

Witness name: The Scottish Infected Blood Forum

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Dated: 10<sup>th</sup> August 2022

**INFECTED BLOOD INQUIRY**

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**EXHIBIT WITN7165006**

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## **Financial Review Group**

### Final Report

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# CONCLUSIONS

Chapter 1 provides the background to the creation of the Review Group, which was a historic Scottish Government commitment to be taken forward following the publication of the Penrose Inquiry report. The membership of the group is listed at **Annex A** and the Terms of Reference for the review can be found at **Annex B**.

The Group considered the UK-wide arrangements already in place to provide financial support for those infected with hepatitis C (HCV) and/or HIV through NHS treatment and their families/carers. Chapter 4 examines the current situation and explains the current scheme criteria in detail.

The Group also considered evidence regarding similar financial support and no-fault compensation systems in this country and in other jurisdictions. This evidence is summarised at **Annex C**.

From the start of the review exercise, the Group committed to openness and transparency with regard to their discussions and evolving position. They were very aware that they were representing a diverse community and that each individual case was unique. The group members brought their own experience to bear and reflected on the adversity suffered by their family and peers over many years.

A survey was developed and shared with the wider community to test their views. The Group also arranged a series of regional meetings which gave people an opportunity to come together and informally discuss the consultation questions. A final national meeting was held on Saturday 31 October 2015 to give people the opportunity to come together for more information and to discuss the draft recommendations. A report on the consultation exercise can be found in **Chapter 3**.

The Group's discussions are also summarised at **Chapter 3**. They concluded that although the situation had been improved to some extent

by the 2011 Contaminated Blood Review, there was still significant unmet need among those affected. A combination of pain, suffering and associated financial loss had irrevocably altered the lives of those affected. Many had died from their infection, leaving their families to deal not only with grief, but long-term loss of support. Carers had sacrificed their own careers and opportunities because of their caring responsibilities. Although it is impossible to place a monetary value on these experiences, the Group are of the view that the depth of the physical and emotional suffering involved can only be addressed by introducing new financial support arrangements.

In reaching their conclusions the Group have tried to balance the complex and varied impacts of infection with an approach that will minimise bureaucracy and maximise benefits to those affected. Harm has a number of different strands, some capable of objective assessment, others less so. They have considered the design, delivery and ongoing evaluation of a new scheme, using evidence from those affected and from comparable schemes. Capturing the huge complexity of health and social impacts and embedding them in a scheme under generalised principles is obviously very challenging. The Group have tried to reach common understanding and agreement about the nature, scope and key features of the harm and economic consequences suffered by those infected and their families/carers. This wide-ranging discussion has resulted in the critical components of the scheme. However, the Group recognises that one size does not fit all and there will be some people affected who are disappointed by the proposals. The Scottish Infected Blood Forum members have recorded a Note of Dissent with regard to the final proposals of the Group, which can be found at **Annex D**.

They Group have tried to evaluate the consequences of infection in a proportionate and balanced way, with the full knowledge that their proposals will be subject to rigorous scrutiny by Scottish Ministers, the Parliament and the public. They were clear that consistency of delivery and assessment was a key concern, as was the scheme being responsive to the unique Scottish context and any emerging evidence with regard to the impact of infection. It was desirable to reduce the administrative burden and associated decision times as much as possible.

In the proposals the Group have outlined the essential characteristics of a new support system. Necessarily, to aid transition they are based upon some of the approaches taken by the existing schemes and are presented as high-level objectives. They are listed below but not presented in any order of priority, since the Group considers that an effective system should meet all of them.

## KEY RECOMMENDATIONS

**Chapter 2** describes the proposals in detail. In summary, the Group recommends the following:

### Proposal 1. Annual payments

- The annual payments for HIV and advanced HCV (currently known as Stage 2) should be increased from £15k p.a. to £27k p.a. to reflect Scottish full-time gross median income.
- Co-infected HIV and advanced HCV beneficiaries currently receive £30k p.a. That amount should be raised to £37k to reflect additional health needs. This should be payable in all co-infected HIV and HCV cases, including those currently at Stage 1 HCV (chronic infection), to reflect the additional health impacts and complications of co-infection. All co-infected people who are currently at Skipton Fund Stage 1 should also automatically receive a £50k lump sum as they would do were they to qualify for Stage 2 of the Skipton Fund.

### Proposal 2. Supporting widows, widowers

- When the primary recipient dies, the increased annual payments should convert into a pension for surviving spouses of 75% of the relevant level of annual payment. To qualify you must be, or have been, married to or in a civil partnership with the primary recipient at the point of death. This would mean £27,750 in co-infected cases and £20,250 for those infected with HIV or at HCV Stage 2 only.
- The proposed annual payment should continue for a full year after the date of death of the primary recipient, to provide transition support. Thereafter, it should convert into payment at 75% p.a. to the spouse until death.
- Widows of those who died at current Skipton Stage 1 should also be able to apply for this payment where the virus contributed directly to the death of the primary recipient.

### Proposal 3. Increased lump sum payment for chronic hepatitis C infection

- The Ross Expert Group report recommendation related to chronic infection with HCV should be fulfilled. That is: all those chronically infected with HCV should receive a £50k lump sum payment. For those infected with HCV who have already received the £20k Stage 1 lump sum from the Skipton Fund, this would mean an additional £30k lump sum.
- If any individuals in receipt of the higher lump sum payment for chronic infection subsequently transition to the current Stage 2 (cirrhosis, liver cancer, liver transplant, B-cell non-Hodgkin's lymphoma) then they should receive the remaining £20k lump sum they would become eligible for at Stage 2, and



become eligible for annual payments. In effect, the additional £30k lump sum is released from the current £50k Stage 2 payment. A total lump sum of £70k would still be payable, with £50k for Stage 1 and a further £20k for Stage 2 under the new arrangements.

## **Proposal 4. Support and Assistance Grants**

- A new Support and Assistance Grants scheme should be established, with greater funding than the existing discretionary schemes. Scottish Government currently allocates ~£300k p.a. to the discretionary funds distributed by the Caxton Foundation – to allow sufficient flexibility and responsiveness to the new target group this should be increased to £1m p.a. and distributed through a new Grant scheme.
- The grant should be administered in Scotland, either by an existing Scottish body, or via a new body established specifically for this purpose.
- The scheme should be available to anyone in receipt of payments or their families/carers.
- The scheme should have simple mechanisms for application and payment, and a transparent appeals mechanism which involves patient representatives.
- All commitments made by the Eileen Trust, Macfarlane Trust and Caxton Foundation to make regular payments, including winter fuel payments, should be honoured by the new fund under the existing terms of payment.
- Applicants should indicate what they wish to use the funding for, against a set list of activities/needs, and sign an undertaking to use it for that purpose. All assessments, but particularly means-testing, should be minimised and simplified as much as possible.

## **Proposal 5. Further work**

- Recipients of the ongoing annual payments should have the option of converting these into a one-off lump sum payment by way of final settlement.
- Access to insurance products, and additional loading of premiums due to infections, should be given further consideration.
- The operation of the schemes should be subject to periodic review in conjunction with beneficiaries.
- The current thresholds for Stage 1 and Stage 2 of the Skipton Fund should be the subject of a specific, evidence-based review to create new criteria based on health impact, rather than focusing predominantly on liver damage.
- This review should also thoroughly evaluate the criteria for attributing HCV to the cause of death, including death certificate data.
- Applicants may have historically been rejected from the Skipton Fund without sufficient justification, openness and transparency. It should be open to these applicants to reapply to the new scheme using more uniform, published principles. A future review should consider suitable principles for the evaluation and decision-making process.

## Operation of the scheme - proposals

- None of these proposals should require recipients to sign any sort of waiver to prevent individual legal action for damages etc.
- A new Scottish scheme should be established that is sensitive to the unique Scottish context. This should encompass current and future HIV and HCV beneficiaries.
- All of these payments should not be taken into account for the purposes of entitlement to benefits and should be exempt for taxation purposes.
- Eligibility for payments should be on the balance of probabilities – i.e. medical records not absolutely required.
- Appeals mechanism – a credible, transparent appeals mechanism should be established for all parts of the improved schemes. Applicants should be able to appear in person at their appeal and bring an appropriate representative.
- Accountability – the new structures established in Scotland should have affected patients involved in Governance/oversight.
- The group agreed as a principle that nobody should receive less financial support due to the new arrangements. The same level of support should at least be maintained.
- Any new arrangements should be subject to periodic future review to ensure they are fit for purpose.

## CHAPTER 1 - BACKGROUND

There are five payment schemes that currently provide financial support to patients infected with hepatitis C and/or HIV, as a result of infected NHS blood or blood products. The HIV financial support schemes (Macfarlane Trust/MFET Limited and Eileen Trust) pre-date devolution and are managed and funded solely by the UK Department of Health. The two hepatitis C support schemes (Skipton Fund and Caxton Foundation) post-date devolution and although they operate as UK schemes, the Scottish Government fully funds all costs (currently £2.5m a year) for qualifying persons within Scotland. The Scottish Government has already contributed £32m in direct payments to these schemes. Payments are ex-gratia for which there is no liability.

