



**The All-Party Parliamentary Group (APPG) on
Haemophilia and Contaminated Blood**

Inquiry into the current support for those affected by the contaminated blood scandal in the UK

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This report was written by Diana Johnson MP and Jason McCartney MP and funded by The Haemophilia Society.

January 2015



'You can't give us back our health. But you can give us back our dignity. This tortured road has been too long for many of us. But for the rest of us, please let this be the final road to closure.'

- person infected with hepatitis C through contaminated blood, written evidence to our
Inquiry



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The Inquiry has been conducted, and this report produced, in association with **The Haemophilia Society** (www.haemophilia.org.uk), the UK's independent charity for everyone affected by a bleeding disorder.



THE
HAEMOPHILIA
SOCIETY



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Glossary of terms

‘The APPG’	The term ‘the APPG’ is used throughout this report to refer to the All-Party-Parliamentary Group on Haemophilia and Contaminated Blood.
Caxton Foundation	A registered charity – set up and funded by the Department of Health and the devolved health authorities – which provides discretionary means-tested support to people <i>with haemophilia</i> and <i>without haemophilia</i> who contracted hepatitis C following treatment with NHS blood products, and their families. Those co-infected with HIV and HCV do not qualify for support from the Caxton Foundation, but only the MacFarlane Trust.
Co-infected	In this report, use of the term ‘co-infected’ should be taken to mean an individual is infected with both the HIV and HCV viruses. Co-infected people are eligible for discretionary support from MacFarlane Trust or Eileen – they are not eligible to register with the Caxton Foundation.
Contaminated Blood Tragedy / Scandal	From the 1970s through to the 1990s, we now know that much of the blood provided to patients through the NHS – either for blood transfusions or as blood factor concentrate/cryoprecipitate for those with bleeding disorders – was infected with Hepatitis C and HIV. Thousands of people with and without bleeding disorders were thus infected with these viruses. The “contaminated blood scandal/tragedy” describes this affair.
DWP	The Department for Work and Pensions
Discretionary / non-discretionary payments	<p>Two different types of assistance which the five trusts give to those infected by contaminated blood products, and their families.</p> <p>Non-discretionary payments are made to primary beneficiaries. They take the form of both lump sum payments and ongoing payments. The bodies providing these payments – namely, two private companies, MFET and Skipton – have no discretion in administering them and all who can prove they have contracted certain conditions following NHS treatment with blood products are entitled to equal sums. They are not means-tested based on a recipient’s income.</p> <p>Discretionary payments, however, can take various forms, from small lump sums to pay for various things, regular winter fuel payments, payments to the children of beneficiaries, vouchers for use at specific shops and regular ongoing payments. They can also take the form of in-kind support such as advice claiming benefits, dealing with debt or finding work. They are paid both to primary beneficiaries and to the families, carers and dependants of those affected (secondary beneficiaries).</p> <p>The size of discretionary payments, the eligibility criteria for accessing them and indeed what support is given at all is entirely at the discretion of those administering this support – namely the three charities MacFarlane Trust, the Eileen Trust and the Caxton Foundation. Much, but not all, of this support is means-tested: prospective recipients need to prove they are in ‘need’ by providing statements proving they require this help and/or having a sufficiently low household income.</p>
Eileen Trust	A registered charity – set up and funded by the Department of Health – which provides discretionary means-tested support to <i>people without haemophilia</i> who contracted HIV following treatment with NHS blood products, and their families. The MacFarlane Trust provides the same support to those <i>with haemophilia</i> .



Haemophilia	A hereditary bleeding disorder, almost exclusively confined to men. People with haemophilia lack particular blood clotting factors necessary to enable blood to clot. This results in spontaneous internal bleeding and often leads to joint damage. Section 1.2. gives an account of the effects of haemophilia.
HCV	The hepatitis C Virus (HCV). Section 1.2. of this report gives a brief account of the effects of the virus. People infected get different levels of support from the Government depending on their level of infection. Those with chronic HCV ('Stage' 1 HCV) get less than those with cirrhosis, primary liver cancer or B-cell non-Hodgkin's Lymphoma ('Stage 2' HCV).
HIV	Human Immunodeficiency Virus. Can lead to Advanced Immunodeficiency Syndrome (AIDS). See section 1.2 for an account of the effects of the virus.
MFET	The Macfarlane and Eileen Trust. Entirely distinct from the Macfarlane Trust and Eileen Trust, which are both charities, MFET is a private company limited by guarantee – set up and funded by the Department of Health – which provides non-discretionary non-means-tested ongoing payments and lump sums to those <i>with and without haemophilia</i> who contracted HIV following treatment with NHS blood products.
MacFarlane Trust (MFT)	The Macfarlane Trust. A registered charity – set up and funded by the Department of Health – which provides discretionary means-tested support to <i>those with haemophilia</i> who contracted HIV following treatment with NHS blood products, and their families. The Eileen Trust provides the same support to <i>those without haemophilia</i> .
NHS	The National Health Service.
Primary / secondary beneficiary	A primary beneficiary is a recipient of support from any of the five trusts who has been infected by HIV and/or hepatitis C following NHS treatment. A secondary beneficiary is a widow, carer or dependant of such an individual who has been able to register with any of the five trusts by virtue of their relationship with the primary beneficiary.
Secondary infected/infectee	This is used throughout the report to refer to anyone who was infected with Hepatitis C or HIV through personal contact with a family member, friend, partner or otherwise; and is thus eligible for support from the trusts. This is used instead of the term used by the trusts themselves – "infected intimate" – to refer to this community. This is because "infected intimate" is not a popular term amongst secondary infectees. It neglects the fact that some such individuals were infected in other ways, e.g. their HIV/HCV-infected child infected them when they treated them for a cut.
Skipton Fund	A private company limited by guarantee – set up and funded by the Department of Health and the devolved health authorities – which provides non-discretionary non-means-tested ongoing payments and lump sums to <i>those with haemophilia</i> and <i>those without haemophilia</i> who contracted HCV following treatment with NHS blood products.
'The Trusts'	The term 'trusts' is used in this report to refer to both private companies limited by guarantee – the Macfarlane and Eileen Trust (MFET) and the Skipton Fund –; and all three charities – the Caxton Foundation, the Macfarlane Trust, and the Eileen Trust – tasked with supporting people infected as a result of the contaminated blood tragedy, and their families.



Foreword – Diana Johnson MP and Jason McCartney MP

Between 1970 and 1991 the Department of Health estimate over 30,000 people may have been infected with Hepatitis C treatment following treatment with NHS blood products, however just under 6000 people have been identified. Over 1,500 others were infected with HIV in the same way between 1978 and 1985. Infection with one, or both of these viruses has had a devastating effect on the people infected, not to mention their families, who have often had to invest heavily in their care, many of them unable to return to work in the modern-day labour market upon the deaths of their partners.

That is why successive Governments, in response to lobbying efforts by campaigners, have gradually expanded a patchwork of support to help meet their needs. Rather than giving payments directly to those affected, it was decided that this support should be delivered at arm's length from the Government through external organisations solely funded by the Department of Health. Today, those affected by the tragedy can register with, and obtain support from, two private companies – which provide ongoing payments and lump sums to those directly infected – and three registered charities – which provide a variety of different kinds of discretionary assistance. Which trust they can register with depends on the virus they are infected with and, in some cases, the way they were infected.

Despite the gradual expansion of support under numerous Governments, those affected by the tragedy are still deeply unhappy with the support they receive from these “five trusts”, as they are known throughout this report. Many of these people are now growing older, and a great deal have sadly already passed away. Those who remain want desperately to see a full and final settlement reached which will at last achieve closure and allow them to live the rest of their lives in dignity. With the Rt. Hon. Alistair Burt MP in ongoing discussions with 10 Downing Street about a final settlement for those affected, and with the Penrose Inquiry – the first ever statutory inquiry into the issue of Governmental culpability for the scandal, in Scotland – due to report imminently, there are hopes that such a settlement might be possible soon.

The APPG on Haemophilia and Contaminated Blood thus feels this is an auspicious time to help contribute to these moves by investigating the quality and sufficiency of the current support arrangements. To do this, we have produced – in conjunction with the Haemophilia Society and with the generous assistance of YouGov – the first ever survey of those affected by the tragedy, disseminated to them through the five trusts. Combined with information obtained from the Department of Health and the five trusts, this report constitutes the most comprehensive appraisal to date of the current system of provision for those infected and their families.

The findings set out in this report are stark and numerous, but five of the most striking issues with the current support arrangements are worthy of particular emphasis:

- **Many trust beneficiaries are in poverty:** The widows/widowers of those who had Hepatitis C and those with chronic (“Stage 1”) Hepatitis C do not presently receive any ongoing payments whatsoever from the five trusts. Consequently many, though it is difficult to quantify, live in a state of poverty. Whilst those whose Hepatitis C has progressed further (“Stage 2”) do receive ongoing payments, these do not presently account for the number of dependants in a household and so many of these people will also be in poverty. Although



the support system for people with HIV is sufficient to keep people out of poverty, the APPG questions whether a poverty line for the *general population* is suitable for those with conditions such as Hepatitis C, HIV and haemophilia, who will face a higher cost of living.

- **“The worst form of modern-day begging that I know of:”** In addition to, or in place of, ongoing payments, beneficiaries can apply for a variety of one-off grants for all manner of goods from the three charities. But to obtain support, people often have to provide financial proofs and statements proving they are in need. Many respondents to our survey find the whole process highly demeaning and onerous, and some have been reduced to tears because of it. Those who do not receive ongoing payments are left to apply for grants and vouchers to purchase basic goods and foodstuffs. It is difficult to conceive how a discretionary one-off support system could possibly be a practical way of providing such assistance to beneficiaries.
- **“Left in the Dark:”** Although most of those who contracted HIV registered with their trust at the time it was set up, the Hepatitis C support scheme, which came later, has a considerable issue of under-registration. Figures suggest a majority of people eligible for registration with the Hepatitis C charity, have not registered. Even those who do successfully register with the charities, however, report being “left in the dark” about the support available to them. In some troubling cases, this has led to people in poverty paying out of their own pockets for things they were unaware the trusts could provide grants for, such as hospital travel – and falling into considerable debt as a result.
- **Hepatitis C infectees’ difficulties registering for support:** Even those who successfully cross the first hurdle and learn about the support available can fall at the second. To obtain payments they must first prove to the relevant trust both that they are infected with Hepatitis C at either Stage 1 or Stage 2, and that they underwent treatment with NHS blood products before the relevant time period. This process can be fraught with difficulties. In the first instance there is a degree of ambiguity in the process of proving viral infection: applicants have been turned down even their own hepatologist said they had Hepatitis C, and an alarmingly high number of appeals against decisions – over 50% - are overturned in favour of the appellant.
- **The structure and financing of the five trusts:** Successive Governments have only ever expanded support in a haphazard and reactive way. There has never been a comprehensive and holistic assessment of the precise level of payments and resources necessary to sufficiently provide for those affected. Consequently we cannot presently be sure whether the current support individuals receive is sufficient for their needs, given the effects of their conditions. The three charities in particular are affected by this haphazard arrangement: their Government funding does not increase in line with the number of beneficiaries registered with them; and there has been no assessment of whether the money they receive is sufficient to provide for registrants. Consequently the Hepatitis C has recently had to reduce its winter fuel payments unexpectedly because of an unexpected spike in registrations, whilst the HIV charity has acknowledged that unless Government funding to the charity is increased to meet beneficiary needs, it will have to considerably curtail the support it offers.



The recommendations the APPG makes in light of these findings are wide-ranging. Amongst other things, we recommend that the Government second a public health doctor to the five trusts to finally carry out an independent assessment of the needs of beneficiaries, and set payments at that level; that ongoing payments be given to those with Stage 1 Hepatitis C and that widows/widowers of Hepatitis C infectees get the same support as the widows/widowers of HIV infectees; that mechanisms be put in place to help beneficiaries unable to register with the Hepatitis C trust; and that the payments individuals receive go beyond a rudimentary measure of poverty for the general population, instead accounting both for the additional costs of living with Hepatitis C, HIV or haemophilia; and providing sufficient recompense to live a comfortable life, rather than one just above the poverty line.

Like so many of those affected by this tragedy who have taken the time to give evidence to this Inquiry, our hope is that we can finally arrive at a settlement to finally achieve closure for those affected. The recommendations set out in this Inquiry do not constitute all that is necessary to do this, but in conjunction with the work being led by the Rt. Hon. Alistair Burt MP, we hope it will go some way towards helping all those affected, and their families, live the rest of their lives in dignity.

Diana Johnson MP

A handwritten signature in blue ink that reads "Diana Johnson".

Jason McCartney MP

A handwritten signature in blue ink that reads "Jason McCartney".

Co-chairs of the APPG on Haemophilia and Contaminated Blood.



Executive summary

Context of the Inquiry

1. Between 1970 and 1991, contaminated NHS blood products caused an estimated 32,718 people to be infected with the hepatitis C virus (HCV) in the course of medical treatment, however just under 6000 people have been identified. Between 1978 and 1985, more than 1,500 people were infected with the HIV virus in a similar way; most of whom were co-infected with HCV also. Many of these people had haemophilia, a rare bleeding disorder for which the main treatment involved injections of blood factor concentrate to prevent internal bleeding. Many others did not have haemophilia, but had received NHS blood transfusions for other reasons.
2. These conditions have affected the physical and mental health, quality of life, and earning potential of those infected in various ways. Their partners, carers and dependants have also had to invest considerable time in their care, often to such an extent that – once their infected partners die – many are unable to find work in the modern-day labour market and remain financially stressed and / or in poverty.
3. Tragically, many of those who were infected have since died. For those who remain – and the families who support them – a haphazard financial support system, established piecemeal by successive governments and funded by the Department of Health, is delivered through five ‘arms-length’ entities – two companies and three charities. These entities are collectively referred to as the ‘five trusts’ throughout this report.
4. This APPG Inquiry investigates the sufficiency and quality of this support system.
5. To do so, we have conducted the first ever survey of all recipients of trust-based support. Provided free of charge by YouGov, it was disseminated to all trust beneficiaries on 16 September 2014, and heavily promoted to affected individuals who may not be registered with a trust via social media pages hosted by The Haemophilia Society and other campaigning organisations. 961 respondents completed the survey by the 28 October deadline. The resultant rich array of quantitative data, and over one hundred pages of qualitative written accounts that accompanied it, form the basis of the APPG’s Inquiry.
6. The Inquiry also draws upon evidence from Written Parliamentary Questions and information provided by the trusts themselves. We have also used a small amount of information provided by trustees, casework from fellow Members of Parliament, and published reports by campaign groups, the Government and others.

Current support arrangements

7. The five trusts each support different groups of beneficiaries. They consist of:
 - Two private companies: the Skipton Fund, which supports those with hepatitis C, and the Macfarlane and Eileen Trust (MFET), which supports those with HIV. People with co-infections can register with and receive payments from both.



- Three registered charities: the Caxton Foundation, supporting people infected with HCV and their families; the Macfarlane Trust, for those with haemophilia who were infected with HIV; and the Eileen Trust, supporting people infected with HIV who do not have haemophilia. People co-infected with both HIV and HCV can only receive payments from one of the latter two trusts.
8. The private companies give non-discretionary ongoing and one-off lump sum payments to all primary ‘beneficiaries who have proved their eligibility. Only primary beneficiaries are able to access ongoing support through the private companies, but in certain circumstances bereaved families of those infected can claim previously unclaimed lump sum payments.
9. The three charities provide discretionary support in various forms, including: grants to purchase anything from necessities (e.g. white goods and foodstuffs) to home renovations, property and holidays; one-off and ongoing lump sum payments (e.g. winter fuel allowances); and means-tested ongoing payments, both for primary beneficiaries to top-up their non-discretionary payments and for widows to help with the loss of non-discretionary ongoing support on their partners’ deaths. This support is available to all primary beneficiaries, as well as their families, widows and carers (‘secondary beneficiaries’). To receive most of this assistance, individuals must prove their level of ‘need’ by disclosing household income and/or providing a statement outlining how support would benefit them.
10. Not all registrants of the five trusts receive the same level of support, and there are some differences in the assistance available to people with HIV and HCV:
- While everyone infected with HIV receives non-discretionary ongoing payments, not all those infected with HCV do. People with chronic HCV (‘Stage 1’ hepatitis C) do not receive any ongoing payments, while those with cirrhosis, primary liver cancer or B-cell non-Hodgkin’s Lymphoma (‘Stage 2’ hepatitis C) receive the same level as for HIV.
 - The Caxton Foundation does not currently offer any ongoing means-tested payments to HCV widows or primary beneficiaries. Only MacFarlane Trust and Eileen Trust registrants (HIV-infected people) currently receive these. This is due to change in 2015-6, with Caxton registrants below the poverty line entitled to some ongoing payments, but the precise level of these is yet to be decided.
 - The MFT and Eileen provides ongoing payments for children (at least £100-a-month). Combined with the discretionary top-up payments, this has the effect of lifting beneficiary households out of poverty. Again, no similar mechanism is in place for Caxton. Although its incoming ongoing payments scheme will account for the number of children, it is not yet known whether these payments will be enough to lift recipients fully out of poverty.
 - Only people with Stage 1 HCV and secondary beneficiaries receive one-off grants for necessities such as white goods and foodstuffs, because other beneficiaries are deemed to be in less acute need, due to automatic entitlement to ongoing payments.
11. To access support, individuals must register with one of the non-discretionary bodies or – in the case of secondary beneficiaries – be associated with an existing registrant. This requires primary beneficiaries to prove that they are infected with HIV or either Stage 1 or Stage 2 HCV; and to provide hospital records showing they underwent treatment with NHS blood products prior to September 1991 (for HCV infection), and 1985 (for HIV infection). Providing this level of proof for HIV infection is rarely problematic due to the relatively



straightforward testing process, and easier access to hospital records from the 1980s and 1990s. For those with HCV, however, testing is often not straightforward, and hospital records dating back to the 1970s can be difficult or impossible to access. This makes meeting the Trusts' criteria particularly difficult for many of those with HCV infection.

12. The funding relationships with Government, and legal status of the five trusts, varies. While the two private companies receive stable payments which rise or fall annually in line with the number of registrants, the income of the three charities is on shakier ground. The Government's allocations to each of the three charities does not increase in line with the number of beneficiaries. Thus, should there be an unexpected spike in registrations – as has happened recently for the Caxton Foundation – the Government is under no obligation to increase funding.

Problems with current support arrangements

13. There is a low level of awareness among those affected by the scandal as to the range of support available, and considerable problems with low take-up of discretionary and non-discretionary assistance. This is a particular problem among those infected with HCV. While some of these issues can be put down to low awareness among those not registered with the trusts that a support system even exists, it is clear that the trusts themselves have failed to inform their own registrants of the help they can apply for:
- Considerably fewer people than are eligible have signed up to various forms of discretionary and non-discretionary payments. In the worst instance, approximately 87% of lump sum payments available to Stage 1 HCV beneficiaries who died before the Skipton Fund was established, in August 2003, have been left unclaimed by their families. Even among trust registrants themselves, take-up is low: around 16% of those receiving non-discretionary support have not registered with their respective discretionary charities.
 - Evidence suggests that this is a particular issue among HCV infectees and secondary beneficiaries registering with the Caxton Foundation. Almost half (48%) of those with Stage 1 HCV responding to the APPG's survey and 50% of secondary beneficiaries said they had never applied for discretionary support – considerably higher than for people with co-infections (10%) and those with HIV (27%). This suggests many were not previously aware of the discretionary support available.
 - Qualitative evidence reinforces the above conclusion, with many people infected with HCV, in particular, reporting that they had never heard of the Caxton Foundation before completing the survey. In September 2014 alone, Caxton registrations increased by 20% - considerably higher than in previous months – in part because of increased awareness generated by our survey. It is now clear that the Skipton Fund never contacted its previous registrants to inform them of the existence of Caxton.
 - People infected with HCV also face difficulties registering with the Skipton Fund. 16% of all claims considered by Skipton have been deferred or rejected, and when an appeal is made to the Skipton Fund's independent appeals panel, more than half are overturned –suggesting ambiguity in Skipton Fund decisions.



- The majority of rejections for the Skipton Fund are due to incomplete hospital records proving they were treated with NHS blood products. Many applications, however, are also rejected on the grounds of insufficient proof of either Stage 1 HCV infection, or that the applicant has progressed from Stage 1 to Stage 2. The most accurate way of proving HCV infection would be to conduct a liver biopsy, but this is an expensive procedure which not suitable for those with haemophilia due to their conditions. Consequently many applicants to Skipton – particularly those with haemophilia – have to rely on other, surrogate tests to prove HCV infection. None of these tests are completely accurate, and this contributes to the uncertainty and ambiguity with respect to Skipton decisions. Some respondents reported being unable to find an NHS hepatologist who would sufficiently back their Skipton claim; conversely, some others who did successfully make hepatologist-backed claims reported being rejected by Skipton’s panel, even though their own hepatologists were certain they had HCV. There is also an unexplained discrepancy between the number of rejections for those with haemophilia and those without haemophilia for Stage 2 Skipton applications, with significantly more people with haemophilia rejected for Stage 2 applications than those without. We fear this may be because Skipton unfairly disadvantages those with haemophilia who generally cannot provide biopsy data over those without haemophilia, who can, in their decision-making processes.

14. Individuals who are able to access discretionary assistance report a range of grievances regarding the way that support is delivered:

- There is a generally low level of awareness about the decision-making process for accessing discretionary support. Some 71% of survey respondents who had accessed discretionary support – when asked to rank their awareness of how their charity makes decisions – gave rankings towards the low end of the scale (0-3). A slightly lower proportion (63%) gave 0-3 rankings when asked about their understanding of the rules and procedures regarding additional support.
- The qualitative evidence reinforces this: a great many respondents reported that when an application for support was submitted, they were never kept updated on the progress of the application and were never told the reasons for a refusal in the event it was turned down. Most concerning, many respondents reported never having been told of the variety of discretionary support available to them. Consequently, some individuals fell into debt paying for items themselves – such as hospital visits – when they could have requested this support from the charities.
- Many respondents reported issues with the process of applying for discretionary support. All respondents who had applied for support were asked to choose from a range of positive and negative words to describe their experiences. A significant minority (35%) used negative words; and when the responses are broken down into sub-groups, only 34% of people co-infected and 41% of those who had never been successful in an application for support used positive words.
- In the qualitative evidence, many respondents reported a strong feeling of ‘begging’ when applying for discretionary assistance. Concerningly, some even said that the



demeaning and onerous process of trying to access support had put them off asking for support altogether, and many had simply given up applying. A great deal of MacFarlane Trust recipients were of the view that the organisation was getting worse, its staff becoming more distant and it becoming harder to access assistance. Others expressed their dissatisfaction with the level of proof required to access support, the waiting times for receiving payments and the difficulty getting into contact with relevant trust staff.

- A great deal of questions were raised by respondents about the fairness of the applications system for discretionary support. When asked whether they were satisfied that support was given fairly to beneficiaries, a majority of respondents reported being either very dissatisfied or fairly dissatisfied. There was a general feeling among many respondents that two people with the same level of need, making two applications for the same support, could be treated very differently by trust staff; and that the system unfairly advantaged those who had the support networks and the wherewithal to negotiate the complex and opaque applications system. Consequently, those in greatest need have not always found the requisite help forthcoming.

15. The financing, structure and appeals process in place for the three charities requires improvement:

- Unlike the two private companies, funding for the three charities does not increase in line with the number of beneficiaries. This became apparent in September of last year when – in part because of the awareness raised by this APPG Inquiry – Caxton registrations spiked. This precipitated an unexpected funding shortfall, and has forced Caxton to reduce the support available to beneficiaries, cutting winter fuel payments, at short notice, by £150. In the longer-term, the future funding outlook for the three charities is bleak: MacFarlane Trust is clear that without further funding, it will have to reduce its spending by 2017; and Caxton acknowledges that it is not able to sufficiently provide for its beneficiaries with the funding it presently has. Both charities presented business cases to the Department of Health for further funding in 2013, and both were rejected.
- Many survey respondents reported their dissatisfaction with the relationship between the charities and the Department of Health, which they suggest mitigates the charities' ability to act as advocates for their beneficiaries. The APPG has also been approached, in confidence, by individual MFT trustees who themselves have expressed concern about the way the charity is run, and in particular its relationship with the DH. It should be emphasized that, given the issues around governmental culpability in the contaminated blood scandal, many trust registrants are understandably still strongly mistrusting of the Department of Health. In order to satisfy registrants, the Department of Health should thus have no influence over the charities, whose sole interest should be to advocate and provide for their registrants.
- If a beneficiary is not satisfied with a decision made by a charity, there is no form of external redress available for them to challenge the decision. Their only resort is to go through the internal appeals system of the charities.



16. Finally, concerns were raised about the failure of the current trust-based system of provision to meet the full needs of all beneficiaries:

- Successive governments have never carried out a holistic independent assessment of the support necessary to meet the full needs of all beneficiaries. Support has expanded haphazardly and the level of ongoing payments have been set without consulting either medical professionals or beneficiaries as to the appropriate level of payments. When asked whether the overall trust-based system of support met their needs, it is thus telling that the overwhelming majority of respondents said it was not sufficient.
- When asked to elaborate on their reasons they were dissatisfied, respondents expressed a range of concerns about the level of ongoing payments; the support for the partners of people who have died, who is entitled to support, and the inability of the charities to provide discretionary support. These are now considered in turn.
- Firstly, respondents raised concerns about the level at which ongoing discretionary and non-discretionary payments were set. Many did not feel that the ongoing support available to them was sufficient to meet their needs and allow them to live comfortably, and did not account for the additional costs of living with HIV or HCV. A great deal of individuals particularly resented that a partner's income was taken into account to calculate eligibility for non-discretionary top-up payments – this carries the implication that partners should be expected to contribute to the care of people infected. Finally, the non-discretionary payments alone do not account for additional costs, and so may not be enough to lift individuals out of poverty. For one, the number of dependants an individual has are not accounted for in the *non-discretionary* payments. Whilst MFT compensates for this through ongoing top-up payments per child, no such mechanism is presently in place for Caxton registrants: an ongoing payments system for people below the poverty line, which will account for the number of registrants in poverty, is set to be introduced, but it is not yet clear whether the payments will be sufficient to lift people *entirely* out of poverty. In addition, at present no mechanism is in place within the ongoing payments scheme to account for the additional costs of living with HIV, HCV or haemophilia, and there remains a strong need for an independent assessment to be carried out to account for these additional costs.
- Secondly, there was a high degree of dissatisfaction with the support system for the carers, dependants and former partners of those who are now deceased. Many primary beneficiaries expressed considerable worry about what would happen to their families upon their death, at which point they would lose entitlement to non-discretionary ongoing payments. Concerns were particularly strong among HCV respondents and their partners, who are not accorded access to the same ongoing payments as HIV widows. One respondent also raised strong objections to the present arrangement wherein, if the partner of someone infected remarries following their partner's death, they lose entitlement to any trust-based support – again, this implies that their new partner should be expected to pay to meet their needs. Given that the Government has recently announced that war widows who remarry will still be entitled to pensions, it seems an apposite time to reconsider this rule.



- Thirdly, many people with Stage 1 HCV relayed to the APPG their considerable dissatisfaction with the denial of ongoing non-discretionary support to them under the current support arrangements. This is predicated on the view that many such people clear the virus, and so do not warrant ongoing support. It is clear from the qualitative evidence our Inquiry has received that many with Stage 1 HCV are in a state of ongoing support, and that even if they have no evidence of the virus they can face considerable disruptions in their lives. This warrants the provision of some form of non-discretionary ongoing payments, at a level to be set independently by a public health doctor, should be paid to them.
- Finally, a wide range of respondents raised concerns that the current support system did not address a whole range of additional needs. Some suggested payments should be made to compensate for the lost potential and earnings due to being infected by the virus. Others raised concerns that there was no compensation for historical disruptions caused by infection. For example, people infected with HCV who have cleared the virus prior to Skipton's establishment are not entitled to any payments, even though infection could have considerably affected them earlier in their lives. Finally, many advocated the provision of a further lump sum payment so that people infected by contaminated blood can provide for their families before they die.

Recommendations

Raising awareness and expanding take-up of trust-based support

1. The Department of Health should undertake a comprehensive review to consider measures to expand take-up of support, to consider whether the medical evidence required to prove infection is appropriate, and to raise awareness of the assistance available, both inside and outside the beneficiary community. Among other things, it should explore:
 - a) whether simplifying the current five-trust structure of provision – for example, by amalgamating some of the trusts – would make it easier for beneficiaries to understand the assistance available and how to access it; and
 - b) ways in which the Government could promote the availability of support to a wider audience, particularly to people infected with HCV and/or those without haemophilia.
 - c) whether the medical evidence presently required to prove infection – particularly with respect to those seeking to prove Stage 1 and Stage 2 HCV infection – is appropriate, or whether different evidence could be used or the bar of proof required lowered.
2. Within the trusts themselves, there is clear evidence of a failure to advertise the support available to their beneficiary population. Measures should be put in place to address this. All recipients of charitable support should be given clear, comprehensive and easily-accessible information on the range of discretionary support available for them to apply for and how they can access it, while the Skipton Fund should work to identify and contact those of its registrants who are not Caxton Foundation registrants. Finally, the charities should also explore ways to ensure those beneficiaries who lack the wherewithal to negotiate the discretionary support system – many of whom are often in the greatest need – are given some form of assistance in accessing it. At present, those who are fortunate



enough to have hepatologists, nurses or family members to help them fill in forms are unfairly advantaged.

3. A specialist service should be established within an appropriate body – perhaps the charities – to assist any registrants of the trusts who are unable to obtain payments due to insufficient medical evidence or hospital records. They should have the powers to pursue lost historical records across the health sector and to provide Skipton registrants who are not sufficiently acquainted with an NHS hepatologist to assist with the gathering of medical evidence for their Skipton Fund applications.
4. Given that virtually all of those with haemophilia alive at the time of infection received treatment with NHS blood products, they should not need to prove they underwent NHS treatment. Merely proving they were infected should be sufficient, and none should be denied payments simply because the NHS lost their hospital records.
5. In England, the families of people infected with HCV who are now-deceased were only given a short window of opportunity, over two months in 2011, to obtain the lump sum payments for people who died before the Skipton Fund was established (29 August 2003). Yet only a small percentage of potential beneficiaries claimed these payments in the time available; and although Skipton does in practice accept late applications, this is not widely advertised. The window of opportunity to claim Skipton payments for people infected who died before August 2003 should now be permanently re-opened and advertised widely.

