried out effectively.

Section 13: Relationships with other organisations

Question 179: What involvement or interactions did the Caxton Foundation have with the Haemophilia Society?

361. Quite a lot. They advertised the debt counsellor role on their website, and they were also in the original Partnership Group. At one meeting they offered to put some FAQs about Caxton on their website (I don’t know if that was ever done). Importantly, they also ran the All Party Parliamentary Group on Haemophilia and Contaminated Blood.

362. I had very little direct contact with them apart from some negotiation on advertising on the Society's website for a Caxton trustee with experience of living with Hepatitis C. It was largely a CEO-to-CEO and Chair to Chair relationship.

Question 180: Please describe the working relationship between the Caxton Foundation and the Haemophilia Society. Were you aware of any difficulties? If so, what were they, how did they impact on the running of the Caxton Foundation and how if at all, were they resolved?

363. I had a long relationship with the Haemophilia Society ("HS") going back to my time at DH and I considered it to have been a good relationship. I had a lot of respect for them and the important work that they do.

364. Unfortunately, when Liz Carroll became Chief Executive of HS, the relationship seemed to deteriorate, possibly because the political campaign for a better settlement for those affected by contaminated blood was gaining momentum. I believe there was a feeling that Liz Carroll was losing objectivity and not being fair and reasonable with us.

365. Things also went downhill with the MFT when the HS made allegations about the Chair of MFT and Jan Barlow in a letter to the Minister and copied it to a number of MPs which were felt to be unwarranted and untrue (MAC0000059_47-1) I was clearly not present when the alleged remarks were made but I am entirely confident that neither Jan nor Roger Evans would have said anything of the kind.

366. Ann Lloyd as Chair felt that Caxton had no choice but to suspend the relationship as a result, because we were a sister organisation of MFT and because allegations against Jan naturally affected Caxton as she was our CEO as well.

367. I don't know how the relationship was resolved. This all happened at the end of my time with Caxton.

Question 181: The minutes of the Board of Directors of Caxton Foundation held 26 February 2015 [CAXT0000076_008] note that the Chair “felt that Caxton had no choice but to suspend relations with the Haemophilia Society for the time being”

a. Did you agree with this decision?

b. How long were relations suspended between the Haemophilia Society and the Caxton Foundation?

c. What impact did this period of ceased relations have on the Caxton Foundation and on the beneficiaries?

368. See my answer to the question above. We were all shocked by the letter written by Liz Carroll which seemed entirely unfounded. I certainly don't recall any dissent with the decision, and I agreed with it although it was unfortunate. It is always disappointing when relationships between connected groups break down, but I felt we had no choice. I don't know what happened after that as that was my last Board meeting.

Question 182: During your tenure with the Caxton Foundation, were there any directors/Trustees 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.

369. There were none.

Question 183: What involvement or interactions did the Caxton Foundation have with the UK Haemophilia Centre Directors Organisation?

370. None that I am aware of, but it is possible that it happened at CEO level. It was nothing I had any involvement with.

Question 184: Please describe the working relationship between the Caxton Foundation 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 Caxton Foundation and how if at all, were they resolved?

371. See above – I was not aware of contact or involved in it if it happened.

Question 185: Please list any particular clinicians you were in regular contact with during your work with the Caxton Foundation.

372. None, apart from Professor Howard Thomas as a member of the Board.

Section 14: Reform of the relevant AHO

Question 186: Please provide details of any consultation or reform process you were involved in, in respect of the Caxton Foundation.

373. None directly, although I was involved in going to speak on one occasion to the APPG on Haemophilia and Hepatitis C.

Question 187: What was your view of the changes made to the Caxton Foundation as a result of the Archer Inquiry?

374. I don't understand this question, as the Archer Inquiry predated Caxton by some margin.

Section 15: Other

Question 188: Do you consider that the AHOs were well run? Do you consider that they achieved their aims and objectives? Were there difficulties or shortcomings in the way in which the AHOs operated or in their dealings with beneficiaries and applicants for assistance?

375. I can only really comment on Caxton. Overall I would say yes they were well run. There were teething troubles at the beginning which meant that we sometimes had unacceptable delays in responding to applications for grants, for example. We inherited a slightly old-fashioned working style from MFT (in particular its staff leadership) which was a bit inefficient – for example, at the beginning the phones were not answered over people's lunch-hour and grants were processed only slowly. But that was addressed and we reduced the turnaround time considerably. There was generally good communication between the AHOs, and the fact that we shared a CEO with MFT obviously helped. No organisation is without hiccups and we had some, but they were

managed and addressed. I think that by the time I left Caxton, we were doing a pretty good job at achieving the objects set out in our Trust Deed.

376. I have mentioned elsewhere in my statement some specific difficulties.

Question 189: Please provide any other information and or views you may have that is relevant to our *Terms of Reference*.

377. I would just like to add that I am confident that all of us who volunteered to be Caxton Trustees did so because we wanted to improve the circumstances of people who were hit hardest by this dreadful tragedy. I was always impressed by the commitment of both Trustees and staff towards achieving that goal. I have talked already about the limitations placed on us as a cash limited charity and some of the administrative and other hiccups on the way. But despite this, I hope and believe that we made a number of peoples' lives less difficult. I am certainly proud of much that we did.

378. Finally, insofar as documents are concerned, I am grateful to the Inquiry for providing me with some documents to assist with this statement. I did not keep paper files during my time with Caxton due to the confidential nature of the material (they were routinely shredded when no longer required). Given the passage of time I have also deleted most of my emails. The very limited number of electronic documents that I do hold are not categorised and cover a range of issues, including but not limited to employment matters.

Statement of Truth

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

GRO-C

Signed _____

Dated _____ 1 March 2021 _____