Following an evidence-based 2011 review of the HCV schemes which resulted in increased payments, the then Cabinet Secretary for Health and Wellbeing, Nicola Sturgeon, committed to a further review of the existing financial support provisions for people who contracted hepatitis C from NHS infected blood and blood products (the Skipton Fund and Caxton Foundation) following the publication of the final Penrose Inquiry report. The Scottish Government subsequently established a Review Group of patient and family representatives in June 2015 following the publication of the Inquiry report. The group was to report to Scottish Ministers as soon as possible, but no later than November 2015.

The current Cabinet Secretary for Health, Wellbeing and Sport in Scotland, Shona Robison, made a Ministerial Statement on Thursday 26 March as the Scottish Government's response to the publication of the Penrose Inquiry report on 25 March. The full text of the statement can be viewed here:

<http://www.scottish.parliament.uk/parliamentarybusiness/28862.aspx?r=9877&i=90485&c=1813886>

Both the Cabinet Secretary and the First Minister, Nicola Sturgeon, apologised to those affected by infected NHS blood and blood products on behalf of the Government of Scotland and the NHS in Scotland. The First Minister's statement can be viewed here:

<http://www.scottish.parliament.uk/parliamentarybusiness/report>.

In line with the Ministerial Statement which reiterated the financial review commitment, the existing financial support arrangements for those infected and their families were to be reviewed as a matter of priority. Ian Welsh of the Health and Social Care Alliance Scotland (the ALLIANCE) was appointed by the Cabinet Secretary as the independent chair of the financial review group that was to take this work forward. The group membership was made up of infected people and their family members along with Scottish Government officials and other relevant experts.

The purpose of the Group was to undertake a review of the existing UK-wide financial support schemes for individuals infected with hepatitis C and HIV through NHS blood and blood products, in respect of individuals infected in Scotland and their families/carers. It has provided recommendations to Scottish Ministers on whether the current system should be changed and, if so, what changes should be made. The membership of the group is enclosed at **Annex A** and the detailed Terms of Reference can be found in **Annex B**.

The Group met on eight occasions. The Cabinet Secretary for Health and Wellbeing chaired the first meeting and the subsequent meetings were under the chairmanship of Ian Welsh from the Health and Social Care Alliance Scotland.

## Consultation Exercise

The group developed a survey to be shared with the wider community to test their views. To allow them to discuss their views in person, the group arranged a series of five regional meetings which gave people an opportunity to come together and informally discuss the consultation questions.

Those who did not want to engage through the survey or a regional meeting had the option of requesting a private, face to face meeting or telephone conversation. A final national meeting was held on Saturday 31 October to give people the opportunity to come together for more information and to discuss the draft recommendations.

The Eileen Trust, Macfarlane Trust, MFET, Skipton Fund and Caxton Foundation assisted with the distribution of the survey but beneficiaries'/registrants' details were not shared.

## Regional meetings

During the last two weeks of August 2015 meetings were held in Edinburgh, Inverness, Dundee, Glasgow, and Aberdeen. They produced more than 10 hours of detailed discussion. The meetings were advertised by Haemophilia Scotland and the Scottish Infected Blood Forum. 86 people attended the meetings, half of these were at the Glasgow meeting. The substance of each meeting was to have a facilitated discussion on the seven key topics

A report on the consultation exercise can be found in **Chapter 3**.



## CHAPTER 2 - PROPOSALS

The discussions of the Group have resulted in four key proposals and a further proposal highlighting areas that require further consideration. Operational proposals are included that make specific recommendations regarding the administration of the scheme. There was a divergence of views across the Group and wider community so the Group identified key principles where agreement could be reached. Given the diversity of views expressed by the Group which each reflected individual experiences and circumstances, the Group has not prioritised or weighted the different proposals. The Group was advised that the final decision of Scottish Ministers would involve consideration of whether the proposals were proportionate, evidence-based and affordable.

Key suggestions involved regular Stage 2 Skipton Fund payments increased to the Scottish median income; a higher level of regular payment for all those co-infected with HIV and HCV; an increased and more flexible discretionary fund; an increased lump sum payment for those at Stage 1 of the Skipton Fund; and strengthened provision for bereaved spouses. Where the primary recipient had died of HCV/HIV, the increased annual payments would convert into a 75% pension for surviving spouses.

The Group ultimately opted to prioritise payments based on broad health impact, rather than focusing predominantly on liver damage as is the case with the existing schemes. They recognised that it was desirable to build on the existing scheme parameters in the first instance, to reduce the administrative burden and to effect a fast transition to the new arrangements. The scheme should be designed to provide a simple, straightforward and speedy way of dealing with need. It should provide appropriate payments with the minimum of delay and without the need for repeated and persistent inquiries.

However, the Group was clear that the scheme parameters should be subject to more detailed future review and more uniform principles for the evaluation of claims should be developed, having regard to the latest international evidence on the impact of infections. It would be key for any review to be taken forward in partnership with scheme beneficiaries to ensure that their needs and preferences are taken into account. There can be considerable unhappiness when claims are allowed or disallowed in circumstances which are not fully understood by claimants.

The Group acknowledged that some of those affected were likely to remain unhappy with the way they would be treated under the proposals. Such people were more likely to support a fixed payment procedure whereby any total budget identified would be split evenly between all categories of recipient, regardless of their circumstances and health status. This view was also reflected by a minority of Group members. The Scottish Infected Blood Forum members have made it clear that their view is that there should be no ongoing prioritisation on the basis of HIV infection, co-infection, severity of HCV illness, financial need or loss of support due to death. They feel that given that the majority of people are currently in the Stage 1 Skipton Fund group, any budget identified should be divided among all of those infected equally, regardless of individual impact. They consider that all those infected have suffered the same harm and deserve to be treated the same. A position statement from the Forum is enclosed at **Annex D** in order to record their view on the proposals, report and review process.

While undeniably simple, this approach could potentially mean that those with more serious impacts only receive a nominal increase to their current support, dependent on the total budget identified. It could conceivably conflict with the principle that nobody should be worse off under the new system than they are under the current system.



## Key points

- The Group favoured a new Scottish scheme that would not be constrained by UK-wide discussions/agreement.
- There was at least some discussion about the court-style damages/solatium model – but also a view that the Group should be trying to address current gaps/shortcomings and helping those in need. A court-style model was not supported by the consultation exercise.
- There was some debate about a simple, universal scheme vs a more complex, tailored scheme – the survey responses supported a simple, universal scheme.
- Although the survey response favored no means-testing or targeting overall, there was also some support for prioritisation based on health and disability.
- The future financial security of families was a major concern for both the infected and the bereaved.
- Infected people have already received basic lump sum payments, regular on-going payments, discretionary payments and court payments dependent on their circumstances.
- Payments have historically been targeted at the most seriously ill and those on very low incomes.
- The historic emphasis has been on the living infected people.
- Infected people have received between £20k and £400k to date depending on circumstances – sums which would likely be taken into account if a court was to calculate a final settlement for damages/solatium.

## Key Principles

Based on the consultation, the Group established some key principles which any proposals would have to meet.

- Nobody should be worse off under any new system than they are under the current system. All existing allocations should at least be maintained on the same terms and at their current level.
- All current categories of people should remain eligible to make an application, including secondarily infected individuals.
- The scheme should recognise all types of loss and suffering including:
  - Pain and suffering
  - Financial losses
  - Ongoing needs.
- The new system should be quickly operational with minimal bureaucracy or 'form filling'.
- That the scheme paid for by Scotland should be accountable in Scotland, and to those affected in Scotland.
- Means-testing should be kept to a minimum.
- That the support available to those who had been bereaved should be the same regardless of which virus caused the death. However, where there had been a greater loss of associated support from the scheme due to a death, this should be recognised in terms of the ongoing 75% payment.
- That nobody should be living in poverty as a result of the infections.
- Any future reviews of a new scheme should be taken forward in partnership with patients and families, using the latest international evidence.

## Proposal 1. Annual payments

- For those who are receiving ex gratia annual payments – both for HIV and advanced hepatitis C – those payments should be increased so that they are in line with the Scottish gross median income for full-time employees.
- These annual payments will ensure nobody is in poverty, and will reflect historic and future financial loss for those most affected by infections.
- The annual payments for HIV and Stage 2 HCV should be increased from £15k p.a. to £27k p.a. to reflect Scottish full-time gross median income. This is necessary to acknowledge that the suffering, losses, and ongoing needs are often felt by partners and that the costs-of-living for those affected are above the Scottish average. This group often suffer particular financial and emotional hardship. This can involve psychiatric injury of such severity that the sufferer is unable to function either in his or her working or social life. They are often unable to obtain adequate life insurance or mortgages without paying a substantial additional premium.
- Co-infected HIV and Stage 2 HCV recipients currently receive £30k p.a. That amount should be raised to £37k to reflect the additional health needs of co-infection. This should be payable in all co-infected HIV and HCV cases, including Stage 1, to reflect the additional health impacts and complications of co-infection. All co-infected who are currently at Skipton Stage 1 should also automatically receive the Stage 2 Skipton payment of a £50k lump sum.
- In the event of a terminal diagnosis beneficiaries should be able to access their entire annual payment upfront rather than instalments, to allow for financial planning. Consideration should be given to the additional needs and

implications of end of life care, both in terms of Support and Assistance grants and access to lump sum alternatives as recommended in Proposal 5.