A holistic assessment of beneficiaries' needs

6. The Government should second a public health doctor to the five trusts to carry out a comprehensive assessment of the needs of their beneficiaries, what money is required to meet them, the level at which funding for the charities should be set, the appropriate discretionary/non-discretionary mix of payments and the appropriate level of payments, commensurate to beneficiaries' needs.
7. In deciding what level of ongoing payments to set for beneficiaries, this review should be guided by four general principles:
 - (a) The household of someone infected should not be expected to contribute to their living costs, care and support of the person infected. In other words, if another earner enters a household, the reduction this causes in non-discretionary top-up payments should not have the effect – in the absence of the other household member's earnings – of pushing the household below the poverty line.
 - (b) The level of payments should account for the additional costs of living with haemophilia, HCV and HIV, as well as any other higher costs associated with, for example, living in London. It should not be based on a rudimentary calculation of the poverty line for the general population.
 - (c) The poverty line alone – even if it is made higher to account for someone's additional costs – is not a sufficient basis on which to set ongoing payments. Payments should be set at a high enough level for beneficiaries to live comfortably, at a level to be set by the public health doctor.



Changes to charitable provision

8. The public health doctor should also establish what level of funding is required for the three charities in light of their beneficiaries' needs. As is already the case with respect to the private companies, funds should then be increased or decreased, according to a formula, in line with the number of registrants to the charities. This should have the twin effects of both ensuring charitable support is not subject to fluctuations based on changes in the numbers of beneficiaries and help foster a more satisfactory relationship between the trusts and the Department of Health.
9. Where beneficiaries are not satisfied with a decision for discretionary support or the management of the trusts, they should be able to approach an independent external adjudicator to overturn the original decision. An appropriate body should be set up for this purpose.
10. To further foster a better relationship between the charities and their beneficiaries and to address beneficiaries' concerns about the trusts' relationship with the Department of Health, a portion of each charity's trustees should be drawn from the beneficiary population, and The Haemophilia Society – as they presently do with respect to MacFarlane Trust – must be permitted to appoint three Caxton trustees. The Department of Health should not appoint trustees to any of the three charities.

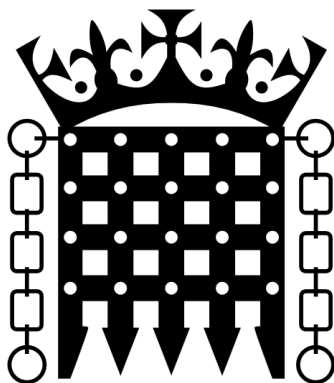
Expanding support to other areas

11. Because many are in a state of ongoing need, individuals with Stage 1 HCV should be entitled to non-discretionary ongoing payments of some kind. It should be left to the Public Health Doctor to decide what level of payments are necessary to meet their needs.
12. The spouses of people with HCV who are now deceased should be entitled to ongoing payments on the same basis as those with HIV who have died, and primary beneficiaries should be given some form of surety, before they die, as to what support their families will be entitled to so that they can plan for the future. When a primary beneficiary with HCV dies, ongoing payments to the family should continue at the same level for nine months, as is currently the case with respect to the families of now-deceased HIV infectees. Finally, if partners subsequently remarry following the deaths of their loved ones, they should not lose entitlement to trust-based support; and conversely the families of a primary beneficiary who themselves subsequently remarries should retain entitlement to trust-based support.
13. Monetary compensation alone, however, is not sufficient to achieve full closure for those affected by the tragedy. Among other things, the APPG feels that these individuals need a public apology from the Prime Minister. They also require priority access to NHS treatment and access to the best therapies available, as was originally recommended by the Archer Inquiry in 2009.
14. We are currently awaiting the publication of the Penrose Inquiry, a Scottish Public Inquiry into the contaminated blood scandal. Although this Inquiry is limited to Scotland, it is looking into pre-devolution events and therefore it is important that the findings of the



Inquiry are properly investigated in relation to possible culpability for the scandal across the UK.

- 15.** The Rt. Hon. Alistair Burt MP is leading discussions with the Prime Minister towards a final settlement. We fully support this work and hope these discussions will reflect the issues raised by respondents to the survey with respect to establishing new forms of payment and addressing the other unmet needs of people affected by the scandal, which are set out in section 3.4 (f) of this report.



Chapter 1

Context of the Inquiry

'I don't think anyone in government has even begun to understand what it has meant to suffer with hepatitis C. The disease itself and the knock-on effects. The bouts of acute tiredness, the months off sick, the memory impairment and general fogginess I blame fairly and squarely for my career having never advanced beyond the bottom rung... I was told that the brain function would barely improve, if at all, when I 'cleared' the disease, and they were correct.

... 'Then there's the impact on my family life. The lack of career progress means that we've never experienced what that would mean to us as a family. The months of being unpaid, my position being made untenable as a way of laying me off. The completely unnecessary bouts of my wife being made a carer and the unnecessary emotional burden imposed on all those around me.'

-Person infected with hepatitis C through contaminated blood, written evidence to our Inquiry.



1.1. Introduction – the infected community

Between 1970 and 1991, an estimated 32,718 people were infected with the hepatitis C Virus (HCV) following NHS treatment with blood products contaminated with the virus.¹ However just under 6000 people have been identified.

Between 1978 and 1985,² more than 1,500 others were infected with the Human Immunodeficiency Virus (HIV) in a similar way. Many³ of these were also infected with HCV.

The infected community can be split into two distinct groups:

- **Those with haemophilia or similar bleeding disorders, infected following NHS treatment with contaminated blood products.** Almost all⁴ those with haemophilia treated over these two decades – a community of around 4,675 people⁵ – became infected with HCV. A lower number – at least 1,437 people⁶, or almost a third of this community – were infected with HIV. Others receiving treatment for von Willebrand Disease (vW) – a different type of inherited bleeding disorder that affects both men and women – were also infected. Almost all of the HIV-infected community have haemophilia, but the HCV infected community is more diverse.
- **Those without haemophilia, infected after undergoing NHS blood transfusions, following intimate contact with their infected partners or through other means.** This includes the majority of those infected with HCV (an estimated 28,043 of the 32,718 who contracted HCV did so following blood transfusions) and a much smaller proportion of the HIV-infected community (at least 93 people).⁷

¹ Annex 2, Table 1, 'Estimate of total number of hepatitis C-infected individuals in UK infected over the period 1970-1991', in Department of Health (2011), *Review of the support available to individuals infected with hepatitis C and/or HIV by NHS-supplied blood transfusions or blood products and their dependants*, pp. 41-42.

² Prof. Christine Lee (2009), 'The best of times, the worst of times: a story of haemophilia', *Clin Med* October 1, 2009, Vol. 9, No. 5, pp. 453-458.

³ Views differ on precisely how many HIV infectees were co-infected with HCV. The Department of Health's 2011 review (Department of Health (2011), *Review of the support available to individuals infected with hepatitis C and/or HIV by NHS-supplied blood transfusions or blood products and their dependants*, p. 6) stated that of the 400 HIV infectees thought to be alive today, some 361 also have hepatitis C. The main charity offering support to HIV victims (the Macfarlane Trust, or MFT) provided the APPG with figures in September showing that of the 309 primary beneficiaries currently registered with the trust, 26 are singularly-infected with HIV. However some campaigning groups have argued that the entire HIV infected community were also infected with Hepatitis C and so should be entitled to support as if they were co-infected – it is simply that those "singularly-infected" are, for various potential reasons discussed later in this APPG report, unable to prove HCV infection.

⁴ Dr Gavin Colthart (2011), *HIV and hepatitis C infection from Contaminated Blood and Blood Products*, Commons Library Standard Note 5698, p. 4.

⁵ Annex 4, 'Reviewing the natural history of hepatitis C infection', in Department of Health (2011), *Review of the support available to individuals infected with hepatitis C and/or HIV by NHS-supplied blood transfusions or blood products and their dependants*, pp. 45-64.

⁶ Written Parliamentary Question 211081, Diana Johnson MP, Answered 27 Oct 2014.

⁷ See Department of Health (2011), *Review of the support available to individuals infected with hepatitis C and/or HIV by NHS-supplied blood transfusions or blood products and their dependants*, p. 6; and Written Parliamentary Question 211081, Diana Johnson MP, Answered 27 Oct 2014.



Infection has often placed considerable financial, emotional and psychological strain on the people infected and their families. Many have found themselves unable to live normal, self-sufficient working lives, their careers heavily disrupted or indeed never given the chance to take off because of their conditions. Their partners and dependants have also often had to devote considerable time – often without recompense – to the care and support of their loved ones. As a result, many have found themselves unable to find jobs in the modern-day labour market upon their partners' deaths.

Many of those originally affected by the contaminated blood tragedy have now died, but for those who remain – and the families they have left behind – a patchwork of support is now in place. It is funded by the Department of Health and delivered at arm's length, through two private companies and three registered charities.

This APPG Inquiry investigates the quality and sufficiency of these support arrangements.



1.2. Haemophilia, hepatitis C and HIV – a prognosis

This section details the effects that haemophilia, HCV and HIV have on people infected, considering each of these conditions in turn.

(a) Haemophilia

Haemophilia is a hereditary⁸ bleeding disorder – almost exclusively confined to men – which is caused by the lack of a particular protein necessary for the normal clotting of blood. People with haemophilia often experience spontaneous bleeding into joints and muscles, which can lead to arthritis and other disabilities. As a rare condition, many health professionals are not aware of the severity, complexity and urgency of treatment required, and even minor injuries require specialist medical attention to prevent long term damage.

The most common forms of bleeding disorder are haemophilia A (factor VIII deficiency), haemophilia B (factor IX) deficiency, and von Willebrand disease (vW), a deficiency of von Willebrand factor (vWF).⁹ The lattermost affects both men and women equally.

Initially, there was no effective treatment for people with inherited bleeding disorders, but from the mid-1960s medical science developed ways to produce concentrated solutions of the blood clotting factors people with haemophilia were deficient in, sourced from a wide range of blood donors. Those with vW could similarly be treated with either factor VIII concentrate including vWF – which carried a risk as it was sourced from blood donors – or with DDAVP, which is not a blood product and so carries no risk.

From the mid-1970s, therefore, UK citizens with these conditions looked forward to considerably more comfortable and fulfilling lives as a steady supply of clotting factor concentrates – storable in domestic fridges, and injectable by patients themselves – became readily available on the NHS.

Unfortunately, we now know that much of the factor concentrate haemophilia patients received throughout this period was contaminated with HIV and HCV.

(b) Hepatitis C

Hepatitis C is one strain of the hepatitis virus, a disease characterised by inflammation of the liver and the loss of functioning of liver cells. It is most commonly transmitted through the blood, as opposed to through food and sexually like other strains of the virus – although, while uncommon, HCV can also be transmitted sexually.

In the 1970s and 1980s, the virus was not taken seriously by many health professionals. Initially called hepatitis Non A Non B (NANB), it was thought relatively rare and harmless compared to other strains of the condition. This was partly due to its longer incubation period – sometimes

⁸ In some rare cases, one can contract it without there being any history of the condition in the family.

⁹ The Rt. Hon. Lord Archer of Sandwell QC, Dr Norman Jones FRCP and Ms Judith Willetts (2009), *Independent Public Inquiry Report on NHS Supplied Contaminated Blood and Blood Products*, p. 10.



several years – which disguised the true number infected for some time. It is now known to have been responsible for most, though not all,¹⁰ of the hepatitis infections from NHS blood products.¹¹

The prognoses for those who contract HCV differ, and the virus can be delineated into three main ‘stages.’ Those who first contract the condition are considered to have acute HCV, which is asymptomatic or mild in most cases. HCV is rarely diagnosed at the acute stage, and 15-25% of people infected are fortunate enough to clear the condition from their bodies at this stage. Those in the acute stage are consequently not eligible for any government-funded support. However, those who progress beyond this do receive government assistance, and the Government delineates two “stages” of HCV infection beyond the acute stage:¹²

- **Stage 1 HCV – chronic HCV:** Those who do not naturally clear the virus at the acute stage (estimated by the Government at three-quarters, or 24,538 of the 32,718 people infected by contaminated blood in total) go on to develop chronic HCV. People with chronic HCV experience the various symptoms classically associated with the virus, including jaundice, moderate-to-severe drowsiness and, in the worst cases, death.

A range of diseases or complications linked with developing HCV – so-called extra-hepatic manifestations (EHMs) – can also develop at the chronic stage. A variety of conditions including diabetes, impaired cognitive functions and thyroid cancer are argued to be associated with HCV, but only five – including cryoglobulinaemia and b-cell non-Hodgkin’s lymphoma – are considered by the Government to be EHMs.

Crucially, not all those at the chronic stage can expect to live with the virus for the rest of their lives. On average approximately 55%¹³ of people clear HCV at this stage, although most require drug treatment to do so, and those undergoing drug treatment often experience severe side-effects. Natural viral clearance without drug treatment is a very rare occurrence.

- **Stage 2 HCV – cirrhosis, advanced liver disease & b-cell non-Hodgkin’s lymphoma:** Twenty years after infection, approximately 15%-20% of those chronic hepatitis C progress to cirrhosis or advanced liver disease. Those with cirrhosis have a higher mortality rate than those with chronic HCV and face greater disruption to their lives

Greater complications arise if one has HIV in conjunction with other conditions. HIV compounds HCV, and those co-infected with both viruses have, on average, a higher risk of mortality and develop cirrhosis sooner and in greater numbers.

¹⁰ Of the two other forms of the virus, hepatitis A is transmitted through food and water and so is not a risk for those undergoing treatment with blood products, while hepatitis B – which is transmittable through blood – was being tested for in blood products from 1971-onwards. Although the test was not infallible, it considerably reduced the risk of spreading infection. Those with hepatitis A or B thus do not qualify for any assistance under the current support arrangements. See Colthart (2011), *HIV and Hepatitis C infection from Contaminated Blood and Blood Products*, Commons Library Standard Note 5698, p. 7.

¹¹ Archer et al (2009), *Independent Public Inquiry*, pp. 54-55.

¹² Annex 4, ‘Reviewing the natural history of hepatitis C infection’, in Department of Health (2011), *Review of the support available to individuals infected with hepatitis C and/or HIV by NHS-supplied blood transfusions or blood products and their dependants*, pp. 45-64.

¹³ Written Parliamentary Question 46453, Diana Johnson MP, answered 16 Mar 2011.



Cirrhosis is treated with anti-viral drugs, and some require liver transplants due to liver cancer, but none of these treatments is likely to clear the condition in the vast majority of cases. Consequently, most of those with cirrhosis are liable to live with the condition for the rest of their lives. Similarly, those who experience the EHM b-cell non-Hodgkin's lymphoma are unlikely to clear the condition. As will be discussed further in Sections 2.2 (a) and 2.5 (b), the Government thus considers these people to warrant ongoing financial support on the same basis as those with HIV, while those with Stage 1 hepatitis C do not receive ongoing payments.

The notion that those who have 'cleared' HCV are no longer affected by it has significant implications for the type and level of Government-funded support given to people affected by contaminated blood. Evidence from the community indicates that the level of suffering experienced by those with Stage 1 HCV – even among those who have 'cleared' the condition – warrants ongoing support. We will return to this subject in greater detail in Section 3.5 (c).

(c) HIV

HIV is a virus which attacks T-cells, also known as CD4 cells, in the blood, which are associated with fighting bacterial infections. HIV alters the DNA of T-cells, inhibiting their functioning and creating more HIV cells.¹⁴

There are several "stages" to HCV infection, and without treatment those with the disease will progress from an early stage where they have flu-like symptoms through to an asymptomatic stage before developing symptomatic HIV, then Advanced Immunodeficiency Syndrome (AIDS) and, ultimately, dying.¹⁵ When HIV first emerged in the 1980s, it was thought that most people infected could not expect to live beyond four years.

Fortunately, effective anti-viral treatment has now been developed to increase the number of T-cells in the body and reduce the level of HIV cells, considerably reducing the mortality of those infected. Nevertheless, the virus still speeds up the ageing of the immune system, compounds pre-existing conditions and makes people more likely to contract a range of conditions including cardiovascular disease, brain impairment and certain cancers. It is also an incurable infection: those infected do not clear the virus.¹⁶ Consequently, as discussed further in Section 2.2. (a), the Government considers people infected with HIV to warrant ongoing financial support on the same basis as those of those with Stage 2 HCV, liver cancer and B-Cell Non-Hodgkin's Lymphoma.

¹⁴ Terrence Higgins Trust website, *The Immune System*, www.tht.org.uk/myhiv/HIV-and-you/Simple-science/The-immune-system.

¹⁵ Terrence Higgins Trust website, *Stages of HIV Infection*, www.tht.org.uk/myhiv/HIV-and-you/Simple-science/Stages-of-hiv-infection.

¹⁶ Written Parliamentary Question 46453, Diana Johnson MP, answered 16 Mar 2011.



1.3. Context of this Inquiry

Several important developments relating to support for the people and families affected by the contaminated blood scandal are underway. This section discusses each development in turn.

Many of those affected remain deeply dissatisfied with current support arrangements.

There have been considerable changes in the support available to those affected over the past two decades. From the first ever government-funded support for people infected with HIV, in 1987, successive governments have gradually expanded provision in 1990-91, 1993, 2003, 2009 and 2011. Section 2.5 of this report gives an account of the historical development of this patchwork of assistance.

Over the years, these support mechanisms have also been subject to a number of reviews – both independent and government-led – which have progressively extended the reach of the support available. The most comprehensive such review was carried out by Lord Archer of Sandwell QC, among others, at the instigation of Lord Morris of Manchester. Convened in 2007, it had broad terms of reference to investigate both the circumstances surrounding the supply of contaminated blood to patients, its consequences for those infected and the further measures necessary to address their needs.¹⁷ It made a number of recommendations around considerably expanding financial support to those affected and their families.

However, representations to the APPG include assertions from many of those infected that current support arrangements are not sufficient to compensate for the losses endured. They wish to see a final and conclusive settlement.

Alistair Burt MP is in ongoing discussions with 10 Downing Street about a possible settlement for the people and families affected.

Within this context, the Rt. Hon. Alistair Burt MP is currently in discussions with the Prime Minister's office on securing a final settlement which would finally help to achieve closure. In conjunction with the APPG, he has conducted a survey asking those affected by the contaminated blood tragedy what present gaps in provision there are and what they would like to see in a final settlement. Results will soon be presented to the Prime Minister.

In Scotland, an ongoing statutory public inquiry into the contaminated blood scandal is due to report imminently.

Much to the chagrin of the people and families affected, successive British governments have persistently refused to conduct a statutory public inquiry into the contaminated blood tragedy in the UK. Many of those infected and various campaigning groups remain convinced that the Department of Health – by, among other things, failing to ensure the safety of British blood supplies – is to some extent culpable in the tragedy. In the minds of many, the service they received by NHS practitioners during this period – notably the refusal of NHS staff to inform people with haemophilia of the risks of taking concentrated blood factor solutions; or even to

¹⁷ Lord Archer et al (2009), *Independent Public Inquiry*, p. 2.



inform many people they had been infected until some time later – was of an unacceptably-low standard.

While no statutory public inquiry to investigate culpability has ever taken place in the UK, in 2008, the Scottish Government appointed Lord Penrose to conduct such a statutory public inquiry into the tragedy in Scotland. It is due to report imminently. Given that Scotland was at the time not a devolved administration, with Department of Health policy decided at a UK-wide level, the conclusions of the Penrose Inquiry will have implications for policy across the UK. Given the imminent publication of Penrose, it seems an apposite time for the APPG to explore the quality and sufficiency of the current support arrangements.

There has never been a holistic review of *all* the support available to those affected by the contaminated blood tragedy; and whether it is sufficient to meet their needs.

Those affected have persistently petitioned the APPG, arguing that existing support is not sufficient to meet their needs. This is partly because any reviews of arrangements to date have tended to be partial, and there has never been a proper, independent and holistic needs-based assessment of what support precisely is necessary in order to ensure victims' welfare.

When the government has expanded support, it has been limited to certain groups. When specific levels of financial support have been set out, they have been decided through an opaque process without consultation with either those affected or public health doctors as to what precisely would be the appropriate sum in light of their particular needs. There remains a strong need for such a comprehensive review of the needs of those affected. By surveying those affected by the contaminated blood tragedy, the APPG hopes to set out the full range of needs expressed by this community.

The three charities are presently in a difficult financial situation. Without further support, their future financial outlook is bleak.

The support given by the three charities which provide assistance is, in the long-term, financially unsustainable. Without increased governmental financial commitments to these charities, the largest HIV charity, the Macfarlane Trust (MFT), has stated that they will have to reduce the support they presently give to beneficiaries to make up their funding shortfall, while the charity which supports people infected with HCV, the Caxton Foundation, say they are unable to support beneficiaries to the extent that they would wish to. These issues, outlined in greater detail in section 3.4 (a), have come to a head in late 2014. Given this, the APPG feels that it is now an appropriate time to assess the purpose and structure of the three charities, their relationship with the Department of Health and the sufficiency of the support they offer.



1.4. The APPG Inquiry – purpose, methodology and evidence base

(a) Terms of Reference

This APPG Inquiry seeks, within the above context, to contribute to the ongoing debate about a possible final settlement by presenting, in detail, the views of those infected, and their families, on the quality and sufficiency of the current support arrangements. Like the community of those who have suffered for so long, we would like to see such a settlement reached by May 2015, and we hope that our report will contribute to these ongoing discussions.

This Inquiry is not concerned with the history of the contaminated blood tragedy, or the issue of culpability on the part of the Department of Health and NHS. We remain resolute in our view that an independent statutory public inquiry would be the best way to investigate these issues. We are also not concerned with setting out, in detail, the totality of support necessary to achieve a full and final settlement. We will not make any recommendations around creating entirely new forms of support to entirely new groups. Nor will we comment in detail on the most appropriate level of payments or mechanisms for support. Alistair Burt MP, in his ongoing discussions with 10 Downing Street, is investigating these issues.

Rather, this APPG Inquiry is concerned with investigating the current support arrangements, delivered through the three charities and two private companies. It has a narrower terms of reference to investigate four issues in relation to these support arrangements:

- **Difficulties accessing and proving entitlement to support, and knowing about what support is available:** Are affected people and families able to produce the evidence necessary to prove that they contracted hepatitis C or HIV and that they underwent NHS treatment in the relevant time period? Also, are they able, once proven eligible for support to negotiate the various mechanisms and processes in place to get any discretionary payments they need from the three charities? What is their experience of applying for this support? Finally, are people aware of the support available, or are there gaps in take-up?
- **The management, funding, governance and accountability structure of the five trusts:** Does the way that funding is allocated to the trusts, and their relationship with the Department of Health, pose issues for their ability to advocate for, and deliver sufficient support to, their beneficiaries? When people are not satisfied with a decision made by one of the three charities, are appropriate mechanisms in place to make an appeal?
- **The trusts' ability to address the needs of their beneficiaries:** Do those affected feel that the current support they receive is sufficient to meet their needs? On what broad basis should payment levels be set – should they be about keeping beneficiaries out of poverty, or should there be a broader aim? On the basis of the APPG's evidence, what are the needs of Stage 1 HCV infectees vis-à-vis Stage 2 infectees and those with HIV?
- **Support for partners of now-deceased infectees:** Are those infected sufficiently confident that, when they die, their families will be sufficiently supported to maintain the quality of life they had when they were alive; and conversely, are the widows/widowers of those who have died satisfied that the support they receive meets their needs? Do the both the HIV and the HCV trusts sufficiently support this group of beneficiaries? Do recipients of support



from one trust receive the same support as those *with the same level of need* registered with another trust?

(b) YouGov Survey of those affected by the Contaminated Blood Tragedy

In investigating these issues, the Inquiry draws from three main bodies of evidence. The most important of these is a YouGov survey of all those affected by the contaminated blood scandal. It takes the form of an online survey, approved by YouGov and made available to complete on YouGov's website. This survey forms the key evidence base for our Inquiry.

On 16 September, a letter was sent out to all trust beneficiaries, by post, informing them of the survey and providing them with a link to YouGov's website to fill in the survey online. Those not able to access the internet were given a phone number to contact so that paper versions could be sent out to them. Respondents had until 28th October to complete the survey. Those affected but not registered were also invited to complete the survey via information provided via social media and The Haemophilia Society newsletter. In addition, every effort was made to contact those not registered with any of the trusts – such as those who could not prove they were eligible for payments – through social media via the Haemophilia Society and various campaign groups.

The survey comprised two sets of questions. The first, drawn up by the APPG and The Haemophilia Society, asked respondents a range of questions about their experiences of accessing support through the trusts, their level of awareness about what support was available, their opinions of the three charities and their views on whether the broader package of trust-based support is necessary to address their needs. The survey also invited written responses and further elaboration throughout. The second, drawn up by Alistair Burt MP, asked respondents about their views on the priorities for a possible final settlement. The survey questions, in full, are copied in the Appendix of this report, section 5.1.

The answers given to Alistair Burt MP's part of the survey are separate and will be used for his ongoing discussions with 10 Downing Street, however the APPG has consulted some of the qualitative written evidence in his part of the survey to inform our Inquiry. For the most part, however, the first half of the survey forms the main evidential basis for this Inquiry.

In total, 961 individuals completed the survey. It is difficult to quantify what percentage of the community this represents because we know that some individuals affected by the tragedy have not registered with the trusts, and that some of these individuals completed our survey. However there were 1,428 registrants of the three HIV and Hepatitis C charities as of September 2014.¹⁸ In terms of the size of the broader community, a 2013 estimate by the Hepatitis C charity, the Caxton Foundation, suggested there were 2400 individuals in that community.¹⁹ Combined with the numbers registered with the HIV charities (701) – which, for

¹⁸ Figures provided to the APPG by the trusts. They are broken down further in Figure 6, p. 45 of this APPG report.

¹⁹ This consists of 2,000 primary beneficiaries and 400 dependant families. Based on estimates made by Peter Stevens, then-outgoing chairman of the Caxton Foundation, during a paper presented to trustees of Caxton. Found at Caxton Foundation (2012), *Minutes of the Meeting of the Board of Directors of Caxton Trustee Limited*, 7 Feb 2013, p. 2.



various reasons,²⁰ can be regarded as a more accurate reflection of the overall size of the HIV infectee community – and accounting for the fact that many of those with HIV are co-infected with Hepatitis C, this would suggest that there are approximately 2000-2500 individuals in some way affected by the contaminated blood scandal – both those infected, and their families – who could have responded to this survey.

Respondents provided the APPG with a wealth of quantitative survey data in conjunction with a rich array of over 100 pages of qualitative evidence. Both were analysed by researchers on behalf of the APPG and are drawn from and quoted throughout this APPG Inquiry.

(c) Evidence provided to the APPG by the three Discretionary Charities

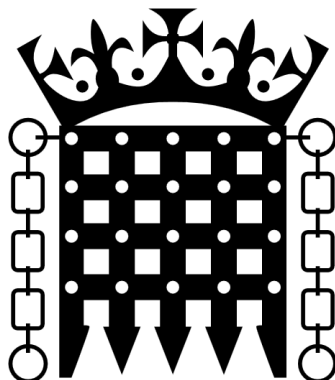
The APPG also sent two appeals for information to the three discretionary charities: initially, on 31 October as survey results were being collated; and again on 13 November once results had been analysed. Information on a range of issues including details of their beneficiaries' circumstances, the type of support they give, gaps in take-up of support and an array of internal reports produced by the charities was requested.

The trusts provided some, but not all, of the information the APPG asked for. They were helpful in providing information in relation to business cases they had made for further funding from the Department of Health in 2013 and in answering an array of technical questions about the support they offer. However they neglected to fully address other requests for information. Most notably, despite the fact that a wealth of internal reports had been produced by trustees of the discretionary charities, they did not give these reports to us at our request on the grounds that that they had been “superseded” by the more recent business cases. This is unfortunate, because some of these reports would likely have been useful in informing our Inquiry – particularly those by the HCV charity, the Caxton Foundation, who have produced six trustee reports on issues ranging from debt in the beneficiary community, estimates of gaps in take-up of assistance and the effects of Hepatitis C. In addition, the charities were also invited to make comments on the number of grant applications refused, the number of Caxton beneficiaries who were in poverty and other information. This was not forthcoming.

(d) Written Parliamentary Questions to the Department of Health

Finally, some 33 Written Parliamentary Questions were also asked by Diana Johnson MP, co-chair of the APPG, addressing a range of queries to the Department of Health. These are referenced throughout the Inquiry.

²⁰ For various reasons elaborated on further in this APPG report, the numbers registered with the HIV charities more accurately reflects the overall size of the infectee community. There are considerable gaps in take-up for (a) those with Hepatitis C and (b) to a much lesser extent those with HIV who do not have bleeding disorders. But individuals with HIV with bleeding disorders – who constitute the vast majority of the HIV infectee community – all registered with their charity at the time it was established, in the late-1980s. Notwithstanding the fact that Eileen's registrant figure may be a slight underestimate, this figure of 701 is thus a more reliable reflection of the actual size of this community.



Chapter 2

The Current Support Arrangements

'If ever an organisation was set up to keep its registrants away, it is the Macfarlane Trust. It's so much easier not to have any dealings with them... To my knowledge, there are no published guidelines saying what grants are available, and for whom, and what extra support is available in terms of regular money. This, along with the intrusive, demeaning means-testing forms they send out, appears to be designed specifically to stop people claiming anything.'

- secondary beneficiary of the Macfarlane Trust, written evidence to our Inquiry.



2.1. Overview

The support arrangements which successive governments have built up for those affected have gradually developed in a piecemeal, haphazard and reactive way, often in response to the lobbying efforts of campaigners and/or threats of litigation by the affected community. There has never been a comprehensive and holistic assessment of the support necessary to meet the full needs of all individuals, and how best it might be delivered. This chapter sets out, in detail, this present system of support and gives an account of its historical development.

