



**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

Executive Summary

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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.





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 charity has recently had to reduce its winter fuel payments 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 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% 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 emphasised 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 need, 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.



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. ¹	<p>All MFT beneficiaries received £20,000 in 1991² then a further £21,500-£60,500, varying dependant on individual family circumstances,³ 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.⁴</p>	£14,574
	Family of an infected person who died before scheme established.		£43,500 ⁵	No entitlement to ongoing payments.

¹ 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.

² Written Parliamentary Question 211081, Diana Johnson MP, answered 27 Oct 2014.

³ 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.

⁴ Written Parliamentary Question 214975, Diana Johnson MP, Answered 25 Nov 2014.

⁵ 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.



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.”⁶</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.⁷ 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.⁸</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.⁹</p>

⁶ Caxton Foundation (2014), *Letter to the APPG Inquiry*, 21 Nov 2014.

⁷ Ibid.

⁸ 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.

⁹ 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. ¹⁰	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.		

¹⁰ 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. ¹¹ The government have extended this service to 2015/16. ¹²		
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.		

¹¹ Andrew Lansley MP, Hansard HC Deb 10 Jan 2011, *Contaminated Blood*, Cols. 33-34.

¹² Written Parliamentary Question 211036, Diana Johnson MP, Answered 27 Oct 2014.