- As with the current arrangements, these payments should be exempt from tax. In real terms this would take recipients above the median income.
- As with the current arrangements, these payments should have no impact on benefits.

## Proposal 2. Supporting widows, widowers.

- When the primary recipient dies or has died in the past, the increased annual payments should convert into a pension for surviving spouses of 75% of the relevant level of annual payment. This would mean £27,750 in co-infected cases and £20,250 for those infected with HIV or at HCV Stage 2 only. Payments are, in part, recognition of injury and harm, so the ongoing payment to widows/widowers should be at 75%, in common with section 7 of the Damages (Scotland) Act 2011 which relates to loss of support.
- These payments would be restricted to the spouse (marriage or civil partnership) of the primary recipient at the point of death. This will avoid assessment difficulties where families are estranged and perhaps in conflict.
- The proposed annual payment should continue for a full year after the date of death of the primary recipient, to provide transition support. Thereafter, it should convert into payment at 75% p.a. to the spouse until death.
- Widows of those who died while infected with HIV or at Skipton Stage 2 in the past should immediately qualify for the 75% annual payment going forward.
- Widows of those who died at Skipton

Stage 1 should be able to apply for this payment where the virus contributed directly to the death of the primary recipient. This should be considered on a case by case basis to determine circumstances – i.e. the group do not want to absolutely rule out Stage 1 recipients. The criteria for establishing the direct causal link to death should be the subject of future review.

- These new payments should have no impact on benefits or taxation.

### **Proposal 3. Increased lump sum payment for chronic hepatitis C infection**

- The first section of the Ross report recommendation related to chronic infection with HCV should be fulfilled. That is: all those chronically infected with HCV should receive a £50k lump sum payment. For those infected with HCV who have already received the £20k Stage 1 lump sum from the Skipton Fund but have not progressed to Stage 2, this would mean an additional £30k lump sum. If it is not possible to implement that recommendation, an intermediate lump-sum payment of an additional £30k should be established for those who have measurable health impacts (such as liver fibrosis but also including extra-hepatic manifestations and mental health issues) but who are not yet eligible for Skipton Stage 2. This group should be prioritised if necessary on the basis of health impacts from moderate disease progression and historic treatments.
- Making this payment to all those chronically infected with HCV rather than a more narrowly prescribed group will avoid the additional administrative burden of assessment and appeals. Given the length of infection it is unlikely that more than a small minority would not have suffered measurable health impact.

- If it is necessary to prioritise on the basis of moderate disease progression, clinical advice would be required on how to establish new thresholds – this should include extra-hepatic conditions and mental health. This work should be undertaken by a group including both clinicians and patients.
- If any individuals in receipt of the additional £30k lump sum payment subsequently transition to the current Stage 2 (cirrhosis, liver cancer etc) then they should receive the remaining £20k lump sum they would become eligible for at Stage 2, and become eligible for annual payments. In effect, the additional £30k lump sum would be released from the current £50k Stage 2 payment. A total lump sum of £70k would still be payable, with £50k for Stage 1 and a further £20k plus annual payments for Stage 2 under the new arrangements.

### **Proposal 4. Support and Assistance Grants**

- A new Support and Assistance Grants scheme should be established, with greater funding than the existing discretionary schemes. Scottish Government currently allocates ~£300k p.a. to the discretionary funds distributed by the Caxton Foundation – to allow sufficient flexibility and responsiveness to the new target group this should be increased to £1m p.a. and distributed through a new Grant scheme.
- The grant should be administered in Scotland, either by an existing Scottish body, or via a new body established specifically for this purpose.
- The scheme should be available to anyone in receipt of payments or their families/carers.
- The scheme should have simple mechanisms for application and payment, and a transparent appeals mechanism



which involves patient representatives.

- Any infected person, their immediate family (to be defined) and/or carers should be able to apply for grants from the scheme.
- Grants could be provided for one or three years.
- The demand on the fund should be monitored and funding adjusted to accommodate it if necessary. The initial years of operation may require increased funding.
- All commitments made by the Eileen Trust, Macfarlane Trust and Caxton Foundation to make regular payments, including winter fuel payments, should be honoured by the new fund under the existing terms of payment.
- We would seek to learn from the Thalidomide Grants model where funding can be used for certain defined activities. Applicants should indicate what they wish to use the funding for, against a set list of activities/needs, and sign an undertaking to use it for that purpose. Assessments should be minimised and simplified as much as possible.
- The Scheme should enable the grant to be used creatively - i.e. to provide a lump sum to certain recipients, or to 'top-up' annual payments where needed. The evolving needs of recipients should be kept under review and the fund adjusted accordingly to accommodate.
- There should be minimal means testing – unless applicants significantly exceed available funds in which case those most in need should be prioritised. The group recognises that in order to channel appropriate funding to those in the most financial need, there may be the need for some residual means testing, especially with regard to large additional sums of money.
- The Group acknowledge that this may require intermittent, random spot-checks on use of money to satisfy audit requirements. However, these should be kept to a minimum and only apply to larger grants. The Group accepts that the audit requirements of the agency in question may make this unavoidable.
- The activities that this grant could be used for would need to be defined, but the Group suggests the following as examples of legitimate expenses for infected patients or their families:
  - Financial support whilst undergoing treatment.
  - Financial support for end of life care.
  - Travel/life insurance – to cover the additional premium related to the infection/s.
  - Respite breaks.
  - Additional health and mobility-related repairs and adaptations to homes.
  - Support with debt and money management.
  - Purchase of essential household items.
  - Support with vehicle repair costs to ensure people can retain their mobility and independence.
  - Financial support to enable people to undergo re-training.
  - Funeral plans.
  - Counselling/psychological support.
  - Tax assistance if in financial need.
  - Providing support to the children of the deceased where they would have had a reasonable expectation that an unaffected parent would have provided that support (driving lessons, education, and training).

- Access to complementary therapies.
- Home help to enable people to stay in their homes.

## **Proposal 5. Further work**

- Recipients of the ongoing annual payments should have the option of converting these into a one-off lump sum payment by way of final settlement. The mechanism for this calculation would require further consideration and scoping. The Group accepts that the characteristics of the scheme have to be established before a mechanism for this payment could be developed and costed.
- Access to insurance products, and additional loading of premiums due to infections, should be given further consideration.
- The operation of the schemes should be subject to periodic review in conjunction with beneficiaries.
- The current thresholds for Stage 1 and Stage 2 of the Skipton Fund should be the subject of a specific, evidence-based review. The review should include independent medical experts, lay members and those infected. It should take account of the latest international evidence on the clinical consequences of HCV infection, including the causal consequences of infection. The remit of this review should be to establish qualification criteria which better reflect the total health impact of infection.
- This review should also thoroughly evaluate the criteria for attributing HCV to the cause of death, including death certificate data. A person other than the primary physician of the deceased can commonly complete the death certificate and so HCV status is often not detected and thus not reported as a cause of death.

- Applicants may have historically been rejected from the Skipton Fund without sufficient justification, openness and transparency. It should be open to these applicants to reapply to the scheme using more uniform, published principles. A future review should consider suitable principles for the evaluation and decision-making process. The assessment and appeals process should have sufficient consistency and reliability to ensure a fair evaluation of the application. The decision-making process should be examined to identify critical decision points, assumptions and items of evidence for which uncertainties could lead to a false classification of risk. The Group considers that there will be cases where the initial evaluation could have been significantly different.
- Any individuals submitting an appeal regarding a decision should be able to appear in person to deliver that appeal and bring with them a representative, lawyer, advocate or other supporter if they wish. They should have access to any evidence and guidance that was used in making the decision in order to properly argue their case. If the appeal is unsuccessful, a detailed explanation for the decision should be available if requested. It should be clear to the person why their appeal has been unsuccessful.

## **Operation of the scheme - proposals**

- None of these proposals should require recipients to sign any sort of waiver to prevent individual legal action for damages etc – primary recipients will still be able to raise actions if they wish.
- A new Scottish scheme should be established that is sensitive to the unique Scottish context. This should encompass current and future HIV and HCV beneficiaries, including families and



carers of those infected. The Scottish scheme should administer all payments – lumps sum, regular and discretionary.