2.2. The Five Trusts – Who they Support, and How they Support Them

Rather than administering the support for those affected directly through the Department of Health or Department for Work and Pensions (DWP), successive governments – in part to avoid the implication of legal responsibility for infecting them – have opted to deliver it through external entities set up by the Department of Health solely for the purpose of supporting them. These trusts are funded solely by ‘*ex gratia*’ payments from both the Department of Health and, in certain instances, the devolved governments. Those affected, and their families, have to register with the trusts and prove their eligibility in order to receive payments from them.

Different people, depending on their condition and their circumstances, are eligible for registration with different trusts. Once registered, they then qualify for different types and levels of support depending on their situations. This section gives an overview of these bodies, the support they offer, and who they provide it to.

Five entities now provide various types of assistance to those affected. In this APPG report, the term ‘trusts’ is used interchangeably to refer to all five of these organisations. These bodies take the form of:

(a) Two Private Companies – MFET and Skipton Fund

Provide non-discretionary ongoing and lump sum payments to primary beneficiaries

Two private companies, limited by guarantee, provide both lump sum and ongoing payments to those directly infected following treatment with NHS blood products (‘*primary beneficiaries*’). These are the Macfarlane and Eileen Trust (MFET), which supports HIV infected people, and the Skipton Fund, which supports people infected with hepatitis C.

The payments these trusts administer are *non-discretionary*, meaning that the two companies administering them have no discretion in allocating these payments: they are not means-tested based on the needs or income of prospective recipients. To receive the payments, an individual has to prove first that they contracted the qualifying condition – Stage 1 HCV, Stage 2 HCV or HIV – *and* that they underwent treatment with NHS-supplied blood products during the time period when NHS blood products are thought to have been vulnerable to the disease. In the case of hepatitis C, the cut-off point is September 1991;²¹ for HIV-infected people, it is 1985.²²

²¹ Skipton Fund website, www.skiptonfund.org.

²² Written Parliamentary Question 214997, Diana Johnson MP, answered 24 Nov 2014. This is “prior to the introduction of heat-treatment of blood products (a process which inactivates HIV) and an HIV screening test for blood donation, both of which occurred in 1985.”



If a HIV infectee wants to obtain support from the MFET, they must provide proofs directly to the Department of Health. For HCV infection, an individual must first register with the Skipton Fund and then provide the proofs, with their hepatologist supplying the information on the level of HCV infection.²³ Some HCV infectees face particular difficulties registering with Skipton, and this issue is discussed further in section 3.2 (b) of this report.

If an individual is successful with registering for non-discretionary support, they will then be paid lump sum and some ongoing payments from the private companies. The precise level of these payments differs depending on the type and level of infection, and are outlined in full detail in Figure 1 below.

Payments are discounted for tax purposes and are not counted as income or savings when deciding eligibility for government welfare assistance. If an individual transfers the savings accrued from these payments over to a partner, they are not considered savings for their partner's tax and benefits purposes, and nor is any capital, such as interest, gained from these payments; but money transferred over to a dependant is not disregarded in these ways.²⁴ Non-discretionary ongoing payments are index-linked and increase each year in line with inflation, but lump sum payments do not.

There are three key differences between the two private companies in the type and level of support they offer to those infected with HIV and hepatitis C, who is entitled to receive it, and the gaps in take-up of support.

First, whilst it is clear that all those *with bleeding disorders* who were infected with HIV obtained their payments when they first became available in 1990 and 1991, and that these compensation schemes thus covered this entire infectee community at the time of establishment, the same cannot be said for HCV infectees or indeed HIV infectees *without bleeding disorders*. The HCV community has the greatest issues with low take-up because Skipton was established later, in 2003, and because HCV has a longer incubation period and is harder to identify. However the non-bleeding disorder HIV community also have a potential problem with low take-up, albeit at a considerably smaller scale. Their lump sum payments scheme was established in 1993, slightly later than for HIV infectees with bleeding disorders, and only half of those who have historically applied obtained lump sum payments at the time they were offered. The rest applied later.²⁵ All new registrations to MFET – the most recent being in 2013²⁶ – are thus from HIV infectees without bleeding disorders.

Second, the two companies differ slightly in how they treat claims from the families of people infected. While families are not entitled, in their own right, to claim any payments from these bodies, in certain instances they are able to claim lump sum payments (but not the ongoing payments) if the person infected died before making a claim to the relevant scheme. How many such families are eligible to claim, and how much they can claim, differs between the two companies. The families of deceased HIV infectees who died *before or since* the HIV

²³ Written Parliamentary Question 210954, Diana Johnson MP, answered 21 Oct 2014.

²⁴ Written Parliamentary Question 211082, Diana Johnson MP, answered 27 Oct 2014 and Written Parliamentary Question 211080, Diana Johnson MP, answered 27 Oct 2014.

²⁵ Caxton Foundation (2014), *letter to the APPG Inquiry*, 21 November 2014.

²⁶ Written Parliamentary Question 214975, Diana Johnson MP, answered 25 Nov 2014.



compensation scheme was established are entitled to claim £43,500 from MFET at any point, although no such payments have been made since MFET's inception in 2010.²⁷ Likewise, the families of a HCV infected person who died *after* the Skipton Fund was established but who, for whatever reason, never made a claim during their lives are also entitled to claim lump sum payments at any point. These lump sums are the same as what the infectee would have obtained had they applied during their lifetimes.

Peculiarly, there is a different arrangement in place for the families of deceased HCV infectees who died *before* the Skipton Fund was established (29 August 2003). In England, they were given a narrow window of opportunity – between January and 31 March 2011 – to claim an infectee's unclaimed lump sums. However, Skipton does still consider claims made after the deadline on a case-by-case basis, based on whether the applicant had a valid reason for missing the original deadline. In practice, to date, no applications have been refused for missing this deadline.²⁸ In Scotland, Northern Ireland and Wales, however, this arrangement does not apply, and no deadline was imposed when, in 2011, they too were given the opportunity to obtain unclaimed Skipton payments.²⁹

Third, and most important, the two private companies differ in the extent of their provision across their respective infected communities, and the level at which lump sum payments are set. While all HIV beneficiaries are entitled to both lump sum and ongoing payments, provision is not comprehensive for those with hepatitis C. Those with 'Stage 1' HCV (see section 1.2) are not eligible for any ongoing payments at all and are only eligible for lump sum payments of £20,000. As outlined in section 1.2 (b), this is grounded on the basis of an independent review in 2011, which established that those in Stage 1 HCV were not in a state of ongoing need.³⁰ Those with 'Stage 2' HCV, however, are in a state of ongoing need and so do receive ongoing payments. They are also eligible for a further, higher lump sum payment of £50,000.

Figure 1 sets out the various non-discretionary payments those with HCV, HIV and those who are co-infected are eligible for from the two companies.

²⁷ Written Parliamentary Question 214996, Diana Johnson MP, Answered 24 Nov 2014. It should be noted that before 2010, two predecessor companies – MSPT 1 and MSPT 2 – existed before MFET. The APPG did not enquire as to the arrangements in place for the families of deceased infectees to obtain lump sum payments from MSPT 1 and MSPT 2, and it is not known what arrangements, if any, were in place for the families of deceased HIV infectees to make MSPT 1 and MSPT 2 claims, and how many such registrants made claims.

²⁸ Written Parliamentary Question 211655, Diana Johnson MP, answered 29 Oct 2014.

²⁹ Caxton Foundation (2014), *letter to the APPG Inquiry*, 21 November 2014.

³⁰ Annex 4, 'Reviewing the natural history of hepatitis C infection', in Department of Health (2011), *Review of the support available to individuals infected with hepatitis C and/or HIV by NHS-supplied blood transfusions or blood products and their dependants*, pp. 45-64.



Figure 1
Non-Discretionary Skipton and MFET Payments – What Beneficiaries Receive

Condition		Private Companies Providing Support	Payments	
			Lump Sum	Ongoing
Hepatitis C	Stage 1 HCV	Skipton Fund	£20,000 (2004-)	No entitlement to ongoing payments.
	Stage 2 HCV		£50,000 on top of the £20,000 above (2004-)	£14,574
	Family of an infected person who died <i>before</i> scheme established (29 August 2003)		<p>England: Window of opportunity, now closed, to claim infectee's Stage 1 and/or Stage 2 payment from January to the end of March 2011, though in practice one can apply late and nobody has yet been rejected.</p> <p>Scotland, Northern Ireland and Wales: Window of opportunity still open.</p>	No Entitlement to ongoing payments.
	Family of an infected person who died <i>after</i> Scheme established but who never made a Skipton claim.		Entitled to claim payments at any time.	
Co-Infected		Both	Both payments.	<p>HIV & Stage 1 HCV: £14,574, MFET.</p> <p>HIV & Stage 2 HCV: £29,148.</p>
HIV	Infected person	Macfarlane and Eileen Trust (MFET), or predecessors. ³¹	<p>All MFT beneficiaries received £20,000 in 1991³² then a further £21,500-£60,500, varying dependant on individual family circumstances,³³ in 1992.</p> <p>In 1993, those without bleeding disorders became eligible to claim the same lump sum payments at the time of registration. Any new registrants can still do so.³⁴</p>	£14,574
	Family of an infected person who died before scheme established.		£43,500 ³⁵	No entitlement to ongoing payments.

³¹ From 1990/1992 to 2010, two predecessor organisations – Macfarlane Special Payments Trust (MSPT) 1 and 2 – provided lump sums to infectees. They have now been replaced by the MFET.

³² Written Parliamentary Question 211081, Diana Johnson MP, answered 27 Oct 2014.

³³ The intention behind the variance at the time was that those who faced higher day-to-day living costs to support dependants should receive greater payments to make up for this. Because of the short life expectancy assumed at the time, no appreciation was given to the fact that those who subsequently married and/or had children could not claim further lump sums and so lost out on payments. The categories for the 1991 lump sum are: under-18: £21,500 / Single adult: £23,500 / Infected by partner: £23,500 / With a partner: £32,000 / With a partner and dependent children: £60,500.

³⁴ Written Parliamentary Question 214975, Diana Johnson MP, Answered 25 Nov 2014.

³⁵ Annex 3, in Department of Health (2011), *Review of the support available to individuals infected with hepatitis C and/or HIV by NHS-supplied blood transfusions or blood products and their dependants*, p. 43.



(b) Three Charities: Caxton Foundation, MacFarlane Trust and Eileen Trust Discretionary payments to primary and secondary beneficiaries.

Three registered charities provide various kinds of other support to those affected ('primary beneficiaries') and their carers, partners and dependants ('secondary beneficiaries'). The support for HIV-infected people and their families is split between two charities: the Macfarlane Trust supports people with haemophilia infected with HIV following the use of NHS blood factor concentrate, and their families, while the Eileen Trust provides the same support to the small number of people who do not have haemophilia who were infected through blood transfusions. A single charity – the Caxton Foundation – supports all those infected with hepatitis C, and their families, regardless of the circumstances of their infection. Those co-infected with HIV and hepatitis C are only eligible to receive support from the MacFarlane Trust or Eileen, and not Caxton.

The support available from these charities is *discretionary*: the three charities have complete discretion as to the amount of and type support they allocate and the eligibility criteria they set for accessing it. They are free to introduce new forms of assistance or to end existing support, as well as to increase, freeze or decrease any payments given out to beneficiaries.

To be eligible for the various kinds of support available, an individual must first register. They can do this if they are registered with one of the non-discretionary private companies, or if they are associated with such a registrant, whether living or dead. A widow/widower of an infectee who subsequently remarries is not presently entitled to register for discretionary support – an issue the APPG returns to in section 3.5 (e).

Once thus registered, they must then meet any eligibility criteria set out by their charity for the particular kind of support they are seeking to access. Some of the assistance offered by the trusts is non means-tested and is given to all beneficiaries regardless of their circumstances. The processes involved in accessing these kinds of payments are relatively straightforward.

However, much of the support offered by the charities is means-tested and allocated only to those which the charities deem to be in greatest need. The application process for accessing this kind of assistance is relatively more testing and time-consuming and, as will be discussed in section 3.3 (c), proves a key source of many beneficiaries' grievances. Individuals seeking to access such support must declare their household income to ascertain whether they are in a sufficient level of financial need. In certain instances, they may also have to provide statements explaining why they are in need of the assistance they are requesting, or even agree to a visit of their home by a member of staff of one of the charities.

As with non-discretionary support, any income individuals receive in discretionary payments is discounted for tax purposes and when calculating benefits eligibility. However, the income of those in the same household³⁶ of an applicant are considered as income in these calculations, as, in certain instances, is other support they are receiving from any of the charities or private companies, including the one they are applying for assistance from. The three charities also

³⁶ Sometimes only the income of the partner of an infectee in the household is considered, and not that of dependants living in the household. This is true with respect to Caxton's ongoing payments scheme, which is currently being introduced.



differ in how they treat income from the welfare system in calculations of eligibility, and these differences are outlined in Figure 2 below.

The three charities provide various forms of cash and in-kind assistance to beneficiaries. While the MacFarlane Trust and Eileen Trust offer broadly identical support for those with HIV infection, with only minor differences, the support provided by the Caxton Foundation to people who were infected with hepatitis C is markedly different. Figure 2 sets out the variety of different kinds of ongoing support offered by the charities, Figure 3 outlines the one-off cash and voucher payments offered by the charities, and Figure 4 sets out the other services offered.



Figure 2

Ongoing regular and lump sum payments – Macfarlane Trust, Caxton Foundation and Eileen Trust

Support offered	Purpose	Level	Who Is eligible & eligibility criteria
Ongoing regular top-up payments for those already in receipt of ongoing payments.	A means-tested top-up for the non-discretionary payments primary beneficiaries receive, allocated to those with the lowest household income, and who are already in receipt of ongoing payments.	<p>MFT: As little as £756 p.a. for households earning £30,001-£37,900 per year to as much as £5676 for those earning below £7600 p.a., with three additional thresholds in-between.</p> <p>Eileen: “Payments are made to a small number of beneficiary households who are judged to have insufficient incomes.”³⁷</p>	<p>HIV infected. No support for HCV infectees.</p> <p>In deciding eligibility, non-discretionary MFET payments are not considered as income, but non-discretionary Skipton payments (in the case of co-infected) are. As regards state benefits, the Eileen trust includes these in its calculation of household income, whilst MFT excludes child benefit, DLA and carers’ allowance.³⁸ The income of spouses is also taken into account.</p>
Ongoing regular payments to those in poverty who are not in receipt of ongoing payments.	Means-tested ongoing payments to registrants within an income below the official poverty line.	The precise payments given have not yet been decided on. It may well transpire that although all those <i>in poverty</i> will receive payments, they will not receive enough payments to take them out of poverty.	<p>This scheme is in the process of being introduced by Caxton for this financial year. Both primary beneficiaries and the widows/widowers registered with Caxton are eligible.</p> <p>Eligibility dependant on whether one is below the poverty line given the number of dependants in the family.³⁹</p> <p>Unlike MFT, the means-test accounts for child benefit, council tax benefit, carers’ allowance and Skipton Stage 2 payments – but not DLA. The income of spouses, but not dependants, is also taken into account.⁴⁰</p>

³⁷ Caxton Foundation (2014), *Letter to the APPG Inquiry*, 21 Nov 2014.

³⁸ Ibid.

³⁹ Categories are: Single with no children – income must be below £9,138 / single with 1 child - £13,728 / single with 2 or more children - £18,258 / partner with no children - £13,728 / partner with 1 child - £18,258 / partner with 2 or more children - £22,788.

⁴⁰ Caxton Foundation (2012), *letter to the APPG Inquiry*, 26 November 2014.



<p>Ongoing payments for widows/widowers of infected individuals who have since died.</p>	<p>When a primary beneficiary dies, the household loses entitlement to non-discretionary payments. Yet the widows of people infected may be unable to find work because of the time they have devoted to caring for their partners.</p> <p>Widows/widowers in a state of financial need are thus given ongoing payments from the MacFarlane Trust or Eileen to help compensate for the loss of ongoing payments and keep them out of poverty.</p>	<p>Whatever money is necessary to top up their income to £19,000 p.a.</p>	<p>Widows/widowers of now-deceased HIV infected. No support for HCV widows.</p>
<p>Ongoing Support for children.</p>	<p>Regular monthly and lump sum payments to the children of people infected, paid to all regardless of income.</p>	<p>At least £100 per month per child, regardless of whether the infected person is living or dead, with higher payments in certain circumstances.</p> <p>£250 payments every summer.</p>	<p>Registrants of the MacFarlane Trust or Eileen, but not the Caxton Foundation.</p>
<p>Winter payments.</p>	<p>Annual lump sums.</p>	<p><u>MFT/Eileen:</u> Means-tested and vary based on income. Those earning up to £15,200 receive £500 and those earning £15,201-£37,900 receive £250.</p> <p><u>Caxton:</u> no income means-test. Was £350 this winter.</p>	<p><u>MFT/Eileen:</u> Only primary beneficiaries.</p> <p><u>Caxton:</u> Both primary beneficiaries and widows/widowers.</p>



Figure 3

One-off cash and voucher payments – Macfarlane Trust, Caxton Foundation and Eileen Trust

Support offered	Purpose	Level	Who Is eligible
One-off lump sums for children.	A one-off lump sum payment given to all children of infected people.	£1200.	All children of HIV infected people. No support to children of HCV infected people.
Support while undergoing hospital treatment.	It is considered of paramount importance that none infected is deterred from undergoing treatment for their condition because of the financial implications of hospital travel and other expenses.	The trusts compensate those undergoing treatment for (1) loss of earnings, (2) travel and (3) additional dietary requirements.	Open to primary beneficiaries of all three charities, but HCV infected take up the bulk of this support.
Support meeting large and rare expenses.	Support is given for renovating, repairing and purchasing properties mobility adaptations for homes and vehicles; funeral expenses when an infected person dies; and holidays.	The charities cover all or part of the cost of these expenses up-front in the form of a grant. Some MFT support used to be given in the form of a loan, but this is no longer the case and is unlikely to recur. ⁴¹	Open to primary and secondary beneficiaries of all three charities. Individuals have to apply to the charity to ask for the support prior to commissioning it. A needs-based assessment will then be made based on household income, supporting statements by beneficiaries and possibly also a visit to the beneficiary's home. Applicants wishing to have renovation and repair work paid for must also provide the charities with a number of different quotes from builders.
Support meeting smaller day-to-day expenses.	Assistance to meet general expenses on anything ranging from white goods to food, transport and clothing.	Assistance can be paid in cash, but so as to ensure the beneficiary spends it appropriately it is most often paid in the form of vouchers which can only be reimbursed at certain venues. Applicants seeking to purchase, for example, food must tell the charity which venue they would like to purchase it in.	Assistance is only available to those registered with the Caxton Foundation. It is means-tested based on income and statements proving 'need.' Some forms of assistance, such as meeting the cost of basic goods, are predominantly for those in poverty.
Other forms of support	Occasionally, the charities also provide support paying off debts and also have money management advisors on hand to help beneficiaries. Some HCV infectees have also occasionally been given money to start businesses in cases where they are unable to obtain start-up finance from another source.		

⁴¹ Caxton Foundation (2012), *letter to the APPG Inquiry*, 26 November 2014.



Figure 4
Other services - the MacFarlane Trust, Caxton Foundation and Eileen Trust

Support Offered	Purpose	Level	Who Is Eligible
Counselling	Primary and secondary beneficiaries of all three charities are entitled to access counselling services delivered by the hepatitis C Trust, and funded by a government grant totalling £300,000 delivered over the three years 2011/12 to 2013/14. ⁴² The government have extended this service to 2015/16. ⁴³		
Respite breaks	Support for those who have been invested in the care of beneficiaries, and beneficiaries themselves, with respite breaks.		Only available to HCV infected and their carers and spouses.
Support for re-training and finding work, accessing welfare benefits and dealing with debt.	All three charities offer beneficiaries a range of services to help them negotiate the welfare system, address debt and find employment.		
Free NHS prescriptions	If primary beneficiaries do not already receive free prescriptions by virtue of any disabilities or infections, they are entitled to claim from the trusts the cost of an NHS prescription pre-payment certificate from the NHS.		

⁴² Andrew Lansley MP, Hansard HC Deb 10 Jan 2011, *Contaminated Blood*, Cols. 33-34.

⁴³ Written Parliamentary Question 211036, Diana Johnson MP, Answered 27 Oct 2014.



2.3. The Five Trusts – Their Funding, Management and the Number of Beneficiaries

(a) How the trusts are funded

The trusts are funded solely by *ex gratia* payments from government bodies, but the precise bodies which fund them differ. The Department of Health is the sole funder of the Eileen Trust, the MacFarlane Trust and MFET, whereas Caxton and Skipton receive Department of Health funding, plus additional contributions from devolved government health authorities in proportion to the number of registrants resident in each nation.

The basis on which funding is allocated also differs. Funding for the two private companies is allocated according to a formula, so that funding increases in line with the number of registrants to the funds. This allows the two private companies to pay non-discretionary payments to beneficiaries at the same level every year, regardless of any fluctuations in the number of new registrants.

Funding for the charities is on a less secure footing. They receive annual allocations from the government, but it is entirely at the funders' discretion how much to allocate. While the charities can – and do – make business cases to the Department asking for more money, the government is free to reject these applications. As recent events have shown (see section 3.4 (a) for a discussion), they are thus vulnerable to unexpected spikes in registrations.

Figure 5 below outlines, for each of these trusts, the year they were established; their legal status; which bodies fund them; how the funding is allocated; how much they were allocated in the most recent financial year; and how much funding they have received since their inception.



Figure 5
The Five Trusts – Their Funding Arrangements

Name of Trust & Year Established	Legal Status	Which Bodies Fund It ⁴⁴	How the Funding is Calculated ⁴⁵	Funding Allocation, 2014/15 ⁴⁶	Total paid to beneficiaries since inception to March 2014 ⁴⁷
Caxton Foundation (2011)	Registered Charities	Funded by the Department of Health and the three devolved health authorities.	Annual allocations. Amount of money allocated in any given year at the discretion of the funders, taking account of the previous year's funding and the Departments' other funding priorities.	£2,380,000	£2,054,042
Eileen Trust (1993)		Solely funded by the Department of Health	However, the Trusts can – and do – make business cases to the Department for further funding.	£100,000	£13,223,552
Macfarlane Trust (1988)			£2,200,000	£67,829,342	
MFET (2010 & 1990/92-2010)⁴⁸	Private companies, limited by guarantee.	Funded by the Department of Health and the three devolved health authorities.	Annual allocations, according to a formula.	N/a: funding always sufficient to meet all approved claims.	£12,888,429, plus a further £67,714,000 from two predecessor bodies MFET replaced.
Skipton Fund (2003)			Funding increases in line with the number of fund registrants so as to maintain the current rate of index-linked payments. However the government is still free to change the funding allocated at will.		£204,190,871
				Total: £13,800,000	Total: £367,900,236

⁴⁴ Written Parliamentary Question 210954, Diana Johnson MP, Answered 21 Oct 2014.

⁴⁵ Written Parliamentary Question 208727, Diana Johnson MP, Answered 12 Sept 2014.

⁴⁶ Written Parliamentary Question 213623, Diana Johnson MP, Answered 17 Nov 2014.

⁴⁷ Data provided to the APPG by the Eileen Trust, Caxton Foundation, Macfarlane Trust, MFET and Skipton Fund during a meeting with the APPG on 10 September 2014.

⁴⁸ From 1990/1992 to 2010, two predecessor organisations – Macfarlane Special Payments Trust (MSPT) 1 and 2 – provided similar non-discretionary support to those affected. They have now been replaced by the MFET, with all previous registrants automatically transferred to MFET.



(b) The Management of the Trusts

Legally, the five Trusts operate as separate and independent entities. All five bodies are managed by their own small complement of staff, with oversight from a board of directors (in the case of the two private companies) or trustees (the three charities).

In practice, the five organisations overlap. They all operate from the same office at Alliance House in London, and since its inception in 2011, the Caxton Foundation has effectively employed all staff on behalf of all five of the trusts, and receives money directly from the Department of Health for these administrative costs. While some staff only work for one of the organisations, many work for several.⁴⁹ The Macfarlane Trust and Caxton Foundation share the same chief executive.

Overlap at trustee level includes three of the MacFarlane Trust's trustees also serving on the Eileen Trust's board. There is less overlap between the HIV and hepatitis C charities: Caxton's Trust Deed only permits up to one Eileen trustee and one Macfarlane trustee to serve as a trustee in Caxton at any one time, and no trustees do so at present.⁵⁰ There is also a degree of overlap with the non-discretionary bodies: the chairman of the MacFarlane Trust and Eileen's two boards of trustees, for instance, are both the sole directors of MFET.⁵¹ Two of Skipton's directors are MacFarlane trustees, and one is a Caxton trustee.⁵²

The Department of Health also holds differing degrees of oversight over each of these five bodies. MFET and Skipton can effectively be seen as Department of Health entities, with little operational independence and directors not permitted to make public representations if they feel, for instance, that there are any issues with take-up of support.

The three charities, in theory, have more independence. As charities, they would be free to publicly advocate for their beneficiaries and issue reports on their needs. Indeed, in business cases requesting further funding from the Department of Health, they have been vocal in asserting that the current funding levels are not sufficient to meet their beneficiaries' needs. MacFarlane Trust and especially Caxton have also produced, at their own discretion, internal reports investigating issues such as gaps in provision and take-up of support and the requirements of those infected.

However, in practice, many beneficiaries feel the trusts act more as conduits to the Department of Health than genuine advocates for them. This issue is discussed in greater detail in section 3.4 (b). This is partly reflected in the trustee representation of these charities, although the APPG feels that the financial arrangements in place with the government and the lack of an independent appeals process for beneficiaries also contribute to this problem. At present three of MacFarlane Trust's nine trustees are appointed by the Department of Health, three are appointed by the board itself and three are appointed by The Haemophilia Society. However, the Department of Health has stated it will soon no longer make appointments to

⁴⁹ Macfarlane Trust (2013), *Annual Financial Accounts for the Year Ending 31 March 2013*, p. 6.

⁵⁰ Secretary of State for Health, Peter Stevens, Roger Evans and Charles Gore (2011), *Trust Deed Establishing a Charity called the Caxton Foundation*, 28 Mar 2011 – Schedule 2, Section 2, p. 9.

⁵¹ Macfarlane Trust (2012), *Annual Financial Accounts for the Year Ending 31 March 2012*, p. 10.

⁵² Caxton Foundation (2012), *Annual Financial Report for the Year Ended 31 March 2013*, p. 5.



MacFarlane Trust’s board, and their three trustees will eventually become board-appointed also.⁵³ All of Caxton’s nine trustees are board-appointed, but four have some professional background in the Department of Health or NHS. One of Caxton’s trustees has experience of living with hepatitis C⁵⁴ following an effort to recruit one such board member in early 2013.⁵⁵ All three of the Macfarlane Trust’s Haemophilia Society-appointed trustees are from the infected community.

(c) The Number of Beneficiaries

Figure 6 shows the current number and type of beneficiaries for each of the three charities, and gives an indication of the trends in the increase/decrease in beneficiary numbers.

Figure 6
The three charities –beneficiary numbers⁵⁶

Charity	Total current beneficiaries (September 2014)	Of which...		Rate of increase/decrease in beneficiary numbers
Caxton Foundation	727	Stage 1	379	Increasing quickly. New registrations rising at a considerably faster rate than deaths. September 2014 saw a particularly large 20% spike in registrations.
		Stage 2	170	
		Widows/widowers	78	
		Dependants/Carers	100	
Macfarlane Trust (MacFarlane Trust)	683	HIV Only	26	Declining slowly. Four deaths last year. All new registrants are people who have a secondary infection.
		HIV & Stage 1 HCV	205	
		HIV & Stage 2 HCV	78	
		Secondary infected ⁵⁷	42	
		Widows/widowers	135	
Eileen Trust	18	HIV & Stage 1 HCV	2	Stable. Approximately one beneficiary dies each year and one new registrant replaces them.
		HIV only, widows/widowers, children & secondary infected	16	

⁵³ Jan Barlow, Chief Executive of MacFarlane Trust and Caxton Foundation, 6 Nov 2014, *Email to the APPG*.

⁵⁴ Jan Barlow, 6 Nov 2014, *Email to the APPG*.

⁵⁵ Caxton Foundation (2012), *Minutes of the Meeting of the Board of Directors of Caxton Trustee Limited*, 2 May 2013, p. 2.

⁵⁶ Figures are as of September 2014, when the APPG was given figures from the trusts. There has since been a considerable increase in Caxton registrations.

⁵⁷ See Glossary for an explanation of the term secondary infected. Note that the Caxton Foundation does not have any secondary infected listed. This is because Caxton’s figures record secondary infected as primary beneficiaries, and draw no distinction between the different methods of infection.



2.4. Three competing charitable needs: differences in beneficiaries supported

The three charities and the two companies can be considered to support three different bases of beneficiaries, and thus have to meet three different types of charitable need. The proportion of their resources devoted to meeting these needs differs markedly between the HIV and hepatitis C charities, and is one of the key underlying reasons why there is such a pronounced difference in support offered for those with different conditions. The three needs are outlined below.

(a) Need 1: Helping Primary Beneficiaries in Poverty.

The provision each charity is able to make for individuals in poverty (defined as 60% of the median income) varies widely.