- Payments should not be taken into account for the purposes of entitlement to benefits and should be exempt for taxation purposes. No payments received should need to be declared when applying for state benefits from Job Centre Plus, or to Her Majesty's Revenue and Customs when claiming Tax Credits or for the purposes of calculating Income Tax. Any income generated from the investment of payments should also be exempt from declaration to Job Centre Plus.
- Eligibility for payments should be on the balance of probabilities – i.e. medical records not absolutely required.
- Appeals mechanism – a credible, transparent appeals mechanism should be established for all parts of the improved schemes. The patient voice should be represented on the appeals panel. There should be the option of an ultimate appeal to the Cabinet Secretary in cases of dispute.
- Accountability – the new structures established in Scotland should have affected patients involved in Governance/oversight (i.e. there should be parity of representation with regard to the background of Trustees or Board members to ensure that purely professional or policy concerns are not thought to dominate their work). The group acknowledges that the agency will need to be seen to be independent and impartial in their actions.
- The Group agreed as a principle that nobody should receive less financial support due to the new arrangements. The same level of support should at least be maintained.
- The fact that an infected person has achieved a 'sustained viral response' due to treatment for HCV should not affect the level of their payments. Successful treatment will not reverse the enduring effects on life expectancy or recognise historic financial loss.
- Any new arrangements should be subject to future review to ensure they are fit for purpose.
- It would be desirable to change the current stage-based terminology for the new scheme to signal a new approach.
- Consideration should be given to the point at which any new arrangements will take effect. Given that there could be delays to implementation this could require retrospective payments. It could also be argued that any new scheme provisions should be payable from the point of the Ministerial Statement following the Penrose Inquiry, given that it formally initiated the review process.

## NEW SCHEME PAYMENTS - SUMMARY TABLES

The following tables attempt to set out the impact these proposals, if implemented, would have for individual recipients depending on their circumstances.

### Lump Sum

Affected Group	Current lump sum payment	Proposed lump sum payment	Effect
Skipton Stage 1 (HCV chronic infection)	£20k	£50k	Additional £30k lump sum for those currently at Skipton Stage 1 who have only received £20k. £50k lump sum in future for newly diagnosed Stage 1.
Skipton Stage 2 (Advanced HCV)	£50k	£20k	In future, individuals newly eligible for Skipton Stage 2 will receive £20k, having already received a higher level lump sum at Stage 1.
HIV/HCV co-infected	Changes only to HCV lump-sums as set out above. HIV/HCV co-infected at Skipton Stage 1 will immediately progress to Skipton Stage 2 (i.e. will receive the Stage 2 lump sum and annual payments).		
HIV	No changes to HIV lump sum payments.		

### Regular Payments

Affected Group	Current annual payment	Proposed annual payment	Additional annual payment	Total over 10 years
Skipton Stage 1 (HCV infection)	£0	£0	£0	£0
Skipton Stage 2 (Advanced HCV)	£15k	£27k	£12k	£270k
Co-infected HIV/HCV	£15k (st 1) £30k (st 2)	£37k (all)	£22k (st 1) £7k (st 2)	£370k
HIV	£15k	£27k	£12k	£270k

### Regular Payments to Widow/ers

Widow/ers of affected group	Current annual payment	Proposed annual payment	Additional annual payment	Total over 10 years
Skipton Stage 1 (HCV infection)	£0	£20,250 (where virus caused death)	£20,250	£202,500
Skipton Stage 2 (Advanced HCV)	£0	£20,250	£20,250	£202,500
Co-infected HIV/HCV	£0	£27,750	£27,750	£277,500
HIV	£0	£20,250	£20,250	£202,500

## CHAPTER 3 - PROCESS

The key points and general views that have emerged from the review group discussions and subsequently guided the proposals are:

### General

- There were remaining policy concerns stemming from the Penrose Inquiry report. While these were important, it was recognised that these may have to be dealt with via different channels – the Inquiry report would be considered the primary, credible source by Ministers.
- The Group noted that given the unanswered questions from the Penrose Inquiry there was the risk of further litigation.
- There was a view that the scheme could encompass specific penalties/tariffs for specific recognition of faults. This may reduce the chances of similar mistakes being made in the future.
- The Chair noted that the Group could not rerun the Penrose Inquiry with regard to culpability and fault, but could note that the Group felt there were outstanding issues.
- There would have to be a mechanism for patients/families to feed their views into the review
- It was noted that carers had also lost out on their own pension and career opportunities.
- The problem of inflated travel and life insurance premiums for infected people was highlighted.
- People may have been deterred or prevented from applying to the Skipton Fund as their medical records had been destroyed.
- A key consideration was to give people a choice in the way they received additional support.
- It was recognised that some people would want a lump sum/final settlement alternative but also noted that many would actually receive less in real terms under such an arrangement.
- It was recognised that new registrants/beneficiaries will continue to come forward.

### Categories of infected people

- It was noted that those infected via plasma pool products could have been exposed to multiple viral infections in addition to HCV/HIV.
- It was noted that there was a time imperative for the Group to make its recommendations and many of those infections (65%) were due to blood transfusions rather than bleeding disorders. These additional health concerns did not necessarily apply to them.

### Damages settlements

- In court settlements liability is often not accepted – it is more about recognition of harm and avoiding the risk of legal action.
- A bespoke assessment on a damages basis would mean significant divergence in the amounts people would receive, given that this was earnings based. Such a scheme would also mean a heavier workload and slower assessment.
- The court damages system was examined: it included payments for solatium (pain and suffering), financial loss (including pension loss), and in the

case of death, compensation for loss of support paid to children and dependents.

- With regard to general principles, a new scheme could be an ex gratia or compensation scheme. A compensation scheme based on court principles would compensate for loss, injury and damage. It would aim to achieve restitution – that is to put the victim back in the position they would have been in without the injury.
- A compensation scheme could feature a contractual arrangement such as that entered into with IRISC and then Capita to provide compensation for ex-miners respiratory conditions and vibration white finger. These featured interim payments and fast-tracked settlements.
- A person could have the choice between a staged settlement featuring periodic payments, or a final settlement. There were various options and a scheme could be designed to reflect these.

## **Current UK-wide schemes**

- The current charities (Caxton, Eileen, Macfarlane) can only act within the constraints of the budgets allocated to them by Government.
- Given their charitable status, the Trustees of the discretionary funds have a responsibility to assess financial need.
- The same support is provided regardless of a person's country of infection or residence.
- With regard to accountability – from among the Trustees there is not a representative based in Scotland with knowledge of that specific context.
- Group members felt that the current appeals process was not sufficiently open and transparent – those appealing were not allowed to attend in person and

the reasons for rejection were not fully explained.

- The current schemes had a small core staff of 10 people supporting up to 4000 registrants/beneficiaries across the UK. Given those constraints they could not afford to carry out individual needs assessments under the current arrangements.
- There was a question regarding what the current lump sum payments were actually for – they were intended as some kind of financial recompense for infection but the principle behind the payments had never been explicitly defined.

## **Discretionary and additional support**

- There were increased care and domestic costs for those with functional limitations.
- With regard to any discretionary fund, there would probably be a backlog of need with regard to additional support, home adaptations etc but after 2-3 years this would likely settle down to predictable levels.
- If the regular payments were adequate this would cover additional caring costs etc and reduce the pressure on a discretionary fund.
- On the subject of insurance, the cumulative risks of haemophilia, HCV, ageing etc could make some people uninsurable. The only way they would get insurance may be for the Government to underwrite them in some way.
- Any charity would require spot-checking for audit purposes if making more flexible discretionary payments. There would also need to be appropriate resources for administration of the fund.



## Bereaved families

- For bereaved families ongoing security was important – they needed to know what finances they would have available in the future.
- In many ways those who have suffered the most impact are the deceased cases.
- Under civil damages arrangements, a widow/er would receive 75% of the pension.
- In a public sector pension, for example, the continuing pension for a widow or widower is one half of your pension.
- It was noted that the bereaved were still suffering the same loss of support as the equivalent financial loss of an infected person.
- The Group suggested that a lump sum option should be included for deceased cases.
- The Group advised that funeral costs should be covered under any arrangement.
- New opinions on medical assessment could be taken account of as the medical evidence evolved.
- Any appeals committee would have to have wider membership than ex-NHS staff and clinicians.

## Scottish or UK scheme

- The Group thought that a Scottish scheme would have more transparency, accountability and political control – currently all 4 jurisdictions had to sign off any revised funding arrangements.
- A smaller number of beneficiaries could mean that the organisation was more responsive to their needs.
- The Scottish historic context had been different with regard to the Protein Fractionation Centre, self-sufficiency and the introduction of heat treatment.
- The current share of UK service delivery costs was small for Scotland – around £35k in total. This would increase significantly for a new Scottish scheme.
- A Scottish agency would have to operate on a cross-jurisdictional, cross-border basis which may cause eligibility issues.
- With regard to a Scottish scheme, it was commented that care would have to be taken during the transition process. The existing information on beneficiaries and applicants would have to be transferred successfully to reduce the administrative burden.
- In the context of establishing a Scottish scheme cross-border issues may be challenging.