Because all of the MFT's primary beneficiaries receive ongoing payments placing them either above or just below the poverty line, both entities are able to focus their resources on means-tested 'top-up' payments which lift them above the poverty line. They do this in two ways, outlined in detail in Figure 2. In the first instance, they provide ongoing discretionary top-up payments to increase the income of the lowest-earning beneficiaries. Discounting welfare benefits,⁵⁸ this measure ensures no MFT primary beneficiary will be on an income below £20,500, whilst no MFT widow/widower will be on an income below £19,000.⁵⁹ Primary beneficiaries infected with both HIV and Stage 2 Hepatitis C get both non-discretionary payments, or £29,148, but those with Stage 1 HCV only receive the £14,574 MFET payment. However non-discretionary payments alone would not, on the own, ensure that all widows/widowers and all those singularly-infected with HIV are lifted out of poverty. This depends on the number of dependants an individual has. A single person with two or more children, for example (poverty line = £22,788), would not be lifted out of poverty by this measure alone. This is why, in the second instance, MFT provides ongoing payments of at least £100 per month per child to all families, regardless of whether the infectee is living or dead. These two measures combined should ensure all primary beneficiaries and widows/widowers are lifted above the poverty line.⁶⁰

It should be noted, however, that whilst MFT is presently able to lift its beneficiaries out of poverty in this way, this may not remain the case in the long-term. Its funding has been frozen by the Government, which limits the increase in the size of payments. Although its ongoing top-up payments increase in line with inflation, the thresholds of eligibility do not.⁶¹ Should an individual with modest earnings which increase with inflation fall into a lower threshold in future, it is thus notionally possible that they would fall below the poverty line.

At present, there is no provision for Caxton registrants to be lifted above the poverty line in this way. Those Stage 2 HCV infectees currently in receipt of £14,574 ongoing payments do not

⁵⁸ Especially following Coalition welfare reforms, it cannot be assumed that all registrants claim JSA or DLA.

⁵⁹ Caxton Foundation (2014), *letter to the APPG Inquiry*, 21 Nov 2014.

⁶⁰ Notionally a remarried widow/widow with one partner in a two-dependant household in which his/her partner was not earning would not be lifted above the poverty line, but (a) a remarried widow is not presently entitled to register with the MFT anyway and (b) given that the widow's partner is not affected by the contaminated blood tragedy there should be no complications for them as regards work and other obligations.

⁶¹ Caxton Foundation (2014), *Letter to APPG Inquiry*, 26 Nov 2014.



presently receive any money to account for any dependants in a household, and this says nothing of widows or those with Stage 1 HCV who receive no ongoing support whatsoever. However, the ongoing payments scheme currently being implemented for Caxton (see Figure 2) will provide top-up payments to primary beneficiaries and widows/widowers and also account for the number of dependants in a household. But it is not yet known whether the payments will be sufficient to lift them entirely out of poverty: it may simply transpire that all those in poverty receive some kind of ongoing payment, but not enough to put them above the poverty line.

In the absence of any sufficient provision for those in poverty, Caxton instead has to focus resources on assisting many beneficiaries with one-off costs for basic goods such as foodstuffs, white goods and other items. The arduous application process for these basic items forms a major grievance of many Caxton registrants, and is investigated in further detail in section 3.3 (c).

More broadly, it should be noted that none of the charities, in meeting this need, account for any additional costs which may result from having HIV, HCV or haemophilia, which may raise the poverty line for this group of beneficiaries. One may also question whether the poverty line alone is an appropriate basis on which to compensate those who have fallen victim to an NHS tragedy for the losses they have suffered; or indeed whether the ongoing discretionary payments should be reduced based on the earnings of an infectee's partner – this carries the implication that the partner of an infectee should devote some of their own earnings to lift their loved one out of poverty. Both these issues are considered in detail in section 3.5 (d).

(b) Need 2: Supporting the widows/widowers and dependants of people who have died.

Both sets of beneficiaries face difficulties meeting household costs once the non-discretionary payments stop, but MFT and Eileen are the only two charities which have the resources to provide ongoing payments to these widows. Given their other commitments, and again notwithstanding the ongoing payments scheme currently being implemented, Caxton cannot do this.

(c) Need 3: Supporting beneficiaries with one-off costs it would be unjust for them to sustain themselves.

Many beneficiaries – whether HIV-infected or HCV-infected, and regardless of income level – are liable to face one-off costs which it would be unjust for them to bear themselves. Grants are awarded to meet various needs, from hospital travel and mobility-related home or car improvements to major home renovations.

Both Trusts issue grants to meet such one-off costs, but given their difficulty balancing the other charitable needs, not all charities are able to provide sufficient help in this area. The MacFarlane Trust has in the past acknowledged that, without increased government funding, there will continue to be unmet need among their beneficiaries in this area.

It is the APPG's view that the difficulty the charities have balancing these competing needs significantly impacts on the quality and sufficiency of provisions for registrants. We investigate this issue in more detail in section 3.5 (b) of this report.



2.5. The Evolution of the Current Support Arrangements

(a) The first support for those with HIV, 1987-1993

The first financial support for those affected by the contaminated blood scandal came in 1987 when, in response to lobbying by the Haemophilia Society, the Department of Health established the Macfarlane Trust (MFT) to support those with haemophilia who had been infected with HIV, and their dependants. MFT was given a single ex gratia payment of £10million to provide discretionary support to its registrants. Registrants received regular monthly payments, annual payments to meet seasonal costs such as winter fuel costs and other discretionary payments.⁶²

These payments were not, however, enough to satisfy those affected by the tragedy, and in 1989 a number of haemophilia patients infected with HIV who had moved legal proceedings against the NHS and other bodies – the Archer Inquiry puts the figure at 970⁶³ – consolidated their claims. In 1990-1991 the Government settled these claims out of court with the provision of two sets of lump sum payments. These were administered through Macfarlane Special Payments Trust 1 (MSPT 1) and MSPT 2. In 1990, £20,000 lump sums were paid to all beneficiaries and some dependants of now-deceased infectees, totalling £24million, through MSPT 1;⁶⁴ and then further payments were made in 1991 from MSPT 2 to 1,437 people according to individual family circumstances,⁶⁵ ranging from £21,500-£60,500⁶⁶ and totalling £42million.⁶⁷ However, they only received these payments on condition of signing a waiver saying they would not bring any further proceedings against a range of public bodies with respect to alleged HIV or hepatitis C infection.⁶⁸

These moves prompted those without haemophilia who had been infected with HIV from contaminated blood to make their own legal proceedings against the NHS. These were settled in 1993 with the establishment of the Eileen Trust, funded by a £500,000 payment,⁶⁹ which provided broadly the same⁷⁰ discretionary support and lump sum payments as MFT and MSPT to non-haemophilia patients. They too had to sign waivers to obtain these lump sum payments. At the time there were some 93 such patients,⁷¹ though unlike MFT the coverage of the compensation scheme was not comprehensive at the time it was established: only half of

⁶² Archer et al (2009), *Independent Public Inquiry*, pp. 76-77.

⁶³ Ibid, p. 78.

⁶⁴ Colthart (2011), *HIV and Hepatitis C Infection from Contaminated Blood and Blood Products*, Commons Library Standard Note 5698, p. 9.

⁶⁵ Archer et al (2009), *Independent Public Inquiry*, p. 47.

⁶⁶ Colthart (2011), *HIV and Hepatitis C Infection from Contaminated Blood and Blood Products*, Commons Library Standard Note 5698, p. 9.

⁶⁷ Written Parliamentary Question 211081, Diana Johnson MP, Answered 27 Oct 2014.

⁶⁸ Ibid.

⁶⁹ Archer et al (2009), *Independent Public Inquiry*, p. 81.

⁷⁰ Colthart (2011), *HIV and Hepatitis C Infection from Contaminated Blood and Blood Products*, Commons Library Standard Note 5698, p. 10.

⁷¹ Written Parliamentary Question 211081, Diana Johnson MP, Answered 27 Oct 2014.



Eileen’s historic registrants were registered at the time of the trust’s establishment,⁷² and MFET still accepts registrations from HIV infectees without bleeding disorders – the most recent acceptance was in 2013.⁷³

As the prognosis for HIV infectees was at that time very bleak – with those infected not expected to live beyond five years –, it was not anticipated that MFT or Eileen would need any further lump sum or indeed regular payments from the Government. MFT and Eileen were expected to prudentially invest their initial payments to meet the needs of their beneficiary population. Fortunately, many of those with HIV have lived much longer than was initially anticipated. Consequently, the Government occasionally had to provide further payments to these charities throughout the 1990s and early-2000s.⁷⁴

(b) First support for those with HCV and expansion of HIV assistance, 2003

By 2003, there were further moves to make new payments to those affected by the contaminated blood scandal. Support was introduced for HCV infectees, and the discretionary support system for HIV infectees was also improved.

By the early-2000s, many people infected with hepatitis C were suffering considerable disruptions due to the virus. In 2001, a number of them took legal action in the English High Court, arguing that their infection was a breach of the Consumer Protection Act. The Judge decided in their favour, and argued that HCV-contaminated blood constituted a “defective product.”

For various reasons,⁷⁵ however, many of them were not eligible for financial compensation, but the judgment nevertheless prompted further campaigning efforts. Following a report on the issue by the Health and Community Care Committee of the Scottish Parliament, the Scottish Executive commissioned an Expert Group to investigate support for those affected by the tragedy. This Expert Group investigation – published as the Ross Report in 2003⁷⁶ -- recommended lump sum payments of £10,000 to anyone infected with Hepatitis C at the acute stage; and a further £40,000 to those with chronic HCV.⁷⁷

Although health is a devolved issue and the devolved Governments would be free to establish their own support system if they so wished, in practice they have never done so. Instead, the Ross Report prompted moves by the UK Government to extend compensation to those with Hepatitis C. On 29 August 2003 the then- Health Secretary John Reid MP announced the creation of a private company, the Skipton Fund, to make non-discretionary lump sum payments to those infected with HCV.

⁷² Caxton Foundation (2014), *letter to the APPG Inquiry*, 21 November 2014.

⁷³ Written Parliamentary Question 214975, Diana Johnson MP, Answered 25 Nov 2014.

⁷⁴ Written Parliamentary Question 210955, Diana Johnson MP, Answered 16 Oct 2014.

⁷⁵ Elaborated on further in Donald M. Ross (2003), *Report of the Expert Group on Financial and Other Support*, p. 3.

⁷⁶ Ibid.

⁷⁷ Ibid.



These payments were less generous than those proposed by the Ross Report. Those with acute HCV received nothing, those with chronic HCV (“Stage 1” HCV) received £20,000 lump sums and those who developed to cirrhosis or advanced liver disease (“Stage 2” HCV) received a further £25,000. The Archer Inquiry was unable to discern on what basis the DH set these payments at this level, though they were told they were the DH’s figures and there had been no negotiations.⁷⁸ If an infectee died after the establishment of Skipton on 29 August 2003 but, for whatever reason, did not make a claim during their lives, their families were allowed to make a claim on their behalf⁷⁹ – at the time of Skipton’s establishment, this arrangement was not in place for the families of infectees who died *before* 29 August 2003.

The medical basis and practicality of this Stage 1 / Stage 2 HCV distinction is a matter of considerable controversy. Although it was beyond the scope of the Inquiry to investigate this issue, we did ask the Department of Health to release “all documents ... relating to the advice received from an independent group of experts when the Skipton Fund was first established in relation to the practicality of the Stage 1 / Stage 2 hepatitis C distinction.”⁸⁰ Documents were placed in the Library relating to two meetings between DH officials and an Independent group of experts in October 2003 and January 2004 concerning the medical trigger point for the higher Skipton payment⁸¹ - an issue which the APPG investigates further in section 3.2 (b) of this Inquiry. From answers we have received from the DH, it does not appear that the Government consulted independent experts on *the basis of the Stage 1 / Stage 2 distinction itself* – they merely consulted them on the appropriate trigger point.⁸²

In addition, during this period it also became clear that the financial support system for those infected by HIV was not fit for purpose. Fortunately, primary beneficiaries were living longer than had been predicted, which meant that the initial funds set aside for the trusts were depleting quickly. Though the DH had made further large payments to MFT and Eileen later in the 1990s and early-2000s,⁸³ they were not sufficient, and the two charities faced a funding shortfall, with their reserves quickly depleting.⁸⁴ In 2003 the DH agreed to fund a review of the future needs of MFT beneficiaries, which recommended that funding be increased by 100% to £7million annually for MFT beneficiaries. The DH agreed to a much smaller increase of 11%. However, the funding – crucially – was now put on an ongoing basis, with the trusts now receiving regular annual payments. Some years later, in 2006, MFT themselves presented a report on the needs of their beneficiaries which argued that a similar £7.5million annual payment was needed to meet beneficiaries’ needs,⁸⁵ but these suggestions were not taken forward by the Government.

⁷⁸ Archer et al (2009), *Independent Public Inquiry*, p. 82.

⁷⁹ Initially families were only allowed to obtain the payments of now-deceased loved ones infected with HCV if they had died between 29 August 2003 and 5 July 2004. In January 2006, however, the Government extended support to those who died after 5 July 2004.

⁸⁰ Written Parliamentary Question 211638, Answered 29 Oct 2014.

⁸¹ These can be accessed by going to www.parliament.uk/depositedpapers and selecting 13 November 2014 in the date range.

⁸² A PQ was tabled explicitly asking the DH “what the basis is for the distinction between Stage 1 and Stage 2 Hepatitis C.” However, the only independent advice referenced in the response concerned that relating to the *medical trigger* for the higher Stage 2 payment. No mention was made of any meetings consulting on the medical basis of the Stage 1 / Stage 2 distinction itself. See Written Parliamentary Question 211083, Diana Johnson MP, Answered 27 October 2014.

⁸³ Written Parliamentary Question 210955, Diana Johnson MP, 16 Oct 2014.

⁸⁴ Archer et al (2009), *Independent Public Inquiry*, pp. 84-85.

⁸⁵ *Ibid*, p. 85.



(c) The Archer Inquiry, 2009

By 2009, therefore, in addition to having obtained lump sum payments from MSPT 1 and 2, MFT and Eileen beneficiaries were receiving regular £255 monthly payments (£3060 p.a.), with those in receipt of Income Support receiving higher rates of £300-£500 (£6000 p.a.). They also received annual payments for holidays and winter fuel costs and were able to apply for discretionary payments for home adaptations and other things. By contrast, people infected with Hepatitis C were eligible for lump sum payments from the Skipton Fund, but were otherwise not given any other support.

Those affected by the scandal were still considerably dissatisfied with this support system. Many wanted a more generous system of financial compensation in line with that in Ireland, coupled with a public apology from the Prime Minister and an independent statutory inquiry into the tragedy.

In the absence of a Government-commissioned Statutory Public Inquiry into the tragedy, campaigners decided to take matters into their own hands. With the help of private funding, former Minister for the Disabled Lord Morris of Manchester asked Lord Archer of Sandwell QC, amongst others, to conduct an Independent Public Inquiry into the issue. The Inquiry held hearings between March 2007 and June 2008 and reported in February 2009. It made a range of observations and recommendations with respect to Governmental culpability for the tragedy and the support needed to achieve closure. Most pertinently for our purposes, it recommended:⁸⁶

- The establishment of a statutory committee to advise the Government on haemophilia. Amongst other things, it would have the responsibility of procuring “the best therapies” for those affected by the scandal and securing “readily available access” to treatment related to their conditions.
- Financial support for those affected should be made through the DWP. There should be no intermediary, such as the trusts, administering payments and individuals should be entitled to it through the benefits system.
- Payments should be increased and set at at least the level of that which exists in Ireland.
- These payments should be disregarded for the purposes of calculating welfare benefits.
- Anomalies relating to, amongst other things, the date of the death of the original infectee should be rectified; and the Government should review the conditions under which the widow/widower of an infectee becomes eligible for Skipton, Eileen and MFT support.

In May 2009, the previous Government announced a number of changes to the support system in response to the Archer Inquiry:⁸⁷

⁸⁶ Ibid, pp. 107-110.

⁸⁷ Department of Health (2009), *Government response to Lord Archer’s Independent Report on NHS Supplied contaminated blood and blood products*, 20 May 2009, pp. 9-12.



- Annual payments to those with HIV were to be increased £12,800 per year, well above the previous variable payments averaging £6,400. This funding was administered within the existing support system: MFT and Eileen received the necessary money to administer these payments.
- The funding of MFT and Eileen was increased to allow for higher payments to dependents.
- However, the above arrangements would only be put in place with respect to HIV infectees. The support system for those with Hepatitis C would be reviewed in five years, in 2014, at the tenth anniversary of the Skipton Fund.
- They provided funding for a look-back exercise to identify any patients who may have been infected. This review is still being carried out by the UK Haemophilia Doctors' Organisation (UKHCDO) and its results were due for publication in its annual report, to be published – according to the Government, in response to a Parliamentary Question⁸⁸ – in late 2014.⁸⁹

(d) The Coalition Government's Review, 2011

The previous Labour Government's response to the Archer Inquiry dissatisfied many of those affected by the tragedy. Individuals with HCV were most particularly incensed that they would have to wait five years before the Government would even review the support they received. Fortunately, moves by the new Coalition Government to review the support available came sooner. They were spurred on by a judicial review challenging the basis of the previous Government's rejection of one Archer's recommendation.

Archer had recommended that the Government establish financial support along the lines of the more generous provision available in Ireland. One of the bases the previous Government rejected this proposal was that the Irish had only established their compensation scheme following the establishment of Governmental responsibility for the scandal in that country. As British Governmental culpability had not been established, they argued, there was no basis for extending support to this extent.⁹⁰

This argument was challenged by some Parliamentarians at the time, who argued that Irish compensation for those affected had in fact been established *before* any independent inquiry had accepted legal responsibility. Andrew March, an individual with haemophilia who had been infected with HIV and Hepatitis C, thus sought a judicial review of the basis of the Government's decision. In April 2010, the court found in his favour and rejected the Government's basis for rejecting support along Irish lines. The Coalition Government responded in two ways. Firstly, it reiterated its rejection of comparability with Ireland on a different basis.⁹¹ Secondly, it announced an internal review of aspects of the support for those

⁸⁸ Written Parliamentary Question 211033, Diana Johnson MP, Answered 27 Oct 2014.

⁸⁹ At the time this Inquiry report went to print, this report was not available on the UKHCDO's website.

⁹⁰ Colthart (2011), *HIV and Hepatitis C Infection from Contaminated Blood and Blood Products*, Commons Library Standard Note 5698, pp. 16-18.

⁹¹ In essence, it was argued that it would simply be improper to peg the size of a compensation scheme to that of another country. They asserted that Lord Morris' Private Members Bill – by requiring the Government, by statute, to give consideration to the support offered in Ireland when deciding on the support arrangements – did this.



infected and – as part of this – brought forward the planned review of assistance for HCV infectees. This internal review was published in January 2011 and brought about a number of significant changes to the support arrangements, leaving us with the system we have now:⁹²

- Annual payments of £12,800 were established for those with Stage 2 HCV, administered through the Skipton Fund. The lump sum payment for Stage 2 HCV infectees was doubled to £50,000. Those who had previously claimed the smaller £25,000 lump sum could apply to Skipton to have their payment topped up to £50,000. The £12,800 payments increase in line with inflation.
- Stage 1 HCV infectees did not get access to the same ongoing payments. This was justified on the basis of an independent review by experts,⁹³ which argued that those with Stage 1 HCV were not in a state of ongoing need and so did not warrant ongoing payments.
- A charity, the Caxton Foundation, was set up to provide discretionary support to HCV infectees. Those infected with both HIV and Hepatitis C were barred from registering with Caxton: they could only register with MFT or Eileen.
- The families of HCV infectees who had died prior to 29 August 2003, before the Skipton Fund was established, were given a window of opportunity to obtain their unclaimed lump sum payments. This window was open from January 2011 through to the end of March 2011 in England, whilst for those in Scotland, Northern Ireland and Wales can still apply. However, within England, individuals are still free to make late applications if they have a good reason for having not applied during this period and, in practice, no application has yet been refused on the grounds of being late.⁹⁴
- Free prescriptions were extended to all primary beneficiaries, and some £300,000 was set aside to provide psychological therapies for all beneficiaries up to 2013/14.
- The funding arrangements for MFT and Eileen were restructured. MSPT 1 and MSPT 2 were dissolved and a new private company – the Macfarlane and Eileen Trust (MFET) – was established. As well as administering lump sum payments, MFET took up the role of paying out the £12,800 non-discretionary ongoing payments, with the funding for MFT and Eileen, which had previously provided for ongoing payments, reduced to account for this.

⁹² Colthart (2011), *HIV and Hepatitis C Infection from Contaminated Blood and Blood Products*, Commons Library Standard Note 5698, pp. 3-4.

⁹³ Annex 4, 'Reviewing the natural history of hepatitis C infection', in Department of Health (2011), *Review of the support available to individuals infected with hepatitis C and/or HIV by NHS-supplied blood transfusions or blood products and their dependants*, pp. 45-64.

⁹⁴ Written Parliamentary Question 211080, Diana Johnson MP, 27 Oct 2014.



Chapter 3

Current support arrangements – an appraisal

'I have seen her in tears on a number of occasions over the way her applications have been handled. She's been asked to jump through some ridiculous hoops and subjected to delays and refusals without good reason. She is not strong enough to take such a battering.'

- Husband of someone infected with hepatitis C, written evidence to our Inquiry.



3.1. Overview

This chapter forms the main part of the APPG's inquiry and considers, in turn, a range of issues with the current support arrangements for those affected by the scandal. The chief body of evidence it draws from is quantitative and qualitative data from a YouGov survey of all those affected by the tragedy, the details of which are set out further in sections 1.4 (b) and 5.2 of this report. However, this is supplemented by written parliamentary questions and evidence provided to us by the trusts.

All aspects of the current support arrangements are considered in this chapter. Section 3.2 investigates the issue of low awareness of the support available and the difficulties registering for it amongst HCV infectees in particular. Section 3.3 focusses specifically on the non-discretionary support offered by the three charities. It investigates survey respondents' overall impressions of the three charities before going on to investigate awareness of the support available and the difficulties respondents have faced in accessing it.

Section 3.4, continuing with the investigation of charitable discretionary provision, sets out issues with the management, funding and appeals system of the three charities. It explores how there is a perception amongst some survey respondents that the DH has undue influence over the three charities, and investigates potential causes for this in terms of the absence of an effective system of external redress for registrants coupled, unstable Governmental funding arrangements and the representativeness of the boards of trustees of the three charities.

Finally, section 3.5 considers whether the whole system of discretionary and non-discretionary provision is sufficient to meet beneficiaries' needs. It first investigates the charities' difficulties balancing the three competing needs set out in section 2.4 with the limited resources they have available, with Caxton's ability to provide sufficient ongoing payments to widows and primary beneficiaries and MFT's ability to a sufficient grants budget particularly mitigated by these arrangements. It then goes on to assess whether the basis on which those with Stage 1 HCV are denied ongoing payments – that those with the condition are not in a state of ongoing need – is supported by the APPG's survey evidence. Then some consideration is given as to the level at which the discretionary and non-discretionary mix of payments should be set, and questions are raised over whether the poverty line alone is a sufficient basis on which to set payments. The extent to which the partners of now-deceased infectees are sufficiently provided for by the three charities is then investigated, with the gaps in provision between the HCV and HIV charities highlighted. Finally, some exploration is given as to the whole range of needs which are not met under the current support arrangements, but which APPG survey respondents said were in need of being addressed.

The findings of this chapter form the basis of the recommendations of this report, which are then set out in detail in Chapter 4.



3.2. Crossing the first hurdle: difficulties registering with the Trusts

(a) Under-registration

Whilst the initial settlement for haemophilia patients with HIV reached the entire infected community in the 1980s, the same cannot be said for the later settlements for other groups. As discussed in section 2.2 (a), there is a problem of low awareness of the support available amongst the HCV-infected community and, to a lesser extent, those with HIV who do not have bleeding disorders.

The APPG was unable to obtain information on under-registration with Eileen and no representations were received in this area, although the fact that Eileen received a new registrant as recently as 2013⁹⁵ suggests it is an ongoing issue. Furthermore the Archer Inquiry itself observed with respect to Eileen that “there is reason to believe there may be many more [potential Eileen registrants] who would qualify for registration, but since in most cases they were not originally diagnosed as suffering from an ongoing disorder, their cases were not followed up, and often neither they nor their doctors are aware of the cause of their infection.”⁹⁶

There is, however, strong evidence of a particular issue of under-registration within the HCV-infected community. This is likely in part because, in contrast to HIV, the symptoms of Hepatitis C are not particularly distinct from other viruses’ the condition is not always life-threatening; and – most importantly – it can have a relatively long incubation period of several years before symptoms start to emerge. People are thus not always aware they have the condition. In addition a large proportion of the HCV-infected population – approximately 28,000 of the 33,000 the Government estimates to have been infected at the acute stage – did not have haemophilia and were infected following blood transfusions. Some evidence suggests awareness of the support available is particularly low amongst this community of infectees.

It is possible to get an impression of the gap in take-up of a range of forms of support by comparing figures and estimates on the numbers of people potentially eligible for the payments with the actual take-up of support. Figure 7 overleaf, drawing from a variety of sources, attempts to estimate levels of take-up.

The figures show gaps in take-up for a variety of forms of support. This is most dramatic for the families of people infected with Stage 1 HCV who died before the Skipton Fund was established, approximately 87% of whom have not obtained their lump sum payments. However, a gap in take-up is evident for a range of other payments, including Stage 2 lump sums, ongoing Stage 2 payments, and £25,000 top-ups for those who had previously made a Stage 2 Skipton claim before the lump sum was increased in 2011.

It is also possible to arrive at a crude estimate of the proportion of the overall eligible population who have not registered for discretionary support from Caxton, and this is attempted in the lattermost rows of Figure 7. Given that these figures relate to 2012, caution

⁹⁵ Written Parliamentary Question 214975, Diana Johnson MP, answered 25 Nov 2014.

⁹⁶ Archer et al (2009), *Independent Public Inquiry*, p. 81.



Figure 7

Gaps in take-up for various forms of non-discretionary support for HCV infectees

Payment type	Number of recipients	Estimated number who may be eligible	Estimated percentage of non-claimants
Stage 1 Skipton payment to family of recipient who died before 29 August 2003	472, of which 441 treated with cryoprecipitate / concentrate and 31 with a whole blood transfusion. ⁹⁷	3507 ⁹⁸	87%
Stage 2 Skipton payment to family of recipient who died before 29 August 2003	258, of which 236 treated with cryoprecipitate/ concentrate and 22 with a whole blood transfusion. ⁹⁹	702 ¹⁰⁰	63%
Ongoing Stage 2 Skipton Payments	548 (Mar 2012) ¹⁰¹	783, both those registered and not registered with a trust (Mar 2012) ¹⁰²	30%
£25,000 top-ups to those who had previously received a Skipton Fund stage 2 payment of £25,000 before its 2011 increase.	787 ¹⁰³	886 ¹⁰⁴	11%
Registration with Caxton by those eligible.	Overall eligible: 2400 (Feb 2012) ¹⁰⁵	787 (Sept 2014)	Over 50% ¹⁰⁶
	Stage 2 HCV already receiving ongoing Skipton payments: 548 (Mar 2012) ¹⁰⁷	Stage 2 HCV Caxton registrants: 170 (Sept 2014)	Over 50% ¹⁰⁸

⁹⁷ Written Parliamentary Question 211080, Diana Johnson MP, Answered 27 Oct 2014.

⁹⁸ Based on expert estimates of HCV infectees who died prior to 2003 published in Annex 2, “Estimate of the total number of Hepatitis C infected in UK infected over the period 1970-1991”, in Department of Health (2011), *Review of the support available to individuals infected with hepatitis C and/or HIV by NHS-supplied blood transfusions or blood products and their dependants*, pp. 41-42. Derived from Written Parliamentary Question 129969, Nick Harvey MP, Answered 28 Nov 2012.

⁹⁹ Written Parliamentary Question 211080, Diana Johnson MP, Answered 27 Oct 2014.

¹⁰⁰ Written Parliamentary Question 129969, Nick Harvey MP, Answered 28 Nov 2012.

¹⁰¹ Ibid. Again derived from expert assessments of the numbers eligible at the time, published in Annex 2 of the 2011 review. The DH was asked to provide a more up-to-date estimate of the gap in take-up, but they only provided an estimate of the number of people registered with the trusts who had not applied for ongoing payments (27 individuals) rather than an estimate of the overall number who had not obtained payments (See Written Parliamentary Question 215020, Diana Johnson MP, Answered 25 Nov 2014).

¹⁰² Ibid.

¹⁰³ Written Parliamentary Question 213610, Diana Johnson MP, Answered 17 Nov 2014.

¹⁰⁴ Ibid. The Department of Health claim this gap is “because out of date contact details have meant that efforts at contacting these individuals were unsuccessful.” However availability was only advertised online and through telephoning those who had registered numbers – it does not appear to have been advertised by post (Source: Written Parliamentary Question 213611, Diana Johnson MP, Answered 17 Nov 2014).

¹⁰⁵ 2000 primary beneficiaries / 400 dependant families. Based on estimates made by Peter Stevens, then-outgoing chairman of the Caxton Foundation, during a paper presented to trustees of Caxton. Found at Caxton Foundation (2012), *Minutes of the Meeting of the Board of Directors of Caxton Trustee Limited*, 7 Feb 2013, p. 2. The APPG requested this report from Caxton, but it was denied.

¹⁰⁶ Caution: not comparing figures from the same time period.

¹⁰⁷ Written Parliamentary Question 129969, Nick Harvey MP, Answered 28 Nov 2012.

¹⁰⁸ Caution: not comparing figures from same time period.



is advised in comparing them with modern-day figures on take-up, but they nevertheless do suggest that, on a conservative estimate, a majority of those eligible for Caxton registration have not registered for the charity. This is true even with respect to those with Stage 2 HCV – given that these individuals are considered to be in the greatest need, there is less of a reason for them not to register with the charity, suggesting their not registering is due to a genuine lack of awareness of Caxton’s existence.

These figures reveal that there are in fact two reasons for the low take-up. Firstly and most obviously, there has been a failure to communicate the existence of Caxton to potential registrants. Some evidence suggests this is a particular problem among those without haemophilia: a disproportionately-low number of households obtaining Stage 1 and 2 Skipton payments belonged to this community. One respondent to the APPG’s YouGov survey, who did not have haemophilia, relayed to us their view that people within that community only become aware of the trusts through chance:

‘There is not enough information provided for people who have contracted contaminated blood through transfusion. I was made aware through my own consultant in the mid-nineties and two years ago through a conversation with one of my liver specialist nurses. I feel there are many people who are missing out on payment.’

Secondly, and more worryingly, the trusts themselves have not communicated *to those already registered* the availability of certain forms of assistance. 13% of those eligible to have their Stage 2 Skipton lump sum payments topped-up by £25,000 – because they had previously claimed the lower lump sum before the Government increased it in 2011 – have not claimed this money. However all these people, by definition, will already be registered with the Skipton Fund and should be easily contactable by Skipton. The same is true with respect to those 548 individuals with Stage 2 HCV who were receiving ongoing Skipton payments in March 2012, over 50% of whom, on a conservative estimate, did not register with Caxton.

Recent events, as well as written evidence the APPG has received from respondents to our YouGov survey, reinforce this argument. The Skipton Fund has been administering lump sum payments to people infected since 2004, but the Caxton Foundation was only established to provide discretionary support to all Skipton registrants, and their families, in 2011. All those already registered with Skipton when Caxton was established should have been contacted and informed of the discretionary support available. It is clear from the evidence the APPG has received, however, that no such attempt was made.

Many of the people infected with HCV who responded to our survey told us that prior to receiving the APPG’s survey in the post via the Skipton Fund, they had never even heard of the Caxton Foundation. As one respondent, registered with the Skipton Fund, told us:

‘Until I received this letter today I was unaware of any additional support ... Certainly nobody, especially my specialists, has ever mentioned any of the other trusts or foundations. I think this is wantonly neglectful.’

Others had only recently been made aware of Caxton’s existence, often purely by chance. One respondent had only heard of Caxton after writing a letter to the Prime Minister demanding he increase support for those with HCV, in which the Prime Minister mentioned Caxton in his

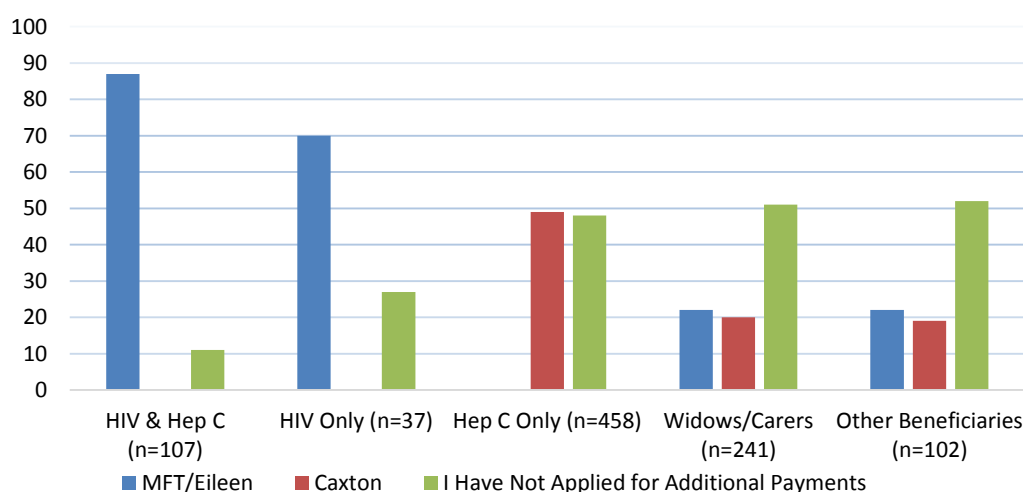


response. Another said they had ‘been infected for 23 years’ but ‘only knew about the Caxton Foundation two months ago.’

Recent events corroborate with this qualitative evidence. In September last year, the Caxton Foundation was told by the Department of Health to contact every Stage 1 registrant of the Skipton Fund who had never been contacted since first receiving their Stage 1 payment. Shortly afterwards, the APPG asked Skipton to disseminate our survey to its registrants by post. These twin events had the effect of raising awareness of the existence of the Caxton Foundation across the beneficiary community. In September 2014 alone, there was a 20% increase in beneficiary numbers – this stands against an increase of only 3% during the entire five months prior to this. It is therefore clear that no effort had previously been made to inform all Skipton registrants of Caxton’s existence. Had this not been so, we would not have seen this spike in registrations.

The quantitative survey evidence supports the conclusion that the Caxton Foundation in particular has an issue with low take-up of support. Respondents were asked if they had ever applied for discretionary support from the charity in which they were eligible to make claims. The results are presented in Figure 8 below.

Figure 8
Percentage of survey respondents who have ever applied for discretionary support from their respective charities



It shows that take-up of support among HCV infected and secondary beneficiaries is significantly lower than take-up for MacFarlane Trust/Eileen support among singularly and co-infected HIV infectees. Some 87% of co-infected HIV infected have accessed support from MacFarlane Trust or Eileen, and just 11% have never accessed support. By contrast, just 49% of those with HCV have applied for Caxton support and an equal proportion (48%) have never applied for any additional payments. This proportion is even lower among widows and carers with just 25% having applied to the MacFarlane Trust, 20% Caxton and 51% having never applied for additional payments – the difference in applications from other beneficiaries, such as dependants, is statistically insignificant from this (21%, 19% and 52%, respectively). Finally, there is also a statistically significant¹⁰⁹ difference in take-up between HIV-infected and co-

¹⁰⁹ This difference has been calculated to be significant at the 95% confidence level (P = <0.05).



infected recipients with respect to MacFarlane Trust/Eileen applications – 70% of HIV-infected people have accessed MacFarlane Trust/Eileen payments, and 27% state they have never applied for additional payments.

Although other factors¹¹⁰ may explain part of this difference, it is clear from the survey evidence that there is an issue of low take-up amongst HCV infectees, those solely infected with HIV and the secondary beneficiary population.

In summary, it is evident from the information available that there is an issue of under-registration for support, particularly – though not exclusively – among those with HCV and secondary infected. To at least some extent, this gap is a result, firstly, of a lack of awareness among infected of the support available; and, secondly, a significant failure among the trusts themselves to communicate the assistance available to their own beneficiaries.

(b) Proving entitlement to non-discretionary Skipton payments

Even once they become aware of the support available, in order to obtain payments individuals must then prove they were infected with HIV or HCV through NHS treatment during the relevant time period. Obtaining non-discretionary payments also allows a primary beneficiary, or their family, to register with the relevant discretionary charity. This is relatively straightforward with respect to most prospective registrants to the HIV trusts and the APPG has not received any representations from HIV infectees highlighting difficulties registering – although again, it is possible that there are issues registering with Eileen.

However, as before, a different picture emerges with respect to people infected with hepatitis C. This chapter investigates the issues related with obtaining Skipton Fund payments.

If an individual wishes to receive Skipton payments, they must first register with the Skipton Fund – as already noted in section 2.2 (a), “registration” occurs prior to acceptance or rejection, and those nominally “registered” with the fund are not entitled to payments unless they provide further proofs.

Two sets of proofs are required. Firstly, they must provide NHS medical records proving that historically, they received NHS treatment before the relevant time period, namely September 1991. Rather than proving that a specific batch of blood was infected, individuals must only provide sufficient evidence to suggest that on ‘the balance of probability’ the cause of their HCV infection is that they underwent NHS treatment. As set out on Skipton’s website, this means proving that:¹¹¹

‘...exposure to hepatitis C is more likely than not to have resulted from ... exposure to blood, blood products or tissue through NHS treatment with one or more of those products that occurred before 1st September 1991 ... It has to have been a probability and not just a possibility that your infection with hepatitis C occurred in this way.’

¹¹⁰ It is possible that, to some extent, a disproportionate number of individuals in certain sub-groups did not need assistance, and so did not apply for it, or alternatively that the support they were looking for was not available as they did not bother to make an application.

¹¹¹ Skipton Fund website, www.skiptonfund.org.



Secondly, their hepatologist must provide, on their behalf, sufficient medical proof that they were infected with either Stage 1 or Stage 2 HCV. Liver biopsies are recognised as the most accurate means of confirming HCV infection, but such operations are highly costly and potentially fatal for people with haemophilia. Indeed Skipton's eligibility criteria, laid down by the Government, explicitly disqualifies people with haemophilia from registering if they had a liver biopsy solely for the purpose of proving HCV infection.¹¹² Consequently, the majority of applicants – both those with a bleeding disorder; and those without – do not support their application with any biopsy data. For applicants unable to produce biopsy data, alternative proofs are accepted. These are different depending on whether an individual wishes to prove Stage 1 or Stage 2 HCV: ¹¹³

- **Proving Stage 1 HCV:** An individual must have been infected with HCV for at least six months without clearing the virus. Viral infection after this point can be proved either by a test showing HCV viral presence in the blood – Skipton recommends a Polymerase Chain Reaction (PCR) test –; or by evidence showing one is undergoing medical treatment for HCV infection.
- **Proving Stage 2 HCV:** This requires applicants to further convince Skipton that they either presently have cirrhosis, or that they are *more likely than not* to progress to it; or alternatively that they have b-cell non-Hodgkin's lymphoma or have been diagnosed with primary liver cancer. Failing this, then in the absence of biopsy data, applicants can either provide Skipton with test results at least three months apart measuring AST, ALT and platelet levels in the blood; or they can provide a variety of other forms of evidence, including evidence from a fibroscan to measure the level of fibrosis in the liver or proof that they are undergoing a liver transplant.

Complete applications are then considered by the five directors of the Skipton Fund – three of whom are not themselves hepatologists. Unclear or more complex applications are considered by the two hepatologist directors. Appeals against rejections can be made to an Appeals Panel whose members are independent of the Skipton Fund. Its membership includes a judge appointed by the Department of Justice, a hepatologist and a haematologist.¹¹⁴

Figure 9 overleaf presents figures on the total number of historic Skipton applications accepted, deferred or rejected since Skipton's inception. It should be noted that Skipton applications are only 'rejected' when the applicant dies: if any application is refused on the grounds of insufficient information, it is only ever 'deferred' pending the provision of further supporting evidence. It also gives figures on number of appeals historically taken to Skipton's appeals panel, and the number of which appeals were found in favour of the appellant.

¹¹² Andrew Lansley MP, Hansard HC Deb 10 Jan 2011, Col 42.

¹¹³ Evidence obtained from Skipton Fund website, www.skiptonfund.org, and from evidence provided to the Haemophilia Society by the Skipton Fund.

¹¹⁴ Skipton Fund website, www.skiptonfund.org,



It shows that a considerable proportion of Skipton applications – some 16% - have been deferred or rejected. This is a large number of applicants unable to obtain Skipton payments. More concerningly, it also shows that of the 412 appeals historically considered by Skipton’s appeals panel, more than half – 210 – have overturned Skipton’s original decision. This is a concerningly high rate for an appeals panel, and suggests that there is a high degree of ambiguity and difficulty interpreting eligibility criteria in Skipton’s decisions. The APPG has even received representations from individuals rejected by Skipton despite the fact that their own hepatologists insisted that they had Hepatitis C.

There are potentially many factors which explain these issues, but from the evidence gathered the APPG has identified three issues in particular.

Firstly, amongst those Skipton applications rejected for a reason other than natural clearance of HCV, the majority of rejections are because of incomplete hospital records proving they had historically undergone treatment with NHS blood products.¹¹⁹ Given that the Skipton Fund was only established well over a decade after the last HCV infections on the NHS, in 2003, it is not surprising that many NHS hospitals have lost hospital records, and the APPG has received written evidence from a number of infected people who are unable to obtain Skipton payments for this reason. Given that applicants themselves can hardly be blamed for the loss of their hospital records, this constitutes a particularly callous reason for refusing a Skipton payment. Although Skipton’s website contains a section advising registrants on ways to pursue lost records from public bodies, it is left to applicants themselves to chase these records. This is most particularly unfair for those with haemophilia, who would almost certainly have undergone NHS treatment during this period. We will return to this issue in the recommendations, in chapter 4.

Secondly, a number of respondents have reported difficulties gaining access to a hepatologist to provide medical evidence to Skipton. There is a patchwork of provision across the NHS, and some applicants are less able to access professional guidance than others. As the Archer Inquiry noted in 2009,¹²⁰

Figure 9
Total Skipton applications and appeals to Skipton’s appeals panel, broken down by outcome.

Skipton Applications ¹¹⁵				
Total Registrations		6871		
Total Completed Applications		6181		
Of which...	Accepted	5181		
	Deferred	299		
	Rejected	...Because virus cleared naturally within 6 months. ¹¹⁶	193	
		... For another reason. ¹¹⁷	508	
	% Applications deferred/rejected		16%	
Appeals to Skipton Appeals Panel ¹¹⁸				
Appeals Considered		412		
Of which found in favour of appellant		210		

¹¹⁵ Written Parliamentary Question 213621, Diana Johnson MP, answered 17 Nov 2014.

¹¹⁶ Written Parliamentary Questions 213619 & 213620, Diana Johnson MP, Answered 17 Nov 2014.

¹¹⁷ Written Parliamentary Question 213788, Diana Johnson MP, Answered 11 Nov 2014.

¹¹⁸ Written Parliamentary Question 210937, Diana Johnson MP, answered 16 Oct 2014.

¹¹⁹ Written Parliamentary Question 213788, Diana Johnson MP, Answered 11 Nov 2014.

¹²⁰ Lord Archer et al (2009), *Independent Public Inquiry*, p. 83.



‘Those who administer the [Skipton] Fund admit that they are totally dependent on the medical advice which they receive. Some hospitals are reluctant to support claims from patients who have been cleared of the virus, and those whose condition could not now be confirmed by a test. Others appear to give the benefit of the doubt to the patient.’

One person with Stage 2 HCV relayed a similar concern to the APPG Inquiry:

‘As a result of not having a consultant who knew me well enough there were several years of delay in making my application to Skipton. I have missed out on regular payments – these should have been backdated.’

Thirdly, there are concerns that there may be difficulties, particularly for those with haemophilia, providing the medical proofs to prove they have progressed to Stage 2 HCV. As noted above, in the absence of biopsy evidence – which is not appropriate for people with haemophilia – Skipton accepts a range of surrogate proofs to prove progression to Stage 2 HCV. It is acknowledged that this surrogate evidence is not perfect, and constitutes a second-best to a biopsy. In 2003-04, as noted in section 2.5 (b), the Government consulted independent experts on the appropriate trigger point for Stage 2 HCV infection.¹²¹ At these meetings, the experts emphasised that:¹²²

‘the issue of using surrogate markers to predict the degree of liver fibrosis was a difficult one; if it were not, clinicians would already have stopped using liver biopsy. No specific index or combination of tests had yet proved perfect.’

The Haemophilia Society has obtained evidence from Skipton suggesting that people with haemophilia in particular – who are reliant on these surrogate tests to prove Stage 2 HCV infection – may face difficulties proving eligibility. Figure 10 below presents data obtained from

Figure 10

Applications accepted, deferred and rejected by the Skipton Fund, broken down by type of bleeding disorder, as at 24 October 2014.¹²³

	Total applicants	Skipton Fund Stage 2 application status		
		Accepted	Deferred	Rejected
With Bleeding Disorder	924	743	136	45
Without Bleeding Disorder	886	792	77	17

¹²¹ Written Parliamentary Question 211083, Diana Johnson MP, Answered 27 Oct 2014.

¹²² File 6, “Additional minutes paper on surrogate markers to predict the degree of liver fibrosis.” Accessible at www.parliament.uk/depositedpapers by selecting 13 Nov 2014 as the date range.

¹²³ Source: Skipton Fund email to Haemophilia Society, 24 October 2014.



the Skipton Fund on the total number of Stage 2 Skipton applications accepted, deferred and rejected since Skipton's inception, broken down by whether or not an applicant has a bleeding disorder. It shows a statistically significant¹²⁴ difference between applicants with haemophilia and those who don't have haemophilia with respect to the number of applications deferred and rejected.

Though there may potentially be a benign explanation for this difference,¹²⁵ it is also possible that the gap in acceptances is because of some form of discrimination against the haemophilia community, who, in the absence of any biopsy data, are solely reliant on surrogate tests to prove infection. This in spite of the fact that Skipton's guidelines for proving Stage 2 HCV infection, as mentioned earlier, theoretically set the bar of eligibility quite low: applicants are only expected to prove that they are *more likely than not* to develop cirrhosis, primary liver cancer or any other conditions which make them eligible for a Stage 2 payment.

This information, in sum, suggests that there is some cause for concern that many individuals who justice demands should receive Skipton Fund assistance are not in fact able to access it, either because the Skipton Fund – sometimes contrary to the representations made by applicants' own health consultants – does not consider their evidence of medical need strong enough; or because through no fault of their own the NHS has lost record of their undergoing treatment. It is a particular injustice to deny those with Haemophilia Skipton payments on the grounds of either incomplete hospital records –given that they almost certainly underwent NHS treatment during the relevant time period –; or of insufficient medical evidence – in the absence of biopsy data. This highlights that there is a need to review the whole medical basis of Skipton payment eligibility and to consider ways in which the trusts could support those struggling to access payments from the trusts. We will return to this issue in our recommendations in chapter 4.

¹²⁴ This difference has been calculated to be significant at the 95% confidence level ($p < 0.05$).

¹²⁵ It is thought by Skipton that those outside the bleeding disorder community apply for support later on in the process of their infection when it is clearer to them that they have developed cirrhosis. In addition, because clinicians will likely already have definitive biopsy data for more of those without haemophilia, a greater proportion will know that they do not have cirrhosis before having to apply. These twin factors may have the effect of inflating the success rate of applications outside the haemophilia community.



3.3. ‘The worst form of modern-day begging that I know of’: accessing discretionary support

(a) Recipients’ overall impression of the three charities

Although the three charities constitute the smaller part of the wider support package – constituting a third (34%) of the Government’s overall financial contribution to the trusts in 2013/14 – they have historically proved the largest source of complaints among all recipients. Consequently, the APPG questionnaire asked respondents a range of questions about their feelings around the process of applying for trust-based support, their opinions of the trust and their knowledge of the decision-making process, and invited respondents to provide further written comments. This has presented us with a rich array of quantitative and qualitative data. This section sets out the results of this survey evidence.

Those who had applied to their trust for discretionary support were presented with a range of potential positive and negative words to describe their overall experience of contacting their trust regarding additional support. They were asked to select one. Figure 11 presents the overall results given by respondents, while figure 12 outlines the proportion of positive responses broken down by beneficiary status, trust applied to and whether or not their application was successful. The results show that the majority of respondents overall used positive words to describe their experiences, but a significant minority – 35% – used negative words. When the responses are broken down further, however, it becomes clear that among some groups of beneficiaries only a minority of respondents have given positive responses. These are: those with hepatitis C and HIV (34%), other beneficiaries (37%), those whose application was unsuccessful (41%) and applicants to the Macfarlane Trust (44%).

A significant number of respondents who chose to provide further written evidence were – corroborating with the overall a results – positive about the trust-based system of provision and expressed their gratitude to the trusts. However within the qualitative evidence, three additional trends in the evidence are apparent.

Firstly, a number of respondents who were positive about their charity qualified their praise with the caveat that the overall support available to the charities was not sufficient to meet beneficiaries’ needs. The trusts, in their minds, did the best job they could in impossible circumstances, with these respondents’ anger being directed at the Department of Health and not Trust staff.

Secondly, a significant minority of those responding to the survey called for the trusts to be abolished entirely and for the support to be delivered in alternative ways, either by the Government directly or in the form of a large one-off lump sum settlement. Many campaigners

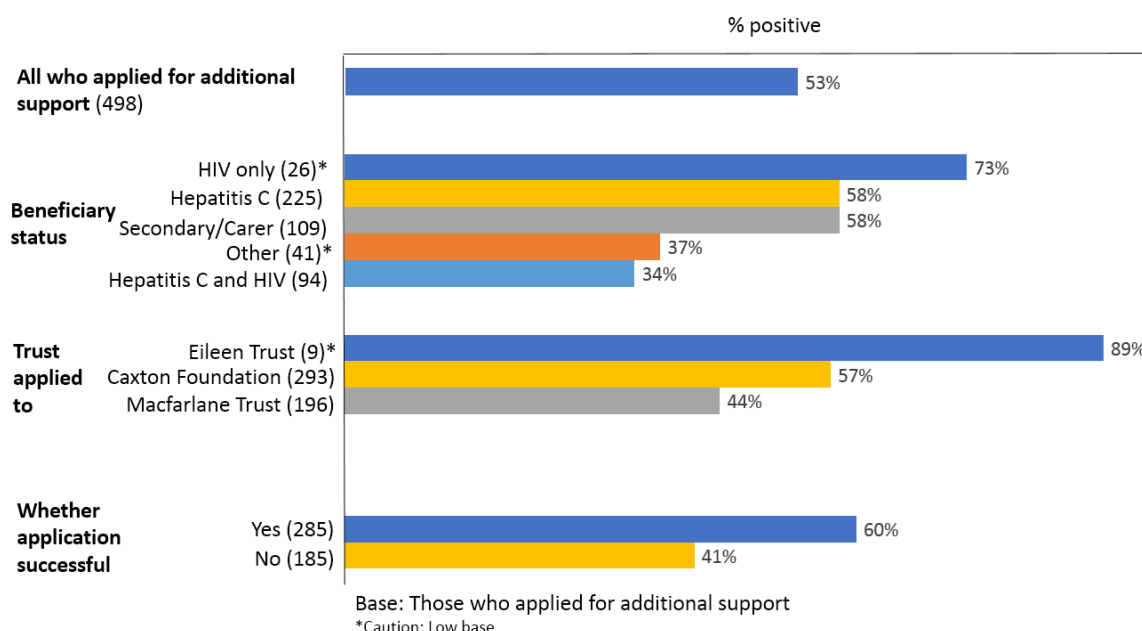
Figure 11
Which of the following words best describes your experience of contacting your trust or fund in regards to additional support? (Please select one)

	All who applied
<i>Base: Those who applied for additional support</i>	498
	%
Helpful	22
Discouraging	17
Supportive	13
Dismissive	11
Respectful	10
Kind	6
Disrespectful	5
Rude	1
Don't know	13
Any positive	53
Any negative	35



have long held the view that the entire trust-based system of provision should be decommissioned, and indeed the 2009 Archer Inquiry itself recommended that all future support be delivered directly through the DWP. It should be emphasised, however, that many respondents in the qualitative evidence by respondents giving positive accounts of the trusts; and it should not be forgotten that, as Figure 11 shows, a majority of respondents used positive words to describe their experience of accessing trust-based support. There is an evident split amongst those affected by the scandal as regards the trusts: whilst a number of respondents would like to see them abolished, amongst many others, such moves would cause undue distress.

Figure 12
Percentage of respondents giving positive words used to describe applying for trust-based support, broken down by beneficiary status, trust applied to and whether application was successful.



Thirdly, a large number of respondents giving further evidence used an additional word to describe their feelings when applying for support: ‘begging’. Like the person with HCV quoted at the head of this section, many respondents expressed their resentment at the begging process involved with applying for discretionary support. As one co-infected person stated:

‘The whole system seems designed to make you feel like a beggar, rather than being given one’s dues for medical negligence of the grossest order.’

For some, the attitude of trust staff contributed to this feeling, with one co-infected person railing against: ‘very unhelpful staff’ in MacFarlane Trust ‘who seemed to think they were ‘doing us a favour.’ I felt like I was begging in a way.’ Someone with HCV, echoing these views, argued the ‘time-consuming’ process of accessing Caxton support ‘made me feel like I was begging rather than being helped by the agency.’



Finally, in repeated written submissions, a considerable proportion of HIV-infected people argued that the MacFarlane Trust was getting worse. Successive respondents expressed the view that MacFarlane Trust's staff had become less personable and its support less generous than in previous years, with the cessation of MacFarlane Trust social events for beneficiaries a particular concern among respondents.

'In the early days of the Macfarlane Trust', claimed one beneficiary, 'I think it was a lot easier to speak to someone in person and also a lot simpler to apply for and receive grants.' Another stated that MacFarlane Trust was becoming more intrusive than in previous years to assess eligibility for claims, with the charity 'even requesting visiting our homes to look at our living arrangements.' In the minds of another, while 'the initial MacFarlane Trust was run very well many years ago,' it has since been reduced to a 'short-staffed office with employees who are indifferent to our needs.'

This is likely in part due to the greater financial pressures currently faced by MFT. The charity, by its own admission, is unable to run the grants budget it would wish, and in order to pay for further grants it recently had to cease weekend visits – a deeply unpopular move which has caused considerable dismay amongst many registrants. Section 3.5 (b) considers this issue in greater detail.



(b) 'Left in the dark': awareness of the support available and how to access it.

The APPG survey asked respondents two questions about their awareness of both the rules and procedures regarding discretionary support; and the decision-making process for accessing it. Figures 13 and 14 below gives a breakdown of the responses received.

Figure 13

On a scale of 0 to 10, how easy or difficult have you found it to understand the rules and procedures regarding additional support?

	All who applied	Successful?	
		Yes	No
<i>Base: Those who applied for additional support</i>	498	285	185
	%	%	%
0 – Very difficult	35	30	43
1	9	8	11
2	11	13	9
3	8	7	9
4	6	8	4
5	11	14	6
6	3	4	2
7	3	4	2
8	2	2	1
9	1	2	1
10 – Very easy	2	2	3
Don't know	8	6	9
0 - 3	63	58	72
4 - 7	23	29	15
8 - 10	6	7	5

Figure 14

On a scale of 0 to 10, how much do you know about how your trust makes decisions and what processes are involved?

	All who applied	Successful?		Charity	
		Yes	No	The Macfarlane Trust	The Caxton Foundation
<i>Base: Those who applied for additional support</i>	498	285	185	196	293
	%	%	%	%	%
0 – Very little	42	38	51	42	43
1	9	7	11	7	10
2	10	11	9	9	11
3	10	12	9	7	12
4	4	5	2	5	3
5	9	13	5	10	9
6	2	3	1	3	2
7	3	2	2	3	3
8	2	2	2	2	3
9	2	3	1	4	<0.5
10 – A lot	3	3	3	4	2
Don't know	3	1	5	5	2
0 - 3	71	68	79	65	76
4 - 7	18	23	10	20	17
8 - 10	7	8	5	9	5



The tables reveal a striking lack of knowledge among trust recipients of the decision-making process and procedures for accessing support through their charities. For both answers, the vast majority of respondents gave scores at the low end of the 10-point scale (0-3). There was no significant difference in experience between the MacFarlane Trust and Caxton Foundation applicants with respect to the answers in figure 13, and at no point were answers from the small number of Eileen Trust beneficiaries statistically significant from those of the MacFarlane Trust, hence the exclusion of these results from the tables. However significantly more Caxton Foundation (76%) than MacFarlane Trust registrants (65%) reported a low understanding of the decision-making process for their charity's support. Perhaps most concerningly, unsuccessful applicants reported a lower understanding than successful applicants for both questions. This suggests that many individuals who simply lack the wherewithal to understand the applications process but who otherwise have a level of need at least equal to other beneficiaries are being denied access to support– a significant issue which will be revisited in section c below.

The qualitative evidence complements these findings. Some respondents relayed their concerns about being – in the words of a co-infected person quoted above – *'left in the dark'* on *'decisions which have a great impact on our future and finances'* once they submitted their applications. The responses of four MacFarlane Trust registrants encompass the broad range of concerns expressed by those affected:

'Decisions made by MacFarlane Trust and MFET seem to be top secret. They never tell me the criteria for grants and are evasive when asked. Funds are sitting in MacFarlane Trust bank accounts and are not distributed when I feel I am in need.'

'The transparency of the decisions is not there and when applications for grants have been declined there is no reason as to why.'

'I have requested information from the Macfarlane Trust on a number of occasions regarding the process of applying for additional funds and the criteria used to ascertain 'charitable need.' But I am none the wiser.'

'If you application is denied, you are never told why; and the means by which MacFarlane Trust calculates top-up payments are never communicated to fund recipients.'

Most troublingly, however, many beneficiaries reported a general lack of awareness as to precisely what discretionary support was available for them to claim. It was claimed by some that the MacFarlane Trust used to publish a booklet setting out in detail what discretionary support was available, but that this booklet was no longer available; and indeed one MacFarlane Trust registrant protested that they had *'never been offered or given a simple list of available help in an easy-to-access form.'*

The concerning consequence of this is that many respondents have lost out on help they were entitled to, and sometimes had to pay out of their own pocket for items they subsequently discovered they could have claimed for. As the charities are averse to paying out retrospectively for claims, most such claimants have been unable to recuperate their money. As one HCV-infected person reported:



'I didn't even know that I could claim my hospital expenses back, and as I've been to seven different hospitals – some over 50 miles away – since losing my job because of this mistreatment, I am now in massive debt. Caxton does not inform you of anything, I had to find it all out via Facebook.'

Another Caxton beneficiary claimed that since first receiving his Skipton payment, he had never had a holiday because he had not been made aware, until recently, that Caxton offered support for this. One had similarly assumed that the only discretionary help he could get would be for disability adaptations to his home, and was never informed of other assistance available. Finally, another respondent stated that:

'Although registered with the Caxton Foundation since being paid from the Skipton Fund, I was not told about the lump sum fuel allowance and was only informed when I made a claim for expenses last year. The Caxton Foundation refused to backdate it.'

Finally, the APPG also received evidence from the widows/widowers and carers of infectees that they were never informed of the discretionary ongoing support available to them. One carer gave evidence to our Inquiry that after her HIV-infected son died, though there were initial hopes that she as a carer might receive ongoing MacFarlane Trust payments, this never came to fruition. However three years later, by chance, she attended a memorial service in which one of MacFarlane Trust's staff, also present, told her she might be eligible. She applied, and began to receive ongoing payments – but for three years prior to this point, she was using her own savings to support herself. Likewise, another respondent – a widow – was never told there was support available to her, and only realised two years ago.

This evidence – echoing the findings of section 2.2 earlier – suggests that the trusts themselves must shoulder some considerable blame for issues with low take-up among beneficiaries. They have evidently failed to notify beneficiaries already registered with the charities of the range of discretionary support available, with the consequence that some people in a severe state of need have been left to fend for themselves.

(c) Difficulties claiming for and proving entitlement to support

A range of concerns were expressed by respondents with respect to difficulties negotiating the charities' application process for discretionary support. The problems experienced fall into four approximate categories. We consider each in turn below.