## Transparency and accountability

- It was noted that historically many of the Skipton Fund decisions about whether an individual was eligible for payment or not were determined by the attitude of the hepatologist in question.
- There were also subjective judgements made on the quality and authority of the anecdotal evidence, such as if it came from a medical practitioner.
- The Group agreed that the existing appeals mechanism could be improved under a new scheme to involve patients or lay people to some extent, as well as including mechanisms for a second opinion by a different clinician or the option of legal advice.



## HIV and HCV impacts

- Group members commented that HIV and HCV were completely different diseases with different impacts – for the co-infected these impacts were magnified.
- There was no legal impediment to the Scottish Government taking responsibility for the HIV payments schemes in the future.
- It was noted that HCV also had complex extra-hepatic manifestations.
- It was recognised that the historic treatments for both viruses could cause severe hardship and long-term health impacts.
- It was noted that the Stage 1 Skipton group have not benefitted from the larger lump sums and regular payments – many of those have debilitating health impacts, those with liver fibrosis for example.
- There was a view that those co-infected with HIV/HCV at Skipton stage 1 should automatically move to stage 2 due to the immune implications of the viral interactions.
- There was view that a specialist medical team should look specifically at this area, monitoring the evolving research. There was a need for further longitudinal studies and research and the new scheme could be involved in that.
- Although new, more effective treatments were increasingly being deployed for HCV it was recognised that people could be treated successfully and still have significant health impacts from long-term infection.
- It was noted that a sustained viral response to HCV treatment may not represent a 'cure'. There could still be reservoirs of the virus in the body.

## New scheme characteristics

- The level of autonomy in the person's spend and amount of application/ bureaucracy required would be important considerations.
- It was desirable to empower the beneficiary so they do not have to continually ask for additional support.
- With regard to gauging moderate liver disease, it was noted that this could be hard to diagnose accurately.
- A review process after 2-3 years would make sure the scheme was still fit for purpose.
- The new scheme should collect beneficiary data from day one to inform the evidence base.
- Any lump sum calculation using life expectancy as a marker could disadvantage those with only a few years left.

## Principles

- Although hepatitis C infection had often been the focus of discussions in the past, financial support considerations for those infected with HIV would have equal weight within the review.
- The group agreed as a principle that nobody should receive less financial support due to the new arrangements. The same level of support should at least be maintained.
- Any new arrangements would have to be subject to future review.
- Scottish Government noted that for a final settlement scheme the financial support that had already been received would probably have to be taken into account. If not, this would mean double or even triple compensation for the same injury if someone had already received ex gratia

and court payments.

- The Group agreed that the proposed scheme would have to be modelled and tested for individual cases.
- Various benchmarks for acceptable levels of income were considered as potential markers for annual payments. This included data from the Joseph Rowntree Foundation, Scottish Government and Treasury guidance on median income.
- In principle, it was agreed that this should be a new Scottish scheme, ideally without associated legislation and additional bureaucracy. It was noted that different components of the scheme could feature different timescales for implementation. Transitional measures could theoretically be taken using the existing scheme infrastructure.
- It was noted that some people may only receive a small payment from a final settlement or lump sum alternative. There would have to be a way of ensuring that they could make an informed choice.
- Benefits should not be affected, as was the case currently.
- The issue of choice was key, as was the issue of how long regular payments would continue after death.
- The scheme should take account of the impact on partners and carers.
- Some Group members felt that the different historic contexts merited a different approach for haemophiliacs, given that they had been exposed to multiple viruses. Others strongly disagreed with treating specific groups differently.
- The danger that future Governments could alter the new arrangements was noted – for that reason some people may prefer a lump sum alternative.

- It was noted that a settlement could be paid in instalments (periodic payments) rather than in a single lump sum.
- The question of precedent was highlighted, and whether the settlement was proportionate to other similar arrangements.
- It was agreed that the discretionary fund model could potentially work well if administered in a flexible and accessible fashion.
- It was agreed that mean-testing should be avoided completely or at the very least minimised.

## Interim payments

- The Group raised the issue of whether it could make an interim recommendation to Scottish Ministers, given that some people were in severe financial need.
- The Chair noted that interim recommendations could be rejected and might unduly affect the remaining process given that the Group had not yet agreed a preferred model.
- The Cabinet Secretary subsequently wrote to the UK Minister for Public Health to raise the possibility of an increased winter fuel payment while awaiting a decision on wider transitional funding measures.

## Current Eligibility

The issue of which claims were currently reimbursed by the Scottish Government was a complex one. Eligibility was currently set out in primary legislation, section 28 of the Smoking, Health and Social Care (Scotland) Act 2005. The legislative power currently only applied to an HCV scheme.

Under the legislation, the relevant infected person must have been infected by NHS treatment in Scotland and resident solely or

mainly in Scotland at the point they originally claimed (or were resident immediately before) financial support from the relevant UK support scheme (original lump sum payment from MFET/MSPT 1 and MSPT 2 and/or the Skipton Fund).

Where the relevant infected person had died, they should have been infected by NHS treatment in Scotland and their sole or main residence should have been in Scotland when they died.

The dual criteria had not caused any problems in practice. Scotland was responsible for all further payments emanating from the original claim. The country responsible for the original stage 1 payment becomes responsible for all future payments from Skipton and/or Caxton.

Although the UK Government currently managed and funded all of the HIV payment schemes, if the Scottish Government was to take over responsibility for those payments in the future it would only be for those people infected by NHS treatment in Scotland.

For HCV claims for infection in England, Wales and Northern Ireland the Fund were not required to apply the additional residence criteria. Only country of infection was relevant.

## **Other scheme models and precedents**

A high level overview of other UK ex gratia, no-fault compensation and damages schemes was given for consideration, including vCJD, Mesothelioma, Armed Forces, Thalidomide, Vaccine Damage and Industrial Injuries. The purpose was to encourage members to think about the various mechanisms and rationales that could drive a new scheme. A summary of the various scheme characteristics is enclosed at **Annex C**.

## **Consultation Exercise**

The group developed a survey to be shared with the wider community to test their views. To allow them to discuss their views in person, the group arranged a series of regional meetings which gave people an opportunity to come together and informally discuss the consultation questions.

Those who did not want to engage through the survey or a regional meeting had the option of requesting a private, face to face meeting or telephone conversation. A final national meeting was held on Saturday 31 October to give people the opportunity to come together for more information and to discuss the draft recommendations.

The Eileen Trust, Macfarlane Trust, MFET, Skipton Fund and Caxton Foundation assisted with the distribution of the survey but beneficiaries'/registrants' details were not shared.

## **Regional meetings**

The substance of each meeting was to have a facilitated discussion on seven key topics. Below is a brief summary of the dominant feeling across the meetings. A much wider range of opinions were expressed at the meetings and detailed notes were considered by the Group as part of the consultation exercise.

In all cases the discussion was limited by there being no guidance about the amounts of money being discussed and by the inherent interrelation between the topics.

## **Lump Sums vs Regular Payments**

In principle, there was a preference for lump sum payments over relying on regular payments. This was because of the greater independence and control lump sums provide, especially with financial advice. However, concerns were raised that ongoing and changing needs might necessitate regular payments for some people. Similarly, that regular payments



might suit some bereaved families better than a lump sum. There were also discussions of the tax and benefits implications of these choices. There were several suggestions about offering people choices about how they received support.

## **Who should be able to make a claim?**

The right of infected people, and their bereaved families, to claim was universal. However, there was strong support for people who had been carers as a result of the disaster (such as partners or parents) to have a claim in their own right. Similarly, there was support for the children of those who were infected having a claim in recognition of the loss of the financial support and the emotional impact of growing up in a home affected by the disaster.

How should bereaved families be supported?

Making sure bereaved families are secure was considered extremely important at all the meetings. Infected people who have survived are concerned about being able to leave their families secure when they pass. Similarly, there was a strong feeling that families should not be disadvantaged as the result of having lost someone already.

## **What general approach? How should support be targeted?**

- There was a divide in opinion between the Glasgow meeting and the other meetings on this point. In Glasgow, there was strong support for a flat payment level. The meeting did not support any assessment or directing different amounts of support to people according to their experience of the contaminated blood disaster. The view was that as a single suffering community there should not be variations in how people were supported.
- In contrast, the non-Glasgow meetings all favoured, in different ways, a combination of approaches with different parts of the

settlement recognising different sorts of loss. Elements which were mentioned in proposals put forward included,

- Something for being infected and the underlying pain and suffering it caused.
- Financial losses, in particular lost earnings and being penalised for being frozen out of the housing market.
- Aggravating legal issues surrounding the infections.
- Ongoing needs, in recognition of the ongoing health problems experienced by many.
- Financial security for families, in recognition that people had been prevented from providing this by the infections.

## **How much assessment should there be?**

At all the meetings the view was expressed that people were sick and tired of having to apply for support, providing evidence of illness or need, and filling in seemingly endless forms. There was a desire to keep the amount of assessment to the minimum which was required for a fair settlement. There were also concerns raised that too much assessment could slow the process down. These considerations were influential in the view of the Glasgow meeting that flat payments were preferable.