Firstly, the APPG survey received numerous comments from recipients expressing their deep resentment at the demeaning, intrusive and overly-bureaucratic processes involved with negotiating access to charitable assistance, with the level of proofs required sometimes bordering on the nonsensical. Troublingly, some found the whole process so stressful that they had simply given up even trying to access assistance:

HCV infected: *'After my last request – for a summer respite break for my son and I after he finished his exams – I was asked for proof that a break would be beneficial. As if you need to prove that you would benefit from a break!'*



HIV infected: ‘... [Applying to the MacFarlane Trust was] a very degrading and humiliating experience. It felt like I had to justify why I needed help and how I was unable to continue to cover the cost myself. Completing the financial aspect of the application was particularly unpleasant.’

HCV Infected: ‘When I applied for funding to have a broken tooth crowned I was told to submit verification from a doctor that my tooth problem was because of hepatitis C plus further verification from my dentist that the work is not for cosmetic reasons. I gave up on this and had the tooth ‘patched’ for the umpteenth time in order to stop the toothache.’

HCV infected: ‘I have simply given up trying. I now have liver cirrhosis – I simply don’t have the energy anymore.’

Others regarded the general demeanour of trust officials discouraging. One family said that with respect to discretionary support applications from their HIV infected son:

‘The trusts are always saying ‘funding is limited so we have to make tough decisions’, ‘you could apply but it is unlikely to be granted.’ Whatever the situation, he always has a battle to get his needs even considered and the usual trust response is ‘can’t you pay for that with your benefits?’; or ‘you need to try other organisations first such as local authority or social services’; or ‘we don’t do grants anymore.’

When support was forthcoming, many respondents expressed their frustration that it was not sufficient to meet their needs. Often a charity would respond to an application by only giving half the money required due – ostensibly – to a lack of funds. For applicants on the poverty line, this would not be sufficient and they would often be unable to purchase the item:

HCV infected: ‘When an occupational therapist stressed I need certain adaptations to the house costing so much, only 50% of the grant was made available. After begging, the allocation went up to 66%! What good is 66% when only 100% will do?’

Finally, there were also general concerns about the quality of service from trusts. Applicants often had to approach particular members of staff to make specific claims. These staff were not always in the office when applicants phoned the trust, and they did not always return emails or messages when left. When they did reply, it would often take over a week:

‘Nobody can help at the time of ringing. Usually you can wait days or even weeks before somebody gets back to you about the issue you’re calling about... I feel like the person on the other end of the phone is being dismissive and just wants to fob you off onto somebody else.’

Secondly and more specifically, some respondents raised more explicit concerns about mistakes made by the charities, difficulties contacting specific staff members and delays experienced when applying for payments.

Many of these complaints centred on the considerable time it often took to obtain payments. For the Caxton Foundation, small grants for low-cost items such as foodstuffs can be processed by staff themselves. The average turnaround time for these grants is four days. However, more expensive claims above an unpublished advisory financial amount – staff are free, at their



discretion, to process some claims above this advised amount – claims must be considered by the National Welfare Committee (NWC), a sub-committee of Caxton’s Board of Trustees.¹²⁶ The NWC meets once every six weeks, with the average turnaround time 13 days after an NWC meeting.¹²⁷

The NWC waiting time proves impractically long for many claims, and even a turnaround time of four days for low-cost necessities is considered too long by some respondents. In addition, waiting times do not of course consider the time it may take beneficiaries to produce the supportive evidence. If claiming for building or repair work, for example, applicants need to provide three quotes from different builders to support their application. This can take some considerable time. The problem is compounded by the fact that the charities do not generally accept retrospective claims. Recipients who pay for goods out of their own pocket because of the lengthy waiting time and submit an application later consequently find themselves unable to reimburse the costs. The following responses were typical of the frustration felt by many beneficiaries regarding this process:

HCV Infected: *‘When my ancient washing machine broke down ... I found that if I ordered one from Curry’s that day, I could take advantage of free, next-day delivery. So I placed the order online and then immediately sent an application to Caxton with a full explanation of the circumstances, but the application was turned down because it was deemed to be ‘retrospective’! ... This is a cruel and callous way to treat the victims of an NHS disaster.’*

Co-Infected: *‘I had a hole in my roof with water seeping through onto the floor and in the electrics. I was told that I needed two quotes and then they may look at it at the end of the month when the committee sat. The committee sat and [by that point,] more damage had been done to the floor, which I have never had any help with.’*

HCV Infected: *‘At times it has been a long and drawn out affair. When my washing machine broke down it took me 3-4 months to get help and I was getting my washing done at a friend’s house. I found this very degrading.’*

Inevitably, building and repair work often has a tendency to run over-budget, but the trusts often prove unwilling to make up the difference in such cases. One MacFarlane Trust claimant – with the backing of a doctor’s note – obtained money from the Trust to make mobility-related improvements to their bathroom. But when the final bill came out as higher than the original quote, the MacFarlane Trust refused to provide the additional money.

In addition, a number of specific concerns were raised about a failure of trusts to make payments that had been promised:

Secondary beneficiary: *‘After my husband died the MacFarlane Trust sent me a letter ... which stated that I would receive a payment each month as I was now a widow. The payments were due to start in January but I did not receive any money until eight months later, after numerous phone calls ... There was no apology. I only received the money after I*

¹²⁶ Caxton Foundation Website, www.caxtonfoundation.org.uk.

¹²⁷ The Macfarlane Trust has a Grants Committee which performs a similar role, although unlike Caxton, as set out in section 2.2 (b), MFT does not have a small grants budget because all its primary beneficiaries and widows/widowers are in receipt of ongoing non-discretionary and top-up payments.



had contacted the person in charge of finance ... I was fortunate in that my daughter took three weeks' unpaid leave to help me cope with all the paperwork which widows have to deal with ... I do not know how people widowed and with little children and no money cope in such a situation.'

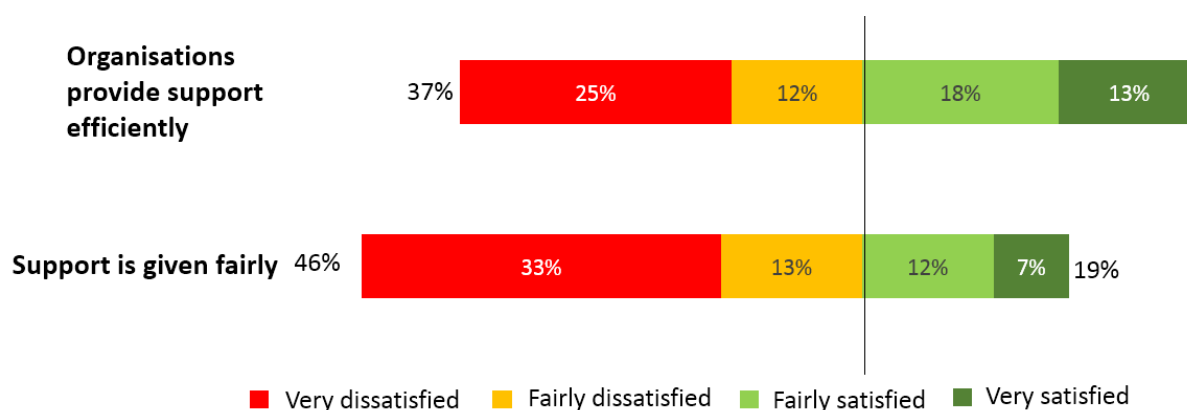
Secondary beneficiary: *'I have had the experience of being told a payment would be in my bank account on a particular day ... only to be told I would not be getting the payment at all, let alone that day. I could have written a cheque against it and had it bounce.'*

Thirdly and finally, some of the information the APPG has gathered raises more fundamental questions about the ability of the present discretionary support system to address the full needs of all applicants; or indeed deliver support equitably to all beneficiaries based on the severity of their needs.

The APPG survey also asked respondents whether they felt the support they received – both discretionary and non-discretionary – was given fairly and efficiently to all beneficiaries. Figure 15 below gives a breakdown of the responses received.

Figure 15

In regards to the overall support you receive, that is the combination of payments made by Skipton or MFET and additional support from the Caxton Fund, Eileen or McFarlane Trust, to what extent are you satisfied that¹²⁸ ...



The responses show high levels of dissatisfaction on both measures. Although less respondents are dissatisfied that the trusts deliver support efficiently, still more are dissatisfied that they do so than are satisfied. Most striking, however, is the strong feeling among beneficiaries that the charities do not deliver support fairly. Indeed, in the qualitative responses, a number of respondents questioned the trusts' ability to make equitable needs-based decisions when allocating support, often backing up their responses with anecdotal evidence:

Co-Infected: *'I know of other haemophiliacs who have in the past had family holidays paid for, education for their children paid for and so on, while other beneficiaries within the same postcode have had to beg to have a new washing machine or fridge. The trusts clearly have their favourites. Personally I fit into the latter part of this multi-tier system and have given up asking for support.'*

¹²⁸ N.b. Percentages do not add up to 100% because they exclude "don't know" and "neither/nor" answers.



HCV Infected: *'I know of two brothers in the same circumstances who both needed double glazing. One allowed £3000 because he didn't appeal as he's not that kind of person. The other one who is more forthcoming did appeal and got £5000. How can this be fair?'*

Co-Infected: *'I have often found that grants applied for, for the same requirement, have sometimes been successful and at other times not. As a close-knit community of co-infected individuals there is a great deal of communication, and it's only during these moments that one finds the unfairness of the whole process: that you have been declined a grant for something while someone else has been successful.'*

Co-Infected: *'Anecdotal evidence suggests that two applications for the same assistance where all else is equal can be treated differently. This suggests that decisions are based upon little else than the whims of those that happen to attend the decision-making committee on any particular day.'*

One potential issue affecting the success rate is that some beneficiaries, for various reasons, are more able to negotiate the applications process and provide sufficient supportive evidence to satisfy the trusts that they warrant assistance. These may not be the same people who are most in need of discretionary support.

As highlighted in section 3.3 (b), a greater proportion of applicants who had been unsuccessful in their applications for additional support reported a lack of knowledge about the rules and procedures regarding additional support and how their trust makes decisions. This suggests that those who lack the wherewithal to negotiate the payments system are at a natural disadvantage and are unable to obtain payments when they need them. Indeed, among the qualitative responses received by the APPG, many respondents reported that they had assistance from their social worker, hepatologist, haematologist, carer or GP in completing application forms for claims. Other respondents, however, were palpably not able to obtain this level of assistance, and had to fend for themselves. Two respondents summarised the natural inequity inherent in the system in light of this issue:

Co-infected: *'People – because of postcode lottery, personality, educational ability or other reasons have a better relationship and support networks with GPs and healthcare workers. The trust has always been asked for letters of support from these people and therefore some registrants have always been more successful at obtaining grants than others. It seems some people just put in multiple grants for anything they can think of, and others rarely apply for support because it is too much hassle or they feel they won't get it.'*

HIV infected: *'Frontline medical services should instigate this process rather than leaving victims to find out about any support available for themselves at a time when they are extremely vulnerable, totally unable to function in any normal way and can barely cope with everyday life never mind research and cope with the additional bureaucracy involved.'*



(d) Conclusions

These findings, in sum, suggest that while the majority of beneficiaries overall use positive words to describe their experience of contacting their trust regarding additional support, a significant minority were negative about their experiences. When responses are broken down further, it becomes clear that only a minority of Co-infected people, other beneficiaries, unsuccessful applicants and MacFarlane Trust beneficiaries use positive terms.

The qualitative evidence reinforces the view that there are still grave problems with discretionary charitable provision. Many respondents report a general sense that the process of applying for charitable support robs them of their dignity and makes them feel like they are 'begging.' A great deal of MacFarlane Trust registrants further believe that the charity is getting worse and becoming less personal, less engaging and less generous in its grant applications.

In addition, numerous registrants of all charities reported a vast array of problems negotiating access to discretionary support. Among other things, respondents reported that the time-consuming process of compiling claims – coupled with the long waits for obtaining approval from the trusts – meant it was all but impossible to get help when needed; that it was often extremely difficult to get in contact with the appropriate staff members to make claims; and that when support was forthcoming, beneficiaries only received a small portion of what they had asked for or, worse, did not receive payment despite being promised it.

Others reported being kept in the dark by the trusts as to the reasons for their refusing an application, or indeed never even being told by the trusts what support is available to them. The concerning consequence is that some individuals – often in a dire state of need – did not claim for payments they were in fact eligible to receive. Finally, some respondents raised further, more fundamental questions about the ability of the charity-based system of discretionary provision to deliver support equitably to beneficiaries: those with the wherewithal and support to negotiate access are naturally more able to access payments than the less able but no less needy beneficiaries.

The APPG feels that, to at least some extent, these issues can be attributed to factors beyond the control of the charities themselves. In particular, it should be noted that there are no forms of external redress available to beneficiaries if they are dissatisfied with decisions made. Their only recourse is to complain to the charity itself through its internal complaints process. It should also be emphasised that unlike the non-discretionary bodies, Government funding for the charities is set entirely at the discretion of the Department of Health, with no independent assessment of beneficiaries' needs. The charities are simply expected to make do with the money they have available. These twin factors may lie at the root of many beneficiaries' feelings that the decision-making process is not robust enough and does not provide the requisite help to meet their needs. These issues will be revisited in section 3.4.

In addition, the APPG strongly believes that it is completely impractical and insufficient that those infected with Stage 1 HCV and others in poverty should have to go through a discretionary support system to acquire small one-off payments, in voucher form, for basic goods such as foodstuffs and white goods. It is difficult to see how such a system could ever be made to work speedily or easily enough to satisfy beneficiaries who need new washing machines, food or other items – even a four-day waiting time is too long, especially when one



considers the paperwork and quotes needed to even begin applying for Caxton support. Self-evidently, these people are in financial. It would be easier for both the charities and beneficiaries if these individuals were given sufficient regular payments – at a level to be decided by some independent individual, following a review – to cover the costs of these goods and foodstuffs. This would free up Caxton to focus on meeting the other needs of their beneficiaries, such as hospital visits and support for widows. Again, this issue is revisited in section 3.5 (b) and (c).



3.4. Management, funding and appeals system for the three charities

(a) Financial arrangements

As highlighted in Figure 5 of section 2.3 (a), the two private companies offering non-discretionary support are currently funded differently from the three charities. The private companies are in a stable situation: they receive annual allocations from the Government as needed to meet the level of ongoing and lump sum payments required in proportion to the number of registrants. Funding for the charities is on a far less secure footing and entirely at the Department of Health's discretion each year.

This arrangement means that even if the trusts require funding to continue to meet support at the present level, this funding may not necessarily be forthcoming. In November 2013, both the Caxton Foundation and the Macfarlane Trust submitted two business cases to the Department of Health requesting further funding. The Caxton Foundation sought additional money to implement an ongoing payments system for some of their beneficiaries, while MacFarlane Trust wished to increase its allocation from £2.3million to £3.3million in order to both meet an £800,000 funding shortfall – currently being met by its increasingly-diminishing reserves – and provide more extensive grant support to their beneficiaries. In the board minutes of February 2014, MacFarlane Trust's chair, Roger Evans, acknowledged 'potential difficulties in future years if neither an increase... nor reserve funds continued to be available.'¹²⁹ Section 3.5 (b) goes into greater detail on these business cases and the support requested by the charities.

It was not until March 2014 – just weeks before the start of the 2014/15 financial year in April – that the Department of Health finally informed the charities that their business cases had been rejected and funding would be maintained at the previous level. As well as presenting difficulties for MacFarlane Trust's long-term financial sustainability – with the Trust only able to maintain funding at the current level until April 2017 – the charities had very short notice of their allocation for the present financial year, making effective planning difficult.

In addition, as the funding the charities receive does not increase in line with the number of registrants, this poses problems should the number of registrants unexpectedly increase during the financial year. Given that the trend for Caxton is that beneficiary numbers are set to increase in future years, one would expect that the DH would provide increased funds to Caxton each year to meet the needs of these new registrants. In fact the reverse is the case: Caxton's funding actually decreased slightly in 2013/14 to £1.188,676, from £1,204,498.¹³⁰ There are inherent difficulties in such an arrangement, which have become particularly apparent during the course of the APPG's inquiry. As previously noted in section 3.2 (a), in September 2014, the Department of Health told Skipton to contact every Stage 1 registrant of the Skipton Fund who had never been contacted since first receiving their Stage 1 payment. During the same period, the APPG survey was also posted to all Skipton registrants. These twin events had the effect of raising awareness of the existence of the Caxton Foundation to Skipton registrants. In September alone, there was a 20% spike in applications to Caxton. Consequently, Caxton's planned £500 winter fuel payment – which the organisation has previously promised to all beneficiaries – had to be reduced to £350 to make up the shortfall.

¹²⁹ Macfarlane Trust (2014), *A Meeting of the Board of Trustees held on Monday 10 February 2014*.

¹³⁰ Written Parliamentary Question 210955, Diana Johnson MP, Answered 16 Oct 2014.



The APPG feels that the arrangements for the funding of the three charities are not satisfactory, and need to be changed. In order to provide peace of mind to beneficiaries, the charities need more surety as to their funding allocations. These arrangements are clearly unfair on beneficiaries: it is not acceptable that Caxton registrants promised a £500 winter fuel payment just one month previously have been told just before Christmas that – for reasons beyond their control – their payments will be reduced. Neither charity trustees nor staff should have to devote time to making business cases to the Department of Health or worry, at short notice, about funding allocations for the following financial year. This difficult funding relationship also lies at the root of many problems with the current support arrangements, not least the Department of Health/Trust relationship discussed below. We will return to this issue in our recommendations.

(b) The Relationship between the Trusts and the Department of Health

Whilst, as noted in section 2.3 (b), the private companies MFET and Skipton can effectively be seen as part of the Department of Health, this need not be the case with respect to the three charities, which would be completely free under the law to advocate for their beneficiaries and highlight gaps in provision. However, there is a feeling among many campaigners, beneficiaries and even trustees themselves that the Trusts act more as conduits to the Department of Health than charitable organisations. This contributes significantly to many respondents' dissatisfaction with the general demeanour of some trust staff, which they see as cold, dispassionate and unsympathetic. The following accounts of from four respondents to the APPG survey typified many beneficiaries' concerns:

HIV infected: *'There is a recurrent sense that the organisations involved are there to police the support rather than deliver it.'*

Co-infected: *'The MacFarlane Trust is certainly not acting as a charity should, supporting and empowering its beneficiaries, [but] the opposite ... The MacFarlane Trust is and always has been a small part of the DH and its charitable status a convenience behind which the Government can hide and abdicate any responsibility for the MacFarlane Trust's failings. It was flawed from the outset and must be abolished.'*

Co-infected: *'It appears those running the Trust can operate however they wish, with no scrutiny from the Department of Health ... and with a total disregard to the fundamental charitable ethos to which they were meant to take. The task of putting the beneficiaries first is a far cry from what really happens and anyone who dares to ask questions will face reprisals.'*

Co-infected: *'They are a charity but only one donator, the Government, and [they] will not challenge them [the Government] for a decent and appropriate statement following the Government's rulings.'*



It should be stressed that on occasion, the charities have done work highlighting the needs of their beneficiaries, and both MacFarlane Trust and particularly Caxton have conducted research on gaps in provision, low take-up and other matters, surveyed registrants on their problems and highlighted issues in their business cases to the DH. However, it is clear from the way the support is structured and the funding arrangements with the charities that the trusts face a clear conflict of interest between fighting for their beneficiaries and satisfying their funders. Complementing the evidence from beneficiary respondents, the APPG has also been approached, in confidence, by MFT trustees who have stated that they are not happy with how the charity is presently run, and have expressed particular concern about the links between the MFT and the DH.

The APPG believes there should be no such conflict of interest. Much of the charities' funding is discretionary, and it is left to staff and trustees themselves to allocate various grants on the basis of need. In order for beneficiaries to have any trust in these decisions, the Department of Health should have no influence over the management of the charities. We must be sympathetic to the fact that these individuals were only infected with HIV and hepatitis C in the first place because, in their minds, of failings within the Department of Health and NHS in the 1970s and 1980s. Understandably, many do not trust the Department of Health and do not feel comfortable with its level of involvement in the charities as things stand.

The sole concern of each charity should be meeting the needs of their beneficiaries. When they lack the resources to do so sufficiently, they should do everything in their powers to lobby and campaign for further funding. To foster such a culture, there need to be changes in the funding relationship and trustee structure of the charities. The APPG is glad to hear that the Department of Health will no longer be appointing trustees to MacFarlane Trust, but to further improve trusts' relations with beneficiaries, a portion of the charities' trustees need to be recruited from the beneficiary population, and The Haemophilia Society – as they presently do with respect to MacFarlane Trust – must be permitted to appoint three Caxton trustees. Most importantly, the Department of Health also needs less discretion as to the funding it allocates to the charities. These issues will be returned to in the recommendations in chapter 4.

(c) Limited rights of appeal

At present, if a beneficiary is not satisfied with a decision made for discretionary support made by one of the charities, they have two recourses to seek redress. In the first instance, they can appeal internally through the charity itself, requesting that those higher up the charities' decision-making hierarchy – the welfare sub-committee of trustees such as Caxton's NWC in the first instance, and the entire board of trustees in the second – to ask that the decision be reconsidered.

This process can be onerous, time-consuming and, ultimately, fruitless. One co-infected person responding to the APPG's survey, reported that it took them an entire year to overturn an original MacFarlane Trust decision to decline a claim following appeal, despite it having been backed by a social worker, a medical team and an occupational health advisor.



In the second instance, beneficiaries can approach the Charity Commission for England and Wales¹³¹ with a complaint about the overall conduct of their charity. In the past five years, three such complaints have been made in relation to the Caxton Foundation, seven in relation to MacFarlane Trust – one from a former trustee –, and none in relation to the Eileen Trust. Issues raised ranged from the MacFarlane Trust's alleged misuse of money held in reserves, the trusts' allegedly compromising relationship with the Department of Health, their failure to address beneficiaries' needs, the alleged breach of data protection arrangements with beneficiaries and the general governance arrangements of the three charities.¹³²

In each instance, the Charities Commission has not taken complaints forward because they are fundamentally outside its remit. It is at the discretion of charities how to allocate funds, issues around governance are a matter for trustees and data protection is a matter for the Information Commissioner's Office. This highlights that the Charities Commission is not an effective source of redress for beneficiaries: so long as the charities are using their resources in a way which is consistent with their charitable objectives, regardless of whether they are allocating support fairly or in a timely fashion, the Charities Commission has no power to intervene.

In effect, therefore, beneficiaries have very limited rights of appeal. As one secondary beneficiary stated in evidence to our Inquiry:

'In the event of an unjust decision there is no right of appeal or effective means to challenge a decision.'

The APPG argues that if a more effective external complaints system was in place for beneficiaries – one which had powers to judge and overturn individual decisions for support based on their merits and investigate wider issues of conduct by trustees and staff – this would, in time, help address many beneficiaries' broader concerns with the charities. We thus make recommendations to this end in chapter 4.

¹³¹ This is the case even for beneficiaries who live in Scotland, Northern Ireland or Wales.

¹³² Charities Commission for England and Wales to Diana Johnson MP, Freedom of Information Request, 12 Nov 2014, *'Complaints made to the Charities Commission in relation to the activities of the Macfarlane Trust (No. 298863), the Eileen Trust (No. 1028027) and the Caxton Foundation (No. 1142529).'*



3.5. The sufficiency of provision: addressing unmet needs

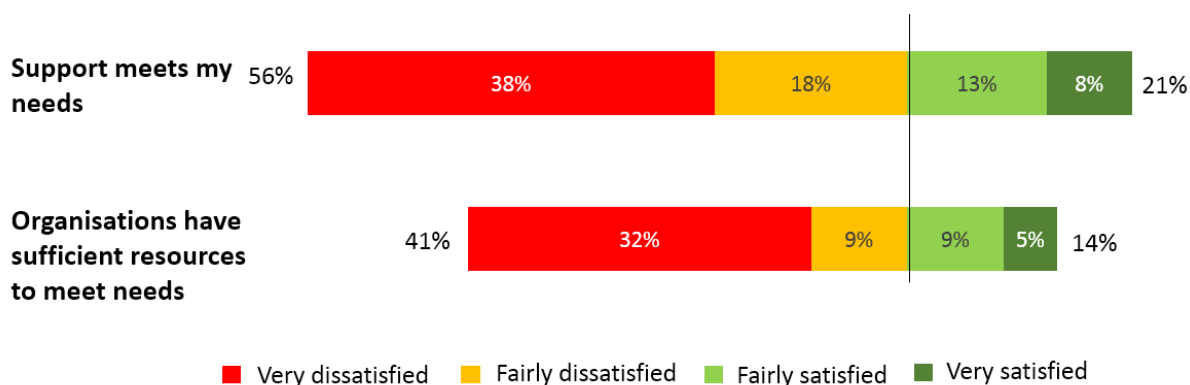
(a) The sufficiency of the overall support package

As noted in previous sections, no government has ever carried out a holistic assessment of the broad range of support necessary to satisfy the needs of infectees and their families. The support arrangements have instead developed haphazardly, often in response to campaigning efforts and even threats of litigation by people infected. The non-discretionary ongoing payment of £14,574 – or £29,148 in respect to people co-infected with HIV and Stage 2 HCV – was not set by independent experts following an appraisal of beneficiaries’ specific needs, but by Department of Health officials.¹³³ Nor, as noted above, were payments to the discretionary bodies set on the basis of such an assessment, with the consequence that many who feel they need assistance – such as Caxton Foundation widows/widowers and those with Stage 1 HCV – do not find it forthcoming.

There remains a need for such a comprehensive assessment to be carried out. To this end, the APPG survey asked respondents whether – in relation to the overall package of discretionary and non-discretionary support – they were satisfied that the trusts were sufficiently-resourced and that the support they provided met their needs as beneficiaries. The results are set out in Figure 16 below.

Figure 16¹³⁴

In regards to the overall support you receive, that is the combination of payments made by Skipton or MFET and additional support from the Caxton Fund, Eileen or McFarlane Trust, to what extent are you satisfied that ...



The results show that a large proportion of respondents feel that the current support package does not meet their needs as beneficiaries. Although a smaller proportion are dissatisfied that the trusts are sufficiently resourced to meet their needs, it is nonetheless considerably higher than the proportion who are satisfied they are sufficiently resourced to do so.

These survey results suggest that there are still considerable unmet needs among the beneficiary population. Many respondents further backed up these headline results with

¹³³ See section 2.5 (c) for a discussion. The Archer Inquiry was unable to obtain precise information from the Government as to how they had arrived at the then-£6,400 p.a. figure for support.

¹³⁴ Figures do not add up to 100% because ‘don’t knows’ and ‘neither nor’s’ are excluded.



written evidence highlighting their level of need. Complementing these qualitative accounts with evidence obtained from the trusts, this section investigates issues of unmet need among the beneficiary community.

(b) Three competing needs – the sufficiency of discretionary support

As noted in Section 2.4, the three charities have to meet three competing needs of their registrants. The charities differ in the degree to which they can meet these needs. Firstly, they have to help primary beneficiaries with one-off costs it would be unjust for them to sustain themselves, such as hospital travel and home adaptations. Evidence the APPG has obtained suggests MFT is presently having difficulties, given its other obligations, meeting these needs. Secondly, they have to devote resources to keeping their beneficiaries out of poverty. They differ in the degree to which they can do this, with Caxton unable, with its current resources, to do so. Thirdly, they have some obligation to support the partners of now-deceased infectees, but in practice MFT is the only charity which at present provides sufficient payments to lift such widows/widowers out of poverty.

All three charities have certain needs which they are unable to meet with the resources presently available to them. As Figure 17 below shows, a significant proportion of respondents in each subgroup have been unable to obtain additional discretionary support from the charities, despite applying for it. The proportion of rejections is considerably higher amongst HCV infectees who have applied for additional support.

Figure 17

Have you successfully received additional grants or top-up payments in addition to your regular payments?

	All who applied	Hep C	HIV	Both	Secondary/ Carer	Other	Primary
Base: Those who applied for additional support	498	225	26*	94	109	41*	345
Yes (%)	57	49	77	74	57	49	58
No (%)	37	46	19	17	37	49	36
Prefer not to say (%)	6	4	4	9	6	2	6

**Caution: low base*

Reports and correspondence from the charities themselves suggest there are indeed certain needs which the charities are unable to meet with the resources presently available to them.

Turning first to MFT, it is clear that for a long period, the charity has had insufficient resources to meet beneficiaries’ needs. In 2003, as mentioned in section 2.5 (b), the Government agreed to pay for a review of the future needs of MFT beneficiaries. It recommended that funding should be increased by 100%, to some £7million annually, to sufficiently provide for them. But



the Government resisted this proposal and implemented a much smaller increase of 11%. A 2006 report by MFT trustees themselves, based on a survey of their beneficiaries, concurred with the 2003 survey: it called for £7.5million annually. Again, this proposal was rejected.¹³⁵

Even after the Government provided MFT beneficiaries with higher ongoing payments in 2009, there is evidence that there continued to be unmet needs amongst the charity's registrants. In 2012, MFT made a business case to the Government requesting permission to use its reserve funding¹³⁶ to help meet some of these needs. Informed by a survey of its beneficiaries which the MFT had commissioned, it argued that since the establishment of MFT, the beneficiary community had changed considerably and that "their needs are greater than they have ever been."¹³⁷

It is readily acknowledged by the MFT themselves that it has never been sufficiently resourced to meet non-recurrent needs to help beneficiaries find work and fund home adaptations and respite breaks. Consequently, in 2011/12, the value of grant applications refused – equating to £73,625 – almost equalled the £74,080 accepted. Funds are "insufficient to provide for the majority of the ... beneficiaries" and "MFT has never had sufficient funding, without risking the availability of funds for regular payments, to meet more substantial needs."¹³⁸ The recession, the effects of ageing amongst their infectee population and the reduction in funds from local authorities for occupational therapy, care and other support meant that many of their beneficiaries, they argued, had come into a more severe state of need.¹³⁹

The most acute need identified in the 2012 survey was for one-off grants to fund home adaptations, but it also identified a need for grants to fund respite breaks. There was a particular need for further support widows who, it argued were "barely surviving on their regular incomes", many "left with crippling debts and financial commitments when they were bereaved, which they have not had the income to pay off."¹⁴⁰ MFT's existing grants budget, it was acknowledged, was not sufficient to address these needs.