## **Should there be interim payments?**

It was universally recognised that there was an urgent need for financial support, especially for some people. The general view was that an interim payment should be sought and made if at all possible, however, this should not be allowed to slow down the current process and a full settlement.

## **Who should administer any payments?**

Although there was appreciation expressed for the way the Skipton Fund payments work once applications have been accepted, there was anger expressed about the distribution of discretionary funds. There was universal support for the idea that a single, Scottish body should administer all payments to provide better accountability and a more accessible service. The need to transfer information from the current payment bodies and to ensure that transition arrangements were in place was raised.



## NATIONAL CONSULTATION MEETING - SUMMARY REPORT

**The Station Hotel, Perth  
31st October 2015, 11am-2pm**

### Introduction

The All-Scotland meeting was the concluding element in the consultation exercise conducted by the Scottish Financial Support Review Group.

The purpose of the day was to share the draft of the proposed recommendations from the Group and to gather feedback from the affected community on where they needed to be improved. Although there was a risk inherent in having a meeting like this on a set of proposals which were still under development, the group felt that it was more important to involve those affected than to wait until all areas of work had been completed.

A comprehensive note of the meeting was provided to the Review Group to inform its final meeting in November.

### Primary Feedback

Many people spoke passionately about the inadequacy of the proposals for those who were at Stage 1 of the Skipton Fund. There was a strong feeling of betrayal and a view that the proposals put the interests of those in the current Stage 2 category ahead of those in Stage 1. There were calls from some people for the whole package to be rejected unless it applied to everyone. In particular, it was felt that the proposals for those at the current Stage 1 undervalued the suffering caused by the infections and the resulting financial losses. This aspect of the proposals was the predominant theme of the meeting.

This issue was compounded at the meeting by a misunderstanding about the details of the draft proposal in this area. The proposal presented to the meeting was that the lump sum of £50,000 which is currently paid at Stage

2 would be divided. £20,000 would continue to be paid to those reaching Stage 2 while the other £30,000 would be moved to an interim payment level for those with a measurable health impact as the result of hepatitis C. This £30,000, when combined with the Stage 1 payment of £20,000, would mean that those who were eligible would receive a total of £50,000 in line with the recommendations of the Expert Panel Report under Lord Ross. The misunderstanding appeared to be based on an earlier proposal that the split would be £25,000 and £25,000. Some people had assumed that that the current Skipton 1 payment would be then be deducted from the interim £25,000 and leave people with an additional payment of £5,000. This misunderstanding proved difficult to correct during the course of the meeting. However, even once it had been clarified the fundamental criticism of the two stage approach remained. The prospect of having to demonstrate measurable health impact was strongly opposed. There were several calls for people to contact MSPs, Scottish Ministers, and the media about this issue.

### Specific feedback

The other issues raised in response to the proposed recommendations included:

- It would be fairer to base a system on an assessment of people's individual losses.
- There was support for those who would benefit from the higher levels of support in the proposal receiving it and a view that their need was urgent in many cases.
- The proposal creates a perverse disincentive in relation to taking treatment for hepatitis C.
- The need to address those not receiving any support because of lack of medical records – Stage None – was highlighted.

- The inclusion of mental health and extra-hepatic manifestations in the proposals was welcomed.
- Interest in knowing more about how the proposed lump sum would be calculated.
- The proposals are not sufficiently retrospective.
- Seeking reassurance that the level of payments would rise with inflation.
- Would unmarried partners be entitled to support? What would happen where people have remarried?
- Concern that it could take a long time before payments were made.
- That the discretionary grants scheme amounted to an admission that the proposals were insufficient.
- The clear view of the consultation was that there should be a flat payment and that this had been ignored.
- A concern that means testing would remain.
- Why do we need a scheme paying people to give out money, why not just give their salaries directly to people as part of a lump sum?
- A need for assurances that payments would not be cut in the future.
- Further work must include abolishing the staging of payments.
- Could a lower level of ongoing payments be made at Stage 1.

## Contentious issues

There were heated exchanges on the following topics:

- Whether or not the proposals amounted to £5,000 for people at Stage 1. Clarifications were provided – this was not the case.
- The legitimacy of those on the Financial Support Review Group. Each member then explained why they were on the group.
- Whether or not civil servants were threatening by advising that not making recommendations by the end of November would cause delays. The Chair advised that he saw it as an honest assessment rather than a threat.
- Whether a particular attendee should be able to continue to make contributions. This was followed by a retraction and apology from the Chair.
- Whether the Ross report recommendations should already have been implemented as they were supported by the SNP in opposition. The alternative view was that no Scottish Government had accepted them.
- Whether or not the Scottish Government has accepted the recommendations of the Scottish Infected Blood Forum scoping exercise into support needs. It has since been clarified that they welcomed the report as additional evidence but had not accepted the recommendations.

## Survey results

- There is no clear recommendation that can be extracted from the results, but a simpler and speedier solution was preferred by 65%.
- It is likely that those with less health impact favour equal distribution of funding. Those with more health impact are likely to favour prioritisation based on impact.
- There was not a clear preference for a Scottish solution although more were in favour of this than not.

## General approach

- 46% said there should be a single Scottish body.
- Around 44% said that the existing UK support organisations should continue or be merged into one.
- 65% supported a Scotland-only settlement whereas 55% also supported a UK- wide settlement.
- 60% said that HIV and HCV settlements should be at the same level.

## Assessment

- There was a preference for an equal distribution of funding without testing or targeting – 69%. This correlates with the number of Stage 1 only beneficiaries (70%).
- There was also some support (approx. 40%) for prioritisation based on health/liver damage and disability. To note – the Stage 2 (advanced HCV group) represents about 30% of Skipton beneficiaries.
- 30% thought that damages should be assessed as per a court settlement.

- There was less support (approx. 20%) for means testing or needs based assessment. This 20% probably represents the low income group (under £19k) in receipt of regular discretionary funding.

## Payments

- 46% wanted a lump sum payment in full and final settlement.
- 28% wanted a combination of lump sums and regular payments.
- 16% wanted a choice between lump sum, regular and discretionary payments.
- 86% thought that the payments should be made directly to the infected person rather than to family members and carers.

## Response profile

- 327 people responded – a strong response given that there are a maximum of 538 living people infected in Scotland who have received payments (many of these are no longer in contact with the schemes, despite recent look-back exercises) Most of the respondees were infected people – 296.
- 43% of respondees reported serious and persistent long term health damage – this would seem to correlate with the 40% that support prioritisation based on health damage/disability.
- 98% had received support from the existing schemes – this is not surprising given that the schemes wrote out to their existing beneficiaries.

## Consultation conclusion

The consultation response was very clear on some headline issues:

- There was a general preference for a single lump sum payment because it gave people more control. However, many would accept regular payments. There was general support for providing choice.
- There was a desire to keep assessment to a minimum. There was a majority for no assessment which seems to be in part motivated by the experience of means testing in the current schemes and an association with benefits assessments. However, a significant minority would favour some assessment, although not means testing, to ensure those who needed or deserved more support got it.

- The question of how the bereaved should be supported was of huge concern. It was felt that they needed security and should not be forgotten about.

The group acknowledged that this was primarily a qualitative not a quantitative exercise, aimed at gathering context. The survey represented a snapshot of current thinking among the wider community.



## CHAPTER 4 - HISTORY

### Current financial support schemes

#### Overview

In the UK there are five payment schemes to provide financial support to patients infected with hepatitis C and/or HIV as a result of infected NHS blood or blood products. The HIV financial support schemes (Macfarlane Trust and Eileen Trust) pre-date devolution and are managed and funded solely by the UK Government Department of Health.

The two hepatitis C support schemes (Skipton Fund and Caxton Foundation) post-date devolution and although they operate as UK schemes, the Scottish Government fully funds all costs for qualifying persons within Scotland: currently around £2.5m a year. The Scottish Government has already contributed £32 million in payments to 722 Scottish recipients (at least 191 known deceased) over the last ten years. Payments are ex-gratia payments for which there is no liability.

The current system has evolved largely in an ad hoc manner without firm underlying principles. The five schemes were established as a reaction to the emerging implications of each specific infection and operate according to their own individual criteria.

The UK Health Departments have worked to improve the current system, including introducing annual payments for those with HIV (in 2009) and for those most severely infected with hepatitis C (in 2011). The Caxton Foundation was established to provide discretionary support for those affected only by hepatitis C, operating alongside the Macfarlane Trust and Eileen Trust, the discretionary schemes already established for those affected by HIV. However, many of those affected still have significant criticisms of the schemes and the way in which the system is structured.

### History of schemes

Since 1988, five organisations have been established at different times to make ex-gratia payments to individuals infected with HIV and/or hepatitis C on a UK-wide basis. Three of the five organisations can also provide financial assistance to uninfected family members. To date, the collective system has paid out more than £368 million (£32m from Scotland).

All payments are ex-gratia, which means they are made voluntarily. These payments are additional to any other source of income an individual may receive, and are disregarded for the purposes of calculating income tax and eligibility for calculating other state benefits. In other words, payments are not taxable and nor do they affect a person's entitlement to any state benefits for which they are eligible.

### Background to the existing system of ex-gratia financial support

Before heat treatment of blood products was introduced in Scotland in 1987, and a test for hepatitis C for whole blood donors was developed and introduced in September 1991, 478 people with bleeding disorders such as haemophilia in Scotland were exposed to hepatitis C as a result of NHS-supplied blood products during the 1970s and 1980s. Approximately 2500 transfusion patients were also infected with HCV in Scotland between 1970 and 1991, when screening was introduced.

Approximately 60 people with bleeding disorders and 18 other individuals were infected with HIV by NHS-supplied blood products or blood transfusions in Scotland before the introduction of heat treatment of blood products, and the development and introduction of a test for HIV in 1985. Some people were co-infected with both hepatitis C and HIV.

Beginning in 1988, the UK government has established a number of schemes at different times to provide financial and other support, as set out below.

## **The Macfarlane Trust**

This is a charity funded by the Department of Health which was established in 1988 to provide discretionary support to individuals with bleeding disorders who contracted HIV (including those co-infected with hepatitis C) as a result of treatment with plasma derived blood products, any person that they in turn may have secondarily infected, and their families. It currently provides means-tested regular payments to infected beneficiaries and widows, annual fixed rate payments in respect of dependent children, a means tested winter payment, and a small number of individual grant payments. Its payments policies are set by its Trustees within the funds allocated by government. For more information go to [www.macfarlane.org.uk](http://www.macfarlane.org.uk)

## **Eileen Trust**

This is a charity funded by the Department of Health, which was established in 1993 to provide discretionary support to individuals who contracted HIV (including those co-infected with hepatitis C) as a result of a transfusion with whole blood, and for their families. The Trust provides financial support in the form of means tested regular payments to some beneficiaries, one-off grant payments, and a fixed rate winter payment. Its payment policies are set by its Trustees.

## **MFET Ltd**

This is a company limited by guarantee, funded by the Department of Health and established in 2010 which provides non-discretionary annual payments (£14,749 in 2015/16) to all those infected with HIV as a result of treatment with NHS supplied blood or blood products, and any person that they in turn may have secondarily infected. The size of this payment is set by the Department of Health, and it is currently uprated

annually in line with the Consumer Price Index (CPI).

Historically, there were also two other schemes (the Macfarlane Special Payments Trust and the Macfarlane Special Payments Trust No.2) that made one-off lump sum payments to those infected with HIV, with the awards varying. MSPT was a flat rate payment of £20,000 to each individual with a bleeding disorder infected with HIV, and MSPT No.2 was an out of court settlement to the same group of individuals and their families where payments varied from £2k to £60,500. All new HIV-infected claimants who meet the eligibility criteria receive a lump-sum payment in line with the lump sum payments previously paid to HIV infected individuals under the Macfarlane Special Payments Trusts, which includes the lump sums paid under the out-of-court settlement.

## **Schemes that support those affected by hepatitis C**

### **Skipton Fund Ltd**

This is a company limited by guarantee, funded by the four UK Health Departments and established in 2004 which provides non-discretionary payments to individuals infected with hepatitis C as a result of treatment with NHS supplied blood or blood products. The Scottish Government adopted the scheme under section 28 of the Smoking, Health and Social Care (Scotland) Act 2005. The fund makes payments in two stages:

**Stage 1:** a single lump sum of £20,000 for all individuals with chronic hepatitis C;

**Stage 2:** an additional non-discretionary lump sum of £50,000 and an annual payment (£14,749 in 2015/16, currently uprated annually by the Consumer Price Index (CPI)), for individuals with cirrhosis, primary liver cancer, B-cell non-Hodgkins Lymphoma or who have undergone, or are on the waiting list to undergo, a liver transplant.

The size of the annual stage 2 payment is set by the four UK Health Departments, and is currently updated annually in line with the CPI.

For more information go to [www.skiptonfund.org/payments:](http://www.skiptonfund.org/payments:)

- As of August 2015, 722 people have received the initial (Stage 1) lump sum for infection (£20k),
- 222 have received the larger (Stage 2) lump sum for serious illness (£50k),
- 119 living Stage 2 people receive regular payments for serious illness (£14.7K per year).
- At present we know of approximately 538 people infected in Scotland who may still be living.
- The Fund approves claims on a balance of probabilities basis. It requires evidence from the applicant's medical notes that they probably received treatment with NHS blood or blood products prior to September 1991.
- Claims can be made by secondary infectees or on behalf of someone who died before 29 August 2003.
- The fund is aware that in many cases it would be difficult or impossible to confirm whether or not a particular batch of blood was infected so many years after it was administered.

## Caxton Foundation

This is a charity funded by the four UK Health Departments established in 2011 providing discretionary support to all individuals infected with hepatitis C through treatment with NHS-supplied blood or blood products, and their widows and dependents. It operates on the basis of providing means-tested grants and a fixed rate winter payment that is not means-tested. Its payments policies are set by its Trustees. In addition to financial support it also pays for referrals to debt and benefits advisors.

For more information go to [www.caxtonfoundation.org.uk:](http://www.caxtonfoundation.org.uk:)

- There are 137 registrants with the Caxton Foundation who receive discretionary payments, including 14 widows and 19 family members.
- The Caxton Foundation was created specifically to provide discretionary support those in financial hardship and it does employ means-testing to target resources at that group.
- To be eligible you, or a close relative who has died, must have received a payment from the Skipton Fund.
- In 2014 the number of Caxton registrants receiving funding went up by 50%. Scotland has a greater proportion than the rest of the UK - 13% of total UK registrants.
- There is no mandatory Scottish (or Welsh or NI) trustee on the Caxton Foundation Board - the best candidates are selected and there is an independent component to the assessment.
- Caxton has been set up to meet any charitable need of its beneficiaries. The key areas in which grant support is given: financial support whilst undergoing treatment to cover loss of earnings and costs; respite breaks; health and mobility-related repairs/adaptations; support with debt and money management; financial assistance for essential items.

## Payment Types

The companies (MFET Ltd and Skipton Fund Ltd) provide non-discretionary payments as set by the UK Health Departments to infected individuals, while the charities provide discretionary payments which they set themselves to infected individuals and dependents/uninfected family members. All non-discretionary payments are paid annually while the discretionary payments can be regular or one-off e.g. as a grant for a specific purpose.



## Support for Uninfected Family Members

Payments and other forms of support for uninfected family members are currently treated differently by the three discretionary charitable bodies that are responsible for deciding their own payments policies. All three charities make some payments to and in respect of uninfected family members. The Macfarlane Trust provides regular payments to some widows/bereaved partners by topping up their personal annual income to a total of £19k, and also makes annual payments in respect of uninfected children of both infected and uninfected beneficiaries. The Eileen Trust makes regular payments to some uninfected beneficiaries and all beneficiaries can apply for grants. The Caxton Foundation now provides individual grants to top up the income of infected individuals.

## Concerns about the current payments scheme

Over the years, there have been repeated criticisms from different groups within the beneficiary community about the way that the overall support system has been set up and operates. Financial support was not within the Terms of Reference of the Penrose Inquiry, although it did note stakeholder dissatisfaction with the current arrangements.

Some of the historic concerns regarding the current payment schemes include:

- concerns that beneficiaries are not assessed on an individual basis;
- the needs of some people with chronic hepatitis C infection are not adequately met;
- infected beneficiaries have to deal with more than one scheme;
- the three discretionary bodies operate different payment policies;
- the principle of having to apply for charitable discretionary payments;
- means testing for discretionary payments;
- disparity in payment amounts received by bereaved spouses/partners;
- lack of ongoing provision for bereaved spouses/partners;
- the Ross expert group (2003) recommendations were not implemented;
- groups often point to more generous payments in the Republic of Ireland.



# PENROSE ENQUIRY

## Penrose Inquiry – findings

The Final Report of the Penrose Inquiry was published on 25 March 2015. You can read the report in full here:

<http://www.penroseinquiry.org.uk/>

*With regard to the personal impact of infection, the Executive Summary states the following:*

*Most of those who detailed their experiences had suffered serious symptoms of viral infection, affecting almost every aspect of mental and physical health. Some had also suffered major side-effects from treatment, whether for HIV or HCV. In particular, many witnesses spoke of the significantly debilitating effects of treatment with Interferon, or Interferon with Ribavirin, therapies to treat HCV. Such treatment was not always successful – some individuals had endured three or four unsuccessful courses of therapy. Relatives described watching the suffering of people they loved, including the devastating experience of supporting their children or their partners as they were dying from the effects of infection.*

*For many, viral infection caused adverse psychological and social effects. Relationships were strained by the consequences of infection. Some who were HIV- or HCV-positive decided to conceal their infection from wider family and friends, causing a sense of isolation and even shame. Others confided in colleagues or friends but did not receive the support they had hoped for. A few were shunned.*

*Many who narrated their experiences had also suffered financially. Ability to work reduced when symptoms were serious. The opportunity to build up savings or make pension contributions was impaired. Difficulties with insurance were also reported, and much increased expense had been incurred in this and other respects, although most people had also received some financial support from such schemes as have been set up for this purpose.*

*Not all who contributed to the Inquiry's understanding in this way had experienced a wholly adverse outcome, and a few had been successfully treated for their infection including, in the case of HCV, by liver transplant. But the majority of people had suffered dreadfully and for most of them, life was irremediably altered by viral infection.*

## Penrose Inquiry history

The Inquiry was announced in the Scottish Parliament by the then Cabinet Secretary for Health and Wellbeing, Nicola Sturgeon, on 23 April 2008. Lord Penrose was formally appointed with effect from 12 January 2009.