The Government subsequently agreed to MFT's proposal to commit reserve funding, and all beneficiaries were encouraged to apply to a grants programme to fund home improvements.¹⁴¹ But further evidence suggests there are still unmet needs amongst MFT's registrants. With

¹³⁵ Archer et al (2009), *Independent Public Inquiry*, p. 85.

¹³⁶ As outlined in Section 2.5 (b), MFT did not initially receive ongoing funding from the DH. A reserve of funds was thus set aside by MFT unless future funding was not forthcoming. However, following a review in 2003, the DH decided to provide ongoing annual funding to MFT. Following the 2009 Archer Inquiry, MFT judged that it was no longer appropriate to keep such a high reserve in place given the DH's commitment to future annual funding, hence the 2012 business case to invest these reserve funds on their beneficiary community.

¹³⁷ Macfarlane Trust (2012), *Proposal to commit reserve funding to meet the increasing medical, social, employment and financial needs of its beneficiaries*, p. 10.

¹³⁸ *Ibid*, p. 5.

¹³⁹ *Ibid*, p. 2.

¹⁴⁰ *Ibid*, p. 8.

¹⁴¹ Macfarlane Trust (2013), *Business case for increased funding for the Macfarlane Trust from 2014/15*.



reserve funding quickly depleting, it is possible that the Government may have to commit additional funds to help meet these needs.

In 2013, MFT thus made a business case to the DH, which was subsequently refused, requesting further regular funds to help meet the funding shortfall and provide for these additional needs. “The current level of annual funding from the DH”, they argued, “has now reached a level which is inadequate for the needs of MFT’s beneficiary community.”¹⁴² Again, a particular need for money to provide for one-off grants was identified but the charity has proven increasingly unable to meet this demand – just 21%¹⁴³ of such applications were accepted in 2012/13. The charity was able to increase its grants budget in 2013/14, but only by ending weekend visits for beneficiaries – something deeply unpopular amongst registrants.¹⁴⁴ These developments may offer some explanation as to why there is a perception amongst some respondents to the APPG’s survey that MFT is getting worse.

Likewise, the Caxton Foundation has an issue of unmet needs amongst its beneficiaries. It too made a business case to the Department of Health in 2013 which argued for further funds to provide ongoing payments to its beneficiary population. This would have had the twin effects of providing for widows and addressing poverty amongst its beneficiary population, but the business case was subsequently refused. Although despite this refusal, an ongoing payments system is in the process of being introduced, this is less generous than was planned; and in its most recent correspondence to the APPG the charity acknowledged an “inability to run the level of regular payments ... which it would like.”¹⁴⁵

Undoubtedly the most acute need for Caxton is that for generous ongoing payments, but a wealth of internal reports have been produced by Caxton on the additional needs of its beneficiary population. The APPG requested these reports to help inform our Inquiry, but this request was denied.¹⁴⁶ Nevertheless, it is clear from the minutes of meetings with Caxton’s board of trustees that beneficiary debt is a considerable issue amongst Caxton registrants. One August 2013 report “highlighted that some Caxton clients were experiencing levels of financial need which certainly, in the short-term, could not be alleviated by one-off grants alone.” Much of this debt had arisen as a result of having to leave work to undergo medical treatment and requests for debt relief constitute a large number of the grant requests Caxton receives, with a considerable proportion of them refused on the grounds of incomplete information.¹⁴⁷

¹⁴² Ibid.

¹⁴³ This is as a percentage of the overall monetary value of the grants requested.

¹⁴⁴ Macfarlane Trust (2013), *Business case for increased funding for the Macfarlane Trust from 2014/15*.

¹⁴⁵ Caxton Foundation (2014), *Letter to APPG Inquiry*, 21 Nov 2014.

¹⁴⁶ See section 1.4 (c) for a further discussion.

¹⁴⁷ Caxton Foundation (2012), *Minutes of the Meeting of the Board of Directors of Caxton Trustee Limited*, 1 Aug 2013, pp. 3-4.



Finally, in the long-term Caxton has a need for further funds simply to account for the increase in beneficiary numbers. Caxton is the only charity which is experiencing a net increase in the number of beneficiaries in the long-term, but there is no guarantee that DH funding will increase in line with the number of beneficiaries – indeed, as noted in section 3.4 (a), Caxton’s Government grant has not been increased in previous years despite this trend.¹⁴⁸ This was identified by Caxton, in its most recent correspondence with the APPG, as one of the major issues facing the charity in future, with the September spike in registrations impacting on the charity’s plans to make winter fuel payments.¹⁴⁹

These issues, in sum, highlight the problems inherent in a funding system for the discretionary charities in which the DH provides funds at a level entirely at its own discretion, without any independent and holistic assessment of the precise resources necessary to meet the three needs of beneficiaries. In the absence of such an assessment, the three charities are bound to face an impossible task attempting, with limited funds, to meet the three competing needs of their registrants. The measures which the APPG feels would address these issues are set out in chapter 5.

(c) The Stage 1 / Stage 2 hepatitis C distinction

As noted in section 1.2 (b), a key basis for the present Stage 1 / Stage 2 HCV distinction – which denies ongoing payments to those HCV infected people with chronic HCV – is that many Stage 1 infected clear the virus following treatment and so are not in a state of ongoing need.

From the evidence the APPG has received, it is clear that this is a poor basis for denying such individuals ongoing payments. It should be noted that even according to figures quoted by the government,¹⁵⁰ some 45% of those with chronic HCV do not clear the virus, even with treatment. The implication is that many of these people are in a state of ongoing need, and thus may require consistent support.

Qualitative evidence the APPG has received reinforces this view, suggesting that many HCV infected – even some who clear the virus with treatment – are in a state of ongoing need which should warrant them being paid some form of ongoing payments. The following four comments from three HCV infected people and the husband of a HCV infected person were exemplary of the problems faced by this community:

‘I have attended hospital appointments with my wife and heard repeatedly that the wide range of disabling symptoms that she suffers are caused by hepatitis C. She should not be excluded from ongoing payments because she can’t prove that deterioration of her liver has reached a certain level. I know people who receive Stage 2 payments and are fit enough to work. My wife is not fit enough to work therefore she should also receive those payments.’

‘I am a ‘Stage 1’ however the virus and subsequent treatment have left me unable to work more than three days a week. I am constantly tired and have brain fog. I find it hard to

¹⁴⁸ Written Parliamentary Question 210955, Diana Johnson MP, Answered 16 Oct 2014.

¹⁴⁹ Caxton Foundation (2014), *Letter to APPG Inquiry*, 21 Nov 2014.

¹⁵⁰ Written Parliamentary Question 46452, Diana Johnson MP, 2 Mar 2011.



concentrate and get easily confused and forgetful. I am also a single parent who receives no child support and I am livid that – through no fault of my own – I am struggling so badly with my health and financially.'

'The ex gratia payment of £20,000 is insulting considering I have daily tiredness, aching joints and memory and brain clarity issues. I have undergone two sets of treatment which wiped out 18 months of my life with dreadful side-effects and no success. I have an uncertain future for me and my partner.'

'I was told that the brain function would barely improve, if at all, when I 'cleared' the disease and they were correct ... The disease is not 'cleared', as this survey states. All they actually say is that the virus remains undetectable, which is very different. Just last night I felt as rough as if the disease was back and I woke up in a full night sweat.'

The APPG welcomes the moves by Caxton to provide some form of ongoing payments to Stage 1 HCV infectees and other beneficiaries who are in poverty, but it is not clear at present whether these payments will be sufficient to lift them out of poverty. In any event, on the basis of the above and other evidence, the APPG recommends that the Government consider providing some form of *non-discretionary* payments to all Stage 1 HCV infectees regardless of income. The precise level should be set by an independent public health doctor, at a level commensurate with their needs.

The extension of non-discretionary ongoing payments should also have the effect of addressing many of the key concerns Caxton beneficiaries have about the charity. As emphasised in section 3.3., because a high proportion of Caxton beneficiaries are in poverty and denied ongoing payments, much of its time and resources are devoted to the onerous task of dispensing one-off payments and vouchers to them for basic goods and necessities. Not only is this form of non-discretionary support completely unworkable in practice – it could never be delivered fast enough or easily enough to satisfy recipients – but as noted in section (b) above, it prevents Caxton from addressing the needs of others by providing grants for hospital visits, home improvements or, indeed, ongoing top-up payments, among other things. Providing Stage 1 HCV beneficiaries with non-discretionary support would remove one of the three competing needs Caxton presently has to balance, freeing the charity to devote resources to meet other requirements.

(d) The sufficiency of discretionary and non-discretionary ongoing payments

A number of respondents raised concerns about the sufficiency of the mix of discretionary and non-discretionary ongoing payments. Three particular issues are apparent from the evidence the APPG has received, and these are now considered in turn.

Firstly and most obviously, as has already been set out in detail in section 2.4 (a) and in section (c) above, many Caxton registrants are currently in poverty. This is most palpable with respect to Stage 1 HCV infectees and the widows of now-deceased primary beneficiaries, neither of whom presently receive any ongoing payments. However even Stage 2 HCV infectees in receipt of the £14,574 ongoing payment may be in poverty when one accounts for the number of dependants in their household. As noted before, whilst Caxton's incoming discretionary ongoing payments system will help alleviate these issues by providing some support to those in



poverty, the precise size of the payments is not yet known. Moreover, with respect to MFT registrants, it should also be noted that the charity may not, without further funding, be able to keep its beneficiaries out of poverty in the long-term – an issue discussed in more detail in section 2.4 (a).

Secondly, many MFT recipients raised concerns that because MFT's top-up payments are non-discretionary, the earnings of a spouse in the same household can have the effect of reducing their household earnings. As the husband of one MFT recipient highlighted:

'My wife and I are both retired and I think it is very unfair on her, and on me as a husband, that the only help she can get is from a means-tested fund where MY pension income is taken into account ... She should be afforded the dignity of an income in her own right because her health and pension potential were damaged by the DH, not by me.'

Notionally, the way the system presently operates, for a singularly-infected HIV infectee with dependants, a partner's earnings could have the effect of reducing their ongoing payments to a level below the poverty line. This carries the implication that one's spouse's earnings should then be relied on to push them back above the poverty line and pay for their care and support. Widows' ongoing payments, which account for household rather than just a partner's income, are also threatened in this regard, and one MFT widow giving evidence to our inquiry reported losing all her ongoing payments once her son moved back in with her, as this put her above the £19,000 threshold. Caxton's incoming ongoing support system, given that it is entirely non-discretionary and also accounts for partner's incomes, will face a similar issue: a partner's earnings could erase all possibility of obtaining discretionary payments from Caxton, forcing the partner to devote some of their earnings to provide for their infirm loved one. If one's regular income changes in any of the above ways, their payments can drop as little as a month later, sometimes giving beneficiaries very little time to accommodate.¹⁵¹

Thirdly, whilst the MFT's ongoing payments, including the ongoing payments for children, have the effect of lifting all households out of poverty as defined for the *general population*, this says nothing of any potential additional costs one might face by virtue of having haemophilia, HIV, Hepatitis C or living in an expensive area, such as London. As one co-infected person highlighted:

'The payments above the standard rate are means-tested and don't take account of where you live. As I live in London, I earn more than I would outside of the capital but I also pay more in mortgage and other living costs. This is not taken into consideration.'

Finally, even if ongoing payments do lift individuals above the poverty line, the APPG questions whether the poverty line alone is a sufficient basis on which to provide support to those affected by the contaminated blood scandal. Some respondents raised legitimate questions over whether payments should not be set at a level necessary for beneficiaries to live comfortably and provide for their dependants. As one co-infectee argued:

'Although they may be in a position to meet minimum ongoing requirements, there is a clear need to provide beneficiaries with more substantial funds ... Given the suffering and distress

¹⁵¹ Caxton Foundation (2012), letter to the APPG Inquiry, 26 November 2014.



that has already been experienced – and the need for beneficiaries to be in a position to not worry about their future health and ability to provide for their dependants – ... [A] more substantial financial support or settlement is critical to long-term peace of mind.'

From the evidence received, the APPG feels there is scope for some improvements in the ongoing payments system. It is beyond the scope of the Inquiry to make specific recommendations as to the precise size of ongoing payments or the discretionary/non-discretionary mix. However, we do recommend that the public health doctor, seconded to the charities, should conduct a review into the sufficiency of ongoing payments. Among other things, this review should be dictated by three general principles which, together, will ensure that ongoing payments are sufficient to lift people out of poverty, even accounting for the number of dependants; that the payments account for the additional costs of living with HIV, HCV, haemophilia or a high-cost part of the UK; that the partners of infectees will not have to use their earnings to provide for beneficiaries otherwise in poverty; and that the earnings are set at a level above the poverty line, so that beneficiaries can live more comfortably. These principles are reiterated in greater detail in chapter 4.

(e) Meeting the needs of widows/widowers

A considerable number of respondents were deeply worried about what would happen to their families after they died, at which point they would lose their entitlement to ongoing payments. This was a particular fear among registrants of the Caxton Foundation, which of course provides no ongoing support to widows upon their partner's deaths. A selection of their comments are copied below:

Co-infected: *'My wife gave up a career to help me. Her private pension is negligible. How am I supposed to ensure that she lives a reasonable life after my death? Whatever skills she once had are no longer marketable; she has not been able to keep pace with workplace changes.'*

Co-infected: *'I can't bear the thought of my family still relying on hand-outs in memory of me ... All I want as a victim is to see the rest of my days out with a bit of pride and dignity, and maybe a bit of happiness for my family for the life of pain and misery that I gave them, because of the way these governments have treated us.'*

It is beyond the scope of the APPG Inquiry to investigate the precise level at which widows'/widowers' ongoing payments should be set or to discuss whether they should be entitled to some form of non-discretionary support. It is up to the Rt. Hon. Alistair Burt MP to investigate these issues. However, we will highlight three particular inequities in the support system for widows/widowers, which need to be addressed.

Firstly, for the first nine months after the death of a primary beneficiary of MFET dies, the MFT provides the family with ongoing payments at the same level as before, when they were entitled to non-discretionary MFET payments. This is not the case, however, for the families of deceased Hepatitis C infectees, who receive no similar support from Caxton. Their non-discretionary payments would thus carry on until the end of the quarter, potentially leaving



them with very little time to accommodate to their changing circumstances.¹⁵² This is deeply unfair, and Caxton should be given funds to put in place for its own beneficiaries the same arrangements as MFT.

Secondly and quite obviously, there is presently no ongoing discretionary support system in place for the widows/widowers of now-deceased HCV infectees. These individuals can see their earnings drop considerably once their partner dies. Although of course Caxton is currently putting in place a modest ongoing payments system which would cover widows in poverty, it is evident that this will not be as generous as that currently in place for MFT widows/widowers. Given that many of these individuals will have invested just as much in the care and support of HCV infectees as the widows of HIV infectees, and will thus be equally handicapped, the APPG questions why there should be any difference in the ongoing support accorded to widows registered with either the HIV or the HCV charities. On the contrary, we recommend that Caxton be given funds to put in place the same support for Caxton widows as is currently in place for widows registered with MFT.

Finally, one widow approached the APPG raising the particular concern that at present, if a widow/widower remarries following the death of an infected partner, they are no longer entitled to discretionary support from the trusts. Conversely, should an infected person remarry, their first set of dependants will be excluded from the payment scheme. The implication in both of these cases is that – despite still being in need as a direct result of their relationship to the infected person – others should now be expected to contribute their own income towards the care and support of these individuals. Given that in November of last year, the Prime Minister made moves to close a very similar loophole with respect to war widows' pensions, it seems appropriate that measures now be taken to entitle the re-married widows of now-deceased infectees eligibility for discretionary support from the relevant charity. The similar loophole in which the first family of a remarried infectee is excluded from support should also be closed.

(f) Other unmet needs

Finally and most fundamentally, a great many respondents to the APPG survey raised concerns that the current support arrangements fail to address a whole range of other needs. Many simply do not feel that the support system, as presently conceived, could ever compensate them for some of the losses they have experienced.

Many of these respondents' issues centred on the failure of the trusts to provide sufficient payments to ensure them the quality of life they would have had had they never been infected. The non-discretionary ongoing payments fail to do this, while the rules-based, means-tested discretionary support system often denies recipients the autonomy and liberty they would have enjoyed had they never fallen victim to the contaminated blood tragedy. One secondary

¹⁵² Caxton Foundation (2014), *letter to the APPG Inquiry*, 21 November 2014.



beneficiary railing against Caxton's voucher system, as well as a HCV infected person, echoed the sentiments of many fellow respondents:

Secondary Beneficiary, Caxton Foundation: *'If I had been able to continue in my chosen career then no-one would ever have told me what to spend my salary on! If I had decided to bet the whole lot on a horse, then that would be my choice with my money! Not a good choice, I accept, but a choice all the same. Now we have no choice, no freedom and, consequently, no dignity or self-respect.'*

HCV Infected: *'The levels of monthly payment are not sufficient to maintain a reasonable quality of life in comparison with the level I earned before developing advanced liver disease and subsequent transplant. I am now 10 years behind where I should be in my earning capacity and at the age of 40 I feel this is a gap I will never make up, even with the monthly Skipton Fund payments of some £1200.'*

Others raised similar sentiment that regardless of whether or not infectees were still affected by the viruses, they should receive compensation for the historic effect the viruses had on them in the 1980s and 1990s:

HCV Infected: *'As I have cleared the virus I get no support except if I go begging. I endured the virus for many years, endured the treatment for a year and now endure the severe and ongoing consequences of the treatment. I lost my living through this and now live in poverty I'm 64 and have the outlook and fitness of an 80 year-old.'*

The APPG also received a large volume of submissions from respondents who wished to receive additional lump sum payments now to ensure their families were provided for upon my death, such as the following HCV infected person:

'While a regular payment is useful it does not assist in the same way a lump sum payment would help ... The biggest challenge I face is securing the long-term future of my family.'

In addition, some widows approached the APPG arguing that their ongoing payments should be more generous, and perhaps sufficient to equal the payments received when their primary beneficiary partner had deceased. They raise questions over whether there should be some form of non-discretionary support for widows/widowers:

Widow of HCV infected: *'I feel the trust has not supported me sufficiently by sending me £500 on a yearly basis. Who would possibly think that this could make up for the loss of my husband? For all the suffering the contaminated blood caused to my husband and his loved ones? For the fact that I am no longer able to support myself sufficiently? ... The trust should support me so that I spend the rest of my life without my husband at a level at least equal to the one I used to live while my husband was alive.'*

Finally, the basis on which entitlement to discretionary support was decided was also questioned by some individuals. Some felt that the stipulation that beneficiaries had to be in a state of 'charitable need' set the bar of eligibility too low, and failed to consider non-financial forms of need:



Co-infected: *‘Understandably, the Trustees must meter any grant application and take into account the Trust’s financial resources. However, this does not excuse them failing to understand that charitable need is not necessarily always financial; and to this end, they should not be means-testing beneficiaries as they continue to do.’*

Co-infected: *‘My application was rejected on the grounds they found ‘no charitable need,’ which I completely disagreed with, as it goes against the Macfarlane Trust’s own mission statement. The Macfarlane Trust exists to give help to people with haemophilia who have to cope with the effects of living with HIV infection, and to their families and dependents, and [this] is inconsistent with the Charity Commission’s guidelines.’*

Co-infected: *‘The requirement to prove charitable need is ridiculous since the reason for the ‘charity’ is due to our infection by the Department of Health.’*

These issues fall beyond the scope of the APPG Inquiry. We do, however, encourage Alistair Burt MP to consider the broad range of issues raised by these respondents during his ongoing discussions with the Prime Minister.



Chapter 4

Recommendations

'I refuse to be a victim. Despite everything, I cherish my life and count my blessings. I have faith that this will end soon and maybe then, my talents, intelligence, spirit, sense of justice, experience and energies can be better directed at contributing towards and being part of a better society. I pray for the day when this Trust is out of my life. I do not think that is much to ask.'

- HIV infected person and widow of HIV-infected husband.



4.1. Raising awareness and expanding take-up of trust-based support

1. The Department of Health should undertake a comprehensive review to consider measures to expand take-up of support, to consider whether the medical evidence required to prove infection is appropriate, and to raise awareness of the assistance available, both inside and outside the beneficiary community. Among other things, it should explore:
 - a) whether simplifying the current five-trust structure of provision – for example, by amalgamating some of the trusts – would make it easier for beneficiaries to understand the assistance available and how to access it; and
 - b) ways in which the Government could promote the availability of support to a wider audience, particularly to people infected with HCV and/or those without haemophilia.
 - c) whether the medical evidence presently required to prove infection – particularly with respect to those seeking to prove Stage 1 and Stage 2 HCV infection – is appropriate, or whether different evidence could be used or the bar of proof required lowered.
2. Within the trusts themselves, there is clear evidence of a failure to advertise the support available to their beneficiary population. Measures should be put in place to address this. All recipients of charitable support should be given clear, comprehensive and easily-accessible information on the range of discretionary support available for them to apply for and how they can access it, while the Skipton Fund should work to identify and contact those of its registrants who are not Caxton Foundation registrants. Finally, the charities should also explore ways to ensure those beneficiaries who lack the wherewithal to negotiate the discretionary support system – many of whom are often in the greatest need – are given some form of assistance in accessing it. At present, those who are fortunate enough to have hepatologists, nurses or family members to help them fill in forms are unfairly advantaged.
3. A specialist service should be established within an appropriate body – perhaps the charities – to assist any registrants of the trusts who are unable to obtain payments due to insufficient medical evidence or hospital records. They should have the powers to pursue lost historical records across the health sector and to provide Skipton registrants who are not sufficiently acquainted with an NHS hepatologist to assist with the gathering of medical evidence for their Skipton Fund applications.
4. Given that virtually all of those with haemophilia alive at the time of infection received treatment with NHS blood products, they should not need to prove they underwent NHS treatment. Merely proving they were infected should be sufficient, and none should be denied payments simply because the NHS lost their hospital records.
5. In England, the families of people infected with HCV who are now-deceased were only given a short window of opportunity, over two months in 2011, to obtain the lump sum payments for people who died before the Skipton Fund was established (29 August 2003). Yet only a small percentage of potential beneficiaries claimed these payments in the time available; and although Skipton does in practice accept late applications, this is not widely advertised. The window of opportunity to claim Skipton payments for people infected who died before August 2003 should now be permanently re-opened and advertised widely.



4.2. A holistic assessment of beneficiaries' needs

6. The Government should second a public health doctor to the five trusts to carry out a comprehensive assessment of the needs of their beneficiaries, what money is required to meet them, the level at which funding for the charities should be set, the appropriate discretionary/non-discretionary mix of payments and the appropriate level of payments, commensurate to beneficiaries' needs.
7. In deciding what level of ongoing payments to set for beneficiaries, this review should be guided by four general principles:
 - (d) The household of someone infected should not be expected to contribute to their living costs, care and support of the person infected. In other words, if another earner enters a household, the reduction this causes in non-discretionary top-up payments should not have the effect – in the absence of the other household member's earnings – of pushing the household below the poverty line.
 - (e) The level of payments should account for the additional costs of living with haemophilia, HCV and HIV, as well as any other higher costs associated with, for example, living in London. It should not be based on a rudimentary calculation of the poverty line for the general population.
 - (f) The poverty line alone – even if it is made higher to account for someone's additional costs – is not a sufficient basis on which to set ongoing payments. Payments should be set at a high enough level for beneficiaries to live comfortably, at a level to be set by the public health doctor.

4.3. Changes to charitable provision

8. The public health doctor should also establish what level of funding is required for the three charities in light of their beneficiaries' needs. As is already the case with respect to the private companies, funds should then be increased or decreased, according to a formula, in line with the number of registrants to the charities. This should have the twin effects of both ensuring charitable support is not subject to fluctuations based on changes in the numbers of beneficiaries and help foster a more satisfactory relationship between the trusts and the Department of Health.
9. Where beneficiaries are not satisfied with a decision for discretionary support or the management of the trusts, they should be able to approach an independent external adjudicator to overturn the original decision. An appropriate body should be set up for this purpose.
10. To further foster a better relationship between the charities and their beneficiaries and to address beneficiaries' concerns about the trusts' relationship with the Department of Health, a portion of each charity's trustees should be drawn from the beneficiary population, and The Haemophilia Society – as they presently do with respect to MacFarlane Trust – must be permitted to appoint three Caxton trustees. The Department of Health should not appoint trustees to any of the three charities.



4.4. Expanding support to other areas

- 11.** Because many are in a state of ongoing need, individuals with Stage 1 HCV should be entitled to non-discretionary ongoing payments of some kind. It should be left to the Public Health Doctor to decide what level of payments are necessary to meet their needs.
- 12.** The spouses of people with HCV who are now deceased should be entitled to ongoing payments on the same basis as those with HIV who have died, and primary beneficiaries should be given some form of surety, before they die, as to what support their families will be entitled to so that they can plan for the future. When a primary beneficiary with HCV dies, ongoing payments to the family should continue at the same level for nine months, as is currently the case with respect to the families of now-deceased HIV infectees. Finally, if partners subsequently remarry following the deaths of their loved ones, they should not lose entitlement to trust-based support; and conversely the families of a primary beneficiary who themselves subsequently remarries should retain entitlement to trust-based support.
- 13.** Monetary compensation alone, however, is not sufficient to achieve full closure for those affected by the tragedy. Among other things, the APPG feels that these individuals need a public apology from the Prime Minister, on behalf of successive governments. They also require priority access to NHS treatment and access to the best therapies available, as was originally recommended by the Archer Inquiry in 2009.
- 14.** We are currently awaiting the publication of the Penrose Inquiry, a Scottish Public Inquiry into the contaminated blood scandal. Although this Inquiry is limited to Scotland, it is looking into pre-devolution events and therefore it is important that the findings of the Inquiry are properly investigated in relation to possible culpability for the scandal across the UK.
- 15.** The Rt. Hon. Alistair Burt MP is leading discussions with the Prime Minister towards a final settlement. We fully support this work and hope these discussions will reflect the issues raised by respondents to the survey with respect to establishing new forms of payment and addressing the other unmet needs of people affected by the scandal, which are set out in section 3.4 (f) of this report.



Chapter 5

Appendix



5.1. The YouGov Survey – Questions in Full

1. Which of the following statements best describes your status?

- I have Hepatitis C
 - I am now cleared of Hepatitis C
 - I am HIV positive
 - I have Hepatitis C and am HIV positive
 - I am a secondary beneficiary e.g. widow, partner, child
 - I am a carer for an infected person
 - Other (please specify)
 - Prefer not to say
-

2. If applicable, which of the following statements best describes your beneficiary status?

- I am a primary beneficiary with a bleeding disorder
 - I am a primary beneficiary without a bleeding disorder and infected via blood transfusion
 - I am a primary beneficiary without a bleeding disorder and infected via my partner
 - Other (Please specify)
 - Prefer not to say
 - Don't know
-

3. Which of the following organisations have you received payments from? *Please tick all that apply*

- The Skipton Fund – single payment
 - The Skipton Fund – regular payments
 - MFET
 - None of the above
 - Don't know
-

4. Which of the following, if any, have you applied to for additional support?

- The Macfarlane Trust
- The Caxton Foundation



- The Eileen Trust
- Not applicable – I have not applied for additional payments (if so please go to question 9)
- Don't know

5. Have you successfully received additional grants or top-up payments in addition to your regular payments?

- Yes
- No
- Prefer not to say

6. In relation to your application for additional support, on a scale of 0 to 10, where 0 is very little and 10 is a lot, how much do you know about how your trust makes decisions and what processes are involved?

- 0 - Very little
- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10 - A lot
- Don't know

7. On a scale of 0 to 10, where 0 is very difficult and 10 is very easy, how easy or difficult have you found it to understand the rules and procedures regarding additional support?

- 0 - Very difficult
- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10 - Very easy
- Don't know



8. Which of the following words best describes your experience of contacting your trust or fund in regards to additional support? (Please select one)

- | | |
|--|---------------------------------------|
| <input type="checkbox"/> Helpful | <input type="checkbox"/> Rude |
| <input type="checkbox"/> Respectful | <input type="checkbox"/> Discouraging |
| <input type="checkbox"/> Kind | <input type="checkbox"/> Don't know |
| <input type="checkbox"/> Supportive | |
| <input type="checkbox"/> Dismissive | |
| <input type="checkbox"/> Disrespectful | |

9. In regards to the overall support you receive, that is the combination of payments made by Skipton or MFET and additional support from the Caxton Fund, Eileen or McFarlane Trust, to what extent are you satisfied:

	Very satisfied	Fairly satisfied	Neither satisfied nor dissatisfied	Fairly dissatisfied	Very dissatisfied
The support meets my needs as a beneficiary.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The organisations I deal with have sufficient resources to meet beneficiaries needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I think support is given fairly to beneficiaries.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The organisations provide support efficiently.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



If you would like to provide examples in relation to any of the questions asked, please do so in the following text box (continue on the other side of this sheet of paper if required):

A large, empty rectangular box intended for providing examples in response to the questions.



Section 2 – What you would like to see from the Government

10. The following reform options by the Government have all been discussed previously, and we would like to know how you view their importance. Please select up to three.

- A statutory inquiry
- An apology from the Prime Minister
- Availability of a lump sum payment, rather than ongoing payments, in certain cases.
- On-going monthly payments linked to regular medical assessments
- On-going financial support for widowed partners/spouses
- Priority access to new and/or more expensive medical treatments
- Subsidised schemes to purchase mortgage, life and travel insurance with no disease-related premium
- Government-run mortgages/insurance schemes
- Priority access to new and/or more expensive medical treatments not freely available on the NHS, e.g. prescription drugs and home nursing
- Establishment of a committee to advise the government on Haemophilia and the best way to support beneficiaries
- Charitable trusts to be abolished
- Restructuring of existing trusts into one single body
- More counselling services for victims and families
- Retain the existing system of support, delivered through the five charities.
- None of the above
- Don't know

11. Which of the following statements, best reflects your view?

- All beneficiaries should receive the same amount of financial help regardless of the severity of their infection
- Beneficiaries should receive financial aid according to the severity of their infection and be decided on a case by case basis
- Don't know

12. Thinking about regular payments available to beneficiaries. Do you think the payments should be...

- Limited to someone's lifetime



- Be defined for a number of years and be paid to the family after death
- Be defined for someone's lifetime and then a set period of time after death for their family
- Other (please specify)
- Don't know

P.T.O.