On 5 February 2008, Lord Mackay of Drumadoon published his opinion that the decision of the former Lord Advocate not to hold a Fatal Accident Inquiry (FAI) into the deaths of the Rev. **GRO-A** and Mrs **GRO-A** was incompatible with Article 2 of the European Convention of Human Rights. Petitions for judicial review had been raised by the relatives of these people, who died after they had become infected with the Hepatitis C virus as a consequence of transfusion of blood and blood products. Lord Mackay also held that both the Lord Advocate and Scottish Ministers had statutory powers under which they could set up public inquiries into the deaths of the Rev. **GRO-A** and Mrs **GRO-A** and that such inquiries would satisfy the Convention rights of the deceased.

Following careful discussion, the Lord Advocate and Nicola Sturgeon decided to progress towards establishing a Scottish public inquiry under section 28 of the Inquiries Act 2005. The UK Department of Health did not consider a Joint Inquiry necessary, but it did make evidence available to the Penrose Inquiry.

The Penrose Inquiry ultimately had a remit to investigate the deaths of four specific individuals. More widely, it would investigate the

circumstances of the transmission of Hepatitis C (HCV) and HIV from NHS treatment with blood and blood products and the consequences of the transmission of each of those viruses for all patients affected.

The purpose of the Inquiry was to look into the circumstances in which patients treated by the NHS in Scotland became infected with Hepatitis C, HIV, or both, through the use of blood or blood products. The reference period for this Inquiry begins on 1 January 1974. That date was selected by the Cabinet Secretary for Health and Wellbeing on the basis that the earliest reference in the scientific literature, identified in the Report of the Lindsay Tribunal (Irish Inquiry), to the development of liver disease in haemophiliacs associated with the use of blood factor products was in that year. In the event, biological discoveries and medical and technological developments before 1974 have been reviewed where that has been necessary, or has seemed appropriate, to provide context for events within the reference period.

By the beginning of the 1970s there were experimental programmes aimed at applying heat treatment procedures in the manufacture of other products. In particular, many manufacturers first used heat treatment to try to make other blood products, including factor concentrates, virus-safe. Progressive developments in blood product technology during the Inquiry's reference period provided a focus for investigation generally.

It is beyond dispute that some National Health Service patients treated in Scotland became infected with Hepatitis C or HIV or both diseases as a result of transfusion or infusion of blood, blood components or blood products in the course of medical treatment in this country. It is unquestionably tragic that any National Health Service patient should have become so infected.

The full Terms of Reference for the Inquiry can be found here: <http://www.penroseinquiry.org.uk/terms-of-reference/>

The Inquiry published its Preliminary Report on 8 September 2010 setting out the facts relating to the topics identified in the Inquiry's Terms of Reference and providing a provisional list of issues for further exploration at the public hearings: <http://www.penroseinquiry.org.uk/preliminary-report/>

In cases which attract high public interest, such as this one, Ministers will consider the possibility of various forms of public inquiry, in particular an Inquiry under the Inquiries Act 2005. The Inquiries Act 2005 is a UK wide statute which provides a modern and comprehensive framework for inquiries in relation to matters of public concern. A decision in favour of a statutory Public Inquiry is a matter for the Scottish Ministers. It was considered that an investigation was necessary with the credibility and authority that a full Scottish public inquiry would bring. The Inquiry was entirely independent of Scottish Ministers and approached its task in an entirely impartial way.

The Inquiries Act 2005 specifically provides in section 2 that an Inquiry panel is not concerned with determining civil or criminal liability. However, in carrying out its functions it may be that liability could be inferred from its findings or from any recommendations it makes. The terms of reference for the Penrose Inquiry did not make reference to compensation, and did not permit the Chairman to consider payment of compensation either in relation to individuals or on a collective basis. Levels of compensation or ex gratia payments are matters for Ministers to decide, or for courts to award in individual civil actions. Individuals can also raise an action in the civil courts. Damages are a matter for the Courts to decide and it would be for individuals to seek their own legal advice on whether they had a case or not under the current law.



## OTHER INQUIRIES, INVESTIGATIONS AND RELATED COURT ACTION

### Burton Judgement (2001)

This was the Hepatitis C litigation, wherein claimants complained of infection with the hepatitis C virus through blood transfusions or other blood products. These were actions raised under the Consumer Protection Act 1988 (CPA) whereby certain individuals alleged that blood they received by transfusion was a defective 'product' as it carried Hepatitis C. The judgment of Mr Justice Burton is a wide examination of the English law of product liability. It has not been appealed. Mr Justice Burton ruled that all of the 114 claimants from around the UK were entitled to compensation. The Scottish Executive decided that NHSScotland would make payments to persons whose circumstances were analogous to those who were eligible for awards under the High Court judgement. While the High Court decision is not binding on Scottish courts, a Scottish court would be likely to have regard to a relevant judgement reached elsewhere.

The Product Liability Directive 1985/374 came into effect on 25th July 1985 after a very lengthy process of drafting, lobbying, discussion and negotiation, including intergovernmental and parliamentary discussion. The UK implemented the Directive by passing the Consumer Protection Act 1987 (the CPA), which came into effect on 1st March 1988.

The claimants' definition of the defect was the viral infection of the blood.

### Scottish Executive Investigation into Hepatitis C (2000)

An investigation into hepatitis C and heat treatment of blood products for haemophiliacs was undertaken by the Scottish Executive following allegations made to the media in August 1999 by the Scottish Haemophilia Forum.

None of the allegations made against the SNBTS, nor any of those made against haemophilia doctors, were upheld. The investigation concluded that "SNBTS made very reasonable progress in developing products with reduced viral risk, relative to activity elsewhere."

The final report of the investigation is available: [www.scotland.gov.uk/Resource/Doc/158690/0043060.pdf](http://www.scotland.gov.uk/Resource/Doc/158690/0043060.pdf)

### Scottish Parliament Investigation into Hepatitis C (2001)

The Health & Community Care Committee (HCCC) of the Scottish Parliament undertook a review of the Investigation by the Scottish Executive and examined further allegations made by the Scottish Haemophilia Forum and the Haemophilia Society. The SNBTS provided written evidence and answered questions put to it by the committee at a public hearing.

The proceedings of the committee, the evidence provided and the findings of the committee are available:

[www.scottish.parliament.uk/business/committees/historic/health/reports-01/her01-17-01.htm](http://www.scottish.parliament.uk/business/committees/historic/health/reports-01/her01-17-01.htm)

### Ross Report Recommendations (2003) Ross Report

These recommendations stem from the Ross Report of the Expert Group on Financial and Other Support which was published in 2003. The establishment of the Expert Group had its origins in discussions around the situation of patients who had been infected with the Hepatitis C virus (HCV) via blood.

Having considered a petition calling for compensation for 'HCV in blood' patients, the Health and Community Care Committee of the Scottish Parliament recommended ex gratia financial and other appropriate practical support should be made available for this group of patients. The Health and Community Care Committee recommended 'financial and other appropriate practical support' rather than compensation, partly because they felt that the term 'compensation' is linked to the concept of fault and partly because they felt that money was only one of the things that patients needed to help them lead a reasonable life. They recommended that the level of financial assistance should be determined on the basis of need, having regard to the physical or psychological loss individually suffered, and should include redress for practical difficulties such as the inability to obtain an affordable mortgage

The Committee's recommendation was based on the following principles:

- HCV patients were morally entitled to the same compensation as HIV patients;
- HCV patients were morally entitled to similar support to that given in the support package provided for people who had contracted vCJD from food;
- the unfairness of some people being able to benefit from the CPA judgement but not others.

The Scottish Executive did not agree with this recommendation. It felt that it was a deviation from the principle that the 'NHS does not pay when it has no legal liability for the harm suffered by the patient' and that it would be essential for any new compensation system

to be judged against agreed and published criteria and that these criteria would need to be transparent, equitable and universally applicable. Furthermore, any new system that deviated from the principle should balance the needs of the total patient population against those of any group being provided with financial support.

The Health and Community Care Committee also recommended the establishment of an Expert Group to look at the current compensation system and propose alternatives. The Executive agreed to the establishment of such a group and that it would examine situations where people have been harmed but the NHS is not at fault. It also agreed that the situation of 'HCV/HIV in blood' patients should form part of its wider considerations.

The Ross Expert Group Report subsequently recommended payments of £10,000 to anyone infected