13. Thinking about the total amount of money available to a primary beneficiary, how would you like to see it split across the following options? (Totalling 100%)

- | | | |
|----------------------|-------|---|
| <input type="text"/> | % | A lump sum |
| <input type="text"/> | % | Ongoing payments during the victim's lifetime |
| <input type="text"/> | % | Continued payments to the victim's family |
| <input type="text"/> | 100 % | Total |

- Don't know
-



14. Finally, could you describe what specific actions you would like to see the Government take in order to provide some degree of closure for those (and the families of those) that have suffered.

A large, empty rectangular box intended for the respondent to provide their answer to question 14.



5.2. APPG Contaminated Blood YouGov Survey – A Complete Analysis

(a) Background and objectives

Different schemes were set up by the UK Government in order to support individuals who had become infected with Hepatitis C and/or HIV as a result of being given contaminated blood through NHS treatment. Regular and single payments are given to those directly affected (known as primary beneficiaries) as well as some secondary beneficiaries (widows, partners, children of those affected) and carers of people who became infected. Payments are provided by the Skipton Fund and MFET, while individuals affected can also apply for additional financial support from either the Macfarlane Trust, Caxton Foundation and Eileen Trust.

There are around 2000 beneficiaries of the trusts and all were sent a letter inviting them to take part. Additionally The Haemophilia Society shared the survey on social media, and highlighted the APPG Inquiry and survey in its member's magazine. Campaign groups set up by people affected by contaminated blood also shared information with their members. MPs contacted their constituents who had been affected. In total, 961 responses were received to the survey. This is a good response rate, reflecting the high importance and salience of the issues the survey covered.

It has come to the attention of Members of Parliament, through letters from their constituents, that some beneficiaries have had poor experiences in dealing with trusts. An All Party Parliamentary Group inquiry has therefore been set up to investigate this issue. As part of this work, it was decided to undertake a survey of beneficiaries and, other affected, in order to gain a wider perspective on the experiences of people who have contact with these organisations.

The objectives of the survey were to understand:

- which trusts respondents deal with in relation to regular or single payments and additional support
- to what extent applications for additional support are successful
- the degree of understanding respondents have of how trusts offering additional support make decisions and also how easy it is to understand the rules and procedures
- whether respondents had a positive or negative experience of contacting their trust or fund in relation to additional support
- levels of satisfaction on a range of measures in relation to trusts providing regular or single payments and additional support

The survey took place between 16 September and 28 October 2014. It was mainly administered online, although respondents also had the option to request a paper version of the questionnaire. In order to safeguard their anonymity, letters were sent out to



beneficiaries by the trusts on behalf of the APPG inviting them to take part and including a link to the survey.

(b) Key findings

- The largest group of respondents were primary beneficiaries with Hepatitis C or had previously been diagnosed with it (48%). A further 11% had Hepatitis C and were also HIV positive and four per cent were HIV positive only. A fifth of the sample (20%) were secondary beneficiaries and five per cent cared for an infected person. Eleven per cent described themselves in other ways, for example as the wife or child of an infected person.
- Respondents were most commonly receiving single payments from the Skipton Fund (60%), while 37% received regular payments from the same fund and 22% received payments from MFET. Twelve per cent said they did not receive payment from any of these organisations.
- Just over a half of those responding said they had made an application for additional support (52%). Thirty per cent had applied to the Caxton Foundation, 20% to the Macfarlane Trust and one per cent to the Eileen Trust.
- Over half of those who had applied for additional support were successful (57%). Applicants to the Macfarlane Trust were more likely to be successful than those who applied to the Caxton Foundation (68% and 49% respectively).
- Just over half of applicants for additional support were positive about their experience of contacting their trust.
- However, understanding of how trusts offering additional support operate was low. Most applicants for additional support had little knowledge of how trusts make decisions and what processes are involved (71%). Nearly two-thirds of applicants (63%) reported that they found it difficult to understand the rules and procedures regarding additional support.
- Levels of satisfaction with overall support, that is the combination of payments made by Skipton Fund or MFET and additional support from the Caxton Fund, Eileen or Macfarlane Trust, were low. Only three in ten respondents receiving payments were satisfied that organisations provided support efficiently (31%), a fifth were satisfied the support met their needs (21%) and a similar proportion were satisfied that support was given fairly (19%).
- There are considerable variations in experience by primary beneficiary status – primary beneficiaries who were HIV positive only were most positive about their dealings with trusts and organisations, while those with Hepatitis C and HIV were most negative.
 - All primary beneficiaries with HIV only were receiving payments from MFET, while 51% of this group were also receiving single payments from the Skipton Fund. Most of this group had applied for additional support (70%). Over half had applied to the Macfarlane Trust and they were the only primary beneficiary group to have applied to the Eileen Trust (16%). A high proportion of applicants (77%) were successful in their application for additional support. Applicants who were HIV positive only were most likely



to be positive about their experiences of dealing with their trust in relation to additional support (73%). Levels of satisfaction with overall support from all trusts and foundations they dealt were higher than for other primary beneficiary groups receiving payments, albeit still at a low level (for example, 43% were satisfied the support met their needs).

- Virtually all of those with both Hepatitis C and HIV were receiving payments from MFET (98%), followed by 79% of this group who were receiving single payments from the Skipton Fund. This group of primary beneficiaries were most likely to have applied for additional support (88%), and almost all of them had applied to the Macfarlane Trust (87%). A high proportion (74%) of applicants were successful in their application for additional support. Despite this, applicants in this group were least likely to be positive about their experiences of dealing with their trust in relation to additional support (34%). Levels of satisfaction with overall support from all trusts and foundations they dealt were also especially low among those in this group receiving payments (for example, 73% were dissatisfied in relation to the support meeting their needs).
- Those with Hepatitis C were most commonly receiving single payments from Skipton Fund (67%), followed by regular payments from the same fund (57%). They were less likely than other primary beneficiaries to have applied for additional support (49%) and had applied to the Caxton Foundation (also 49%). This group were also less likely to be successful in their application than other beneficiaries (49%). Fifty-eight per cent of applicants in this group were positive about their experiences of dealing with their trust in relation to additional support, which was in line with average. Levels of satisfaction with overall support from all trusts and foundations they dealt were low and were in line with the average for those receiving payments in this respect. For example, 52% were dissatisfied in relation to the support meeting their needs.

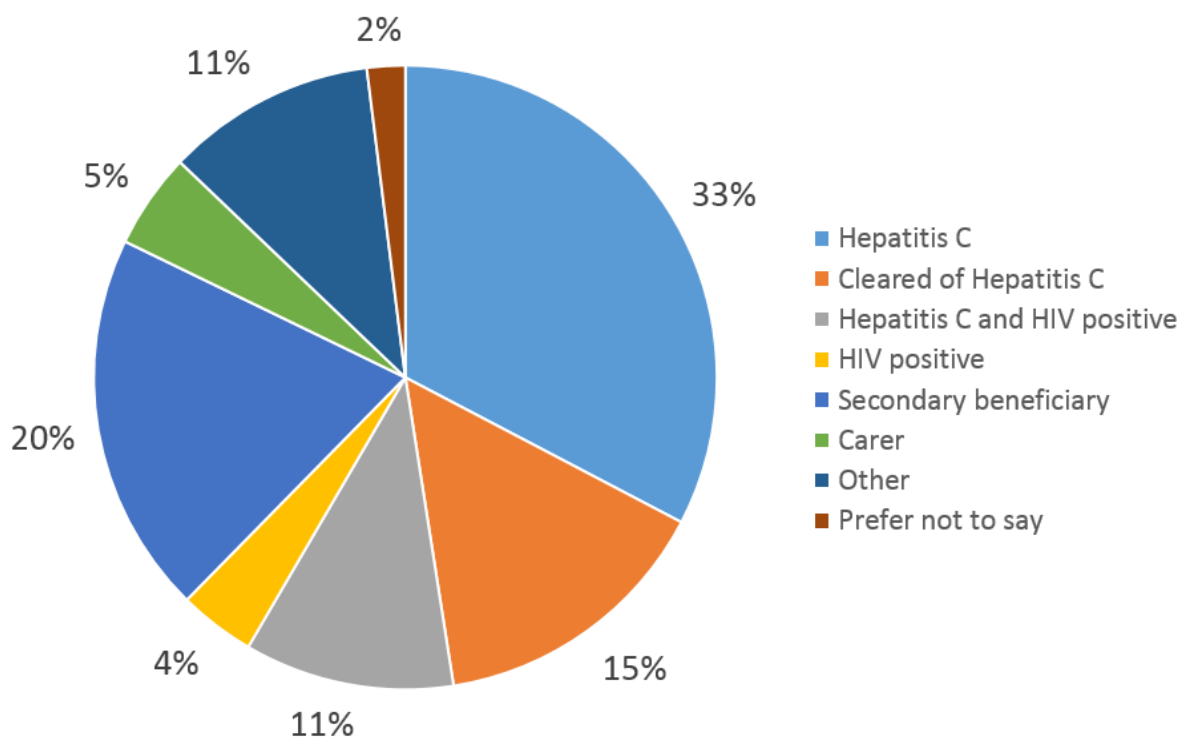
(c) Sample profile

Nearly two-thirds (63%) of those who took part in the survey were primary beneficiaries. As shown in Figure 3.1, the largest group (48%) had Hepatitis C or had previously been diagnosed (33% currently had it and 15% were now cleared of it). A further 11% had Hepatitis C and were also HIV positive. Four per cent were HIV positive only.

A fifth of the sample described themselves as secondary beneficiaries (20%), including widows, partners and children, while five per cent cared for an infected person. Eleven per cent described themselves in other ways, for example as the wife or child of an infected person.



Figure 3.1 Beneficiary status



Base: All respondents (961)

It is also helpful to understand how primary beneficiaries became infected (see Table 3.1). Over half of primary beneficiaries had a bleeding disorder (54%). Thirty-seven per cent did not have a bleeding disorder and had become infected via a blood transfusion, while two per cent had become infected via their partner.

Those with Hepatitis C were equally likely to have contracted it as a result of having a bleeding disorder or because they had had a blood transfusion and did not have a bleeding disorder (45% for each).

Individuals with Hepatitis C and HIV and HIV only were particularly likely to have a bleeding disorder (89% and 65% respectively).



Table 3.1 Type of primary beneficiary by beneficiary status

	Total	Hep C	HIV	Both
<i>Base: All primary beneficiaries</i>	602	458	37*	107
	%	%	%	%
I am a primary beneficiary with a bleeding disorder	54	45	65	89
I am a primary beneficiary without a bleeding disorder and infected via blood transfusion	37	45	14	11
I am a primary beneficiary without a bleeding disorder and infected via my partner	2	2	16	0
Other	3	3	5	0
Prefer not to say	1	1	0	0
Don't know	2	3	0	0

**Caution: low base*

(d) Trusts and foundations providing payments

Respondents were asked which organisations they received payments from and were able to name more than one out of the three options given. As shown in Table 4.1, respondents were most commonly receiving single payments from the Skipton Fund (60%), while 37% received regular payments from the same fund and 22% received payments from MFET. Twelve per cent said they did not receive payments from any of these organisations.

All primary beneficiaries with HIV only were receiving payments from MFET, while 51% of this group were also receiving single payments from the Skipton Fund. Virtually all of those with both Hepatitis C and HIV were receiving payments from MFET (98%), followed by 79% of this group who were receiving single payments from the Skipton Fund.

Those with Hepatitis C only were most commonly receiving single payments from Skipton Fund (67%), followed by regular payments from the same fund (57%).

Other types of respondent (46%) and secondary beneficiaries and carers (27%) were particularly likely not to be receiving any payments from these organisations, compared with only one per cent of primary beneficiaries. They were particularly unlikely to be receiving regular payments from the Skipton Fund (15% of secondary beneficiaries/carers and 14% of others compared with 49% of primary beneficiaries).



Table 4.1 Organisations respondents have received payments from by beneficiary status

	Total	Hep C	HIV	Both	Secondary /Carer	Other	All primary
<i>Base: All respondents</i>	961	458	37*	107	241	102	602
	%	%	%	%	%	%	%
The Skipton Fund – single payment	60	67	51	79	50	37	68
The Skipton Fund – regular payments	37	57	11	27	15	14	49
MFET	22	*	100	98	20	20	24
None of the above	12	1	0	0	27	46	1
Don't know	2	0	0	0	6	3	0
<i>*Caution: low base</i>							
<i>* instead of a figure</i>							
<i>denotes less than 0.5%</i>							



Table 4.2 Organisations respondents have received payments from by type of primary beneficiary

	All primary beneficia ries	...with a bleeding disorder	...without a bleeding disorder and infected via blood transfusion
<i>Base: All primary beneficiaries</i>	602	327	225
	%	%	%
The Skipton Fund – single payment	68	76	57
The Skipton Fund – regular payments	49	36	69
MFET	24	36	7
None of the above	1	1	0



(e) Applications for additional support

Respondents are also able to apply for additional support, which is provided by the Macfarlane Trust, Caxton Foundation or Eileen Trust. As Table 5.1 shows, just over half of those surveyed said they had made an application for additional support (52%). Thirty per cent had applied to the Caxton Foundation, 20% to the Macfarlane Trust and one per cent to the Eileen Trust. Forty-four per cent had not applied for additional support.

Respondents with Hepatitis C and HIV (88%) and HIV only (70%) were most likely to have applied for additional support. Just under half of those with Hepatitis C had done so (49%). Primary beneficiaries with a bleeding disorder were also more likely to have applied (67% compared with 45% of those infected via blood transfusion without a bleeding disorder) – see Table 5.2. The lowest levels of applications were from secondary beneficiaries or carers (45%) and other types of respondents (40%).

Trusts offering additional support cater for different groups of beneficiaries. Applications to the Macfarlane Trust were most likely to come from those with Hepatitis C and HIV (87%) and HIV only (54%). A greater proportion of applications to the Macfarlane Trust had come from those with bleeding disorders (30%, compared with 5% of those infected via blood transfusion without a bleeding disorder).

Levels of applications to the Caxton Foundation were highest among those with Hepatitis C (49%), while only one per cent believed they had support from those with Hepatitis C and HIV, although this can't be the case. There was no difference in the likelihood to apply to this foundation by type of primary beneficiary i.e. how they had become infected.

Among primary beneficiaries, applications to the Eileen Trust had primarily come from those with HIV only (16%). The Eileen Trust only supports those who do not have a bleeding disorder and this was reflected in the survey findings. Two per cent of those without a bleeding disorder and infected via blood transfusion had applied to the Eileen Trust (none of those with a bleeding disorder had applied).



Table 5.1 Organisations applied to for additional support by beneficiary status

	Total	Hep C	HIV	Both	Secondary /Carer	Other
<i>Base: All respondents</i>	961	458	37*	107	241	102
	%	%	%	%	%	%
The Macfarlane Trust	20	*	54	87	25	21
The Caxton Foundation	30	49	0	1	20	19
The Eileen Trust	1	*	16	0	0	1
Not applicable – I have not applied for additional payments	44	48	27	11	51	52
Don't know	4	3	3	1	4	8
All who have applied	52	49	70	88	45	40
<i>*Caution: low base</i>						
<i>* instead of a figure</i>						
<i>denotes less than 0.5%</i>						



Table 5.2 Organisations applied to for additional support by type of primary beneficiary

	All primary beneficiaries	...with a bleeding disorder	...without a bleeding disorder and infected via blood transfusion
<i>Base: All primary beneficiaries</i>	602	327	225
	%	%	%
The Macfarlane Trust	19	30	5
The Caxton Foundation	37	37	38
The Eileen Trust	1	0	2
Not applicable – I have not applied for additional payments	40	31	52
Don't know	2	2	3
All who have applied	57	67	45

As shown in Table 5.3, over half of those who had applied for additional support were successful (57%). Applicants to the Macfarlane Trust were more likely to have been successful than those who applied to the Caxton Foundation (68% and 49% respectively). Due to the small number of applicants to the Eileen Trust it is not possible to make comparisons for this measure.



Table 5.3 Application success rate by trust applied to

	Total	The Macfarlane Trust	The Caxton Foundation
<i>Base: Those who applied for additional support</i>	498	196	293
	%	%	%
Yes	57	68	49
No	37	23	47
Prefer not to say	6	8	4

Reflecting the fact that trusts cater for different beneficiary groups, those with HIV only or both Hepatitis C and HIV were more likely to be successful in their application (77% and 74% respectively than those with Hepatitis C only (49%) – see Table 5.4. There was no difference in the success rate for primary beneficiaries compared with secondary beneficiaries or carers.

Table 5.4 Application success rate by beneficiary status

	All who applied	Hep C	HIV	Both	Secondary/ Carer	Other	Primary
<i>Base: Those who applied for additional support</i>	498	225	26*	94	109	41*	345
	%	%	%	%	%	%	%
Yes	57	49	77	74	57	49	58
No	37	46	19	17	37	49	36
Prefer not to say	6	4	4	9	6	2	6

**Caution: low base*



(f) Knowledge of decision-making processes

Applicants for additional support were asked how much they knew about how their trust makes decisions and what processes are involved, in relation to their application (see Table 6.1). Overall, knowledge was low, with 71% of applicants giving a score of between zero and three, where zero was ‘very little’ and ten was ‘a lot’. Only seven per cent claimed to be knowledgeable (scoring between eight and ten).

Knowledge was lower among applicants to the Caxton Trust than the Macfarlane Trust (76% and 65% gave a score of 0-3 respectively). It was also lower among those whose application was not successful (79% gave a score of 0-3, compared with 68% for those with a successful application).



Table 6.1 Knowledge of decision making processes by whether application was successful and trust applied to

	All who applied	Successful?		Additional Payment trust	
		Yes	No	The Macfarlane Trust	The Caxton Foundation
<i>Base: Those who applied for additional support</i>	498	285	185	196	293
	%	%	%	%	%
0 – Very little	42	38	51	42	43
1	9	7	11	7	10
2	10	11	9	9	11
3	10	12	9	7	12
4	4	5	2	5	3
5	9	13	5	10	9
6	2	3	1	3	2
7	3	2	2	3	3
8	2	2	2	2	3
9	2	3	1	4	*
10 – A lot	3	3	3	4	2
Don't know	3	1	5	5	2
0 - 3	71	68	79	65	76
4 - 7	18	23	10	20	17
8 - 10	7	8	5	9	5

** instead of a figure denotes less than 0.5%*



Applicants were also asked to rate how easy or difficult they found it to understand the rules and procedures regarding additional support (see Table 6.2). Again, understanding was low, with 63% giving a rating of between zero and three, where zero was ‘very difficult’ and ten was ‘very easy’. Those who were unsuccessful were more likely to find the rules and procedures difficult (72% scored 0-3 compared with 58% with successful applications). There was no difference in experience between applicants to the Macfarlane Trust and Caxton Foundation.

Table 6.2 Ease of understanding the rules and procedures regarding additional support by whether application was successful

	All who	Successful?	
	applied	Yes	No
<i>Base: Those who applied for additional support</i>	498	285	185
	%	%	%
0 – Very difficult	35	30	43
1	9	8	11
2	11	13	9
3	8	7	9
4	6	8	4
5	11	14	6
6	3	4	2
7	3	4	2
8	2	2	1
9	1	2	1
10 – Very easy	2	2	3
Don't know	8	6	9
0 - 3	63	58	72
4 - 7	23	29	15
8 - 10	6	7	5



(g) Experience of contacting the trust regarding additional support

Applicants for additional support were given a number of positive and negative adjectives to describe their experience of contacting their trust in regard to additional support and were asked to choose one (see Table 7.1). Over half (53%) were positive, describing the trust they applied to as helpful (22%), supportive (13%), respectful (10%) or kind (6%). Just over a third were negative (35%), describing their trust as discouraging (17%), dismissive (11%), disrespectful (5%) or rude (1%).

As shown in Figure 7.1, applicants who were HIV positive only were most likely to be positive about their experiences (73%) while those with both Hepatitis C and HIV were least positive (34%). Other respondents were also less likely to be positive (37%).

Those who had applied to the Eileen Trust were by far the most likely to describe their experience in positive terms (89%). Interestingly, although applications to the Macfarlane Trust were more likely to be successful, applicants were more likely to describe their experience of contacting the Caxton Trust in positive terms (57% used a positive adjective, compared with 44% for the Macfarlane Trust).

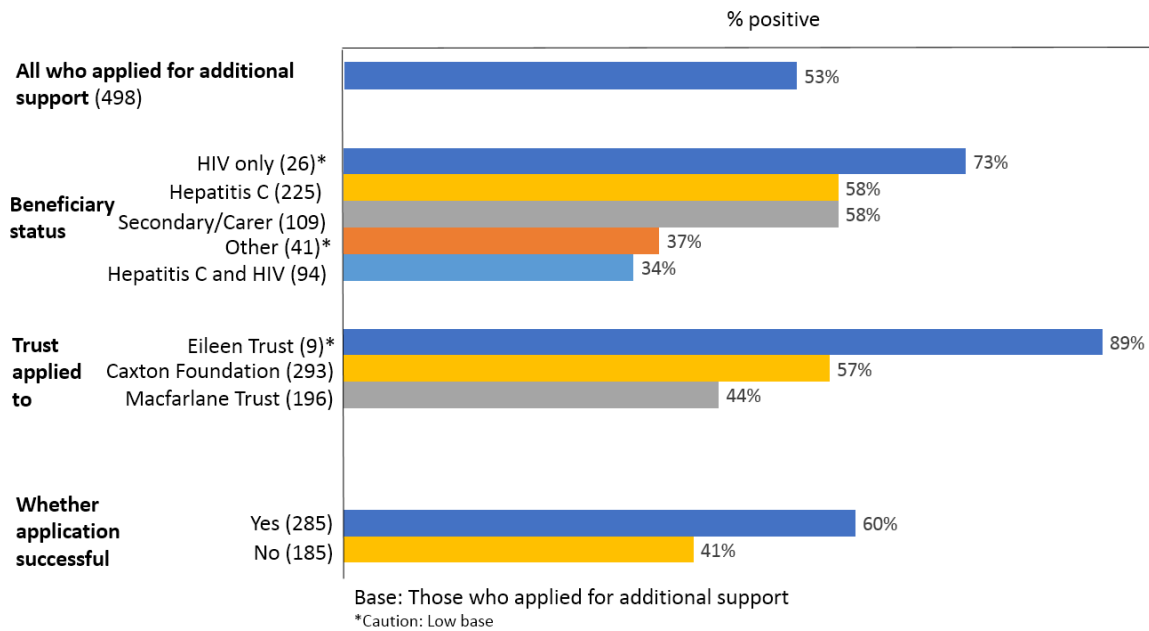
Those whose application had been successful were more likely to be positive (60%, compared with 41% of those who were unsuccessful).

Table 7.1 Experience of contacting the trust regarding additional support

	All who applied
<i>Base: Those who applied for additional support</i>	498
	%
Helpful	22
Discouraging	17
Supportive	13
Dismissive	11
Respectful	10
Kind	6
Disrespectful	5
Rude	1
Don't know	13
Any positive	53
Any negative	35



Figure 7.1 Experience of contacting the trust regarding additional support by beneficiary status, trust applied to and whether application was successful





(h) Satisfaction with overall support received.

Respondents were asked about their satisfaction with the overall support they received, that is the combination of payments made by Skipton Fund or MFET and additional support from the Caxton Fund, Eileen or Macfarlane Trust. Only those who said they received payments from Skipton Fund or MFET were asked these questions. Note that some respondents receive payments from Skipton Fund and MFET and may also have received additional support. Beneficiaries were asked about their overall support and it is not possible to attribute their experiences to particular trusts.

Beneficiaries were asked to rate their satisfaction with overall support in terms of the following:

1. the support meets my needs as a beneficiary
2. I think support is given fairly to beneficiaries
3. the organisations provide support efficiently.
4. the organisations I deal with have sufficient resources to meet beneficiaries' needs

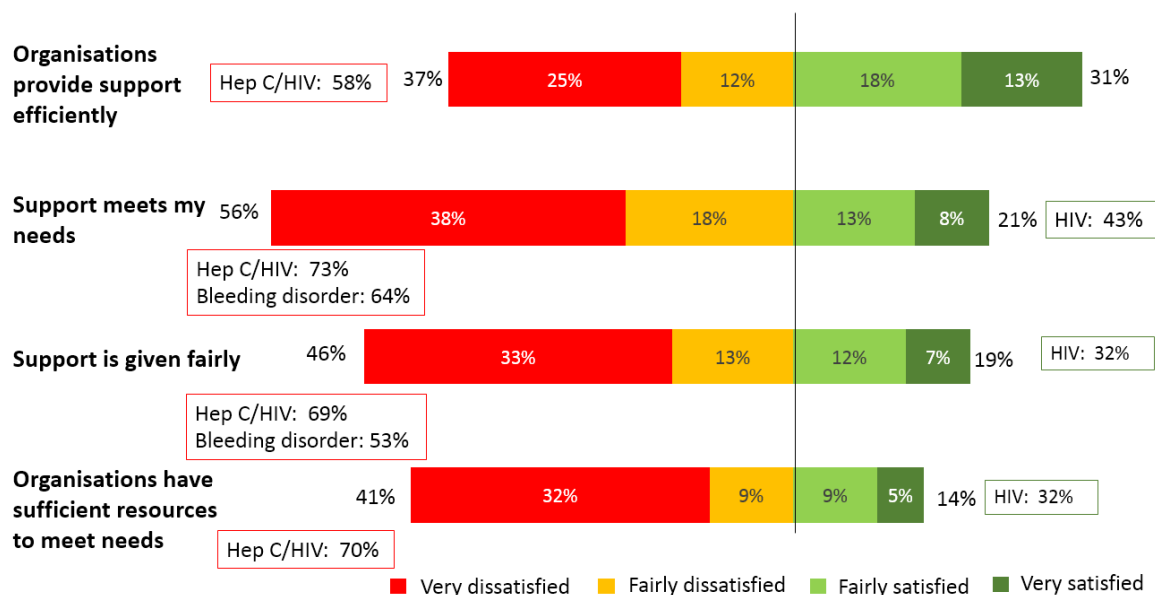
Levels of satisfaction across all elements of service were low (see Figure 8.1). Satisfaction was highest in relation to efficiency (albeit still at a low level): just over three in ten beneficiaries receiving payments (31%) were satisfied that organisations provided support efficiently, compared with nearly two-fifths who were dissatisfied (37%).

A fifth of beneficiaries receiving payments said they were satisfied that the support met their needs (21%), while over half (56%) were dissatisfied. A similar proportion (19%) were satisfied that support was given fairly to beneficiaries, compared with 46% who were dissatisfied.

Beneficiaries were least likely to be satisfied that organisations had sufficient resources to meet their needs (only 14% of beneficiaries receiving payments were satisfied, compared with 41% who were dissatisfied). It should be noted that nearly three in ten were not able to comment (29%).



Figure 8.1 Satisfaction with overall support received



Base: Those who received payments from Skipton Fund or MFET (Total: 823, Hepatitis C/HIV: 107, HIV only: 37 (Caution: low base), Bleeding disorder: 325)

In terms of beneficiary status, levels of satisfaction were highest among those who were HIV positive on three of the measures: forty-three per cent of this group were satisfied the support met their needs (21% overall), 32% were satisfied support was given fairly (compared with 19% overall) and the same proportion were satisfied organisations had sufficient resources (32% compared with 14% overall).

In contrast, those who had both Hepatitis C and HIV were most likely to be dissatisfied across all four measures: seventy-three per cent were dissatisfied in relation to the support meeting their needs (56% overall); 70% were dissatisfied in relation to organisations having sufficient resources (41% overall); 69% were dissatisfied in relation to the fairness of support (46% overall) and 58% were dissatisfied in terms of the efficiency of support (37% overall).

Primary beneficiaries with a bleeding disorder were also more likely than those without a bleeding disorder and infected via blood transfusion to be dissatisfied. Sixty-four per cent of those with a bleeding disorder were dissatisfied that support met their needs (46% of those without a bleeding disorder) and 53% were dissatisfied in relation to the fairness of support (35% of those without a bleeding disorder).

A summary satisfaction measure has been derived by identifying beneficiaries who were satisfied with the organisations they dealt with in terms of their needs being met, fairness and efficiency. At the most positive end of the scale, over one in ten of those receiving



payments were satisfied on all three of these measures (12%), while around three in ten (31%) were dissatisfied on all three.

In line with the findings for individual satisfaction measures, those who were HIV positive only were most likely to be satisfied with all three measures (24%), while those with both Hepatitis C and HIV were most likely to be dissatisfied on all three (49%). Other respondents (46%) were also more likely to be dissatisfied on all three (see Table 8.1). As Table 8.2 shows, among primary beneficiaries, those with a bleeding disorder were more dissatisfied than those without a bleeding disorder (38% and 22% respectively dissatisfied with all three).

Table 8.1 Summary satisfaction measure by beneficiary status

	All receiving payments	Hep C	HIV	Both	Secondary /Carer	Other
<i>Base: Those who received payments from Skipton Fund or MFET</i>	823	454	37*	107	163	52
	%	%	%	%	%	%
Satisfied with all 3 measures	12	13	24	8	13	8
Dissatisfied with all 3 measures	31	28	24	49	26	46
<i>*Caution: low base</i>						



Table 8.2 Summary satisfaction measure by type of primary beneficiary

	All primary beneficiaries	...with a bleeding disorder	...without a bleeding disorder and infected via blood transfusion
<i>Base: Those primary beneficiaries who received payments from Skipton Fund or MFET</i>	598	325	225
	%	%	%
Satisfied with all 3 measures	12	10	14
Dissatisfied with all 3 measures	31	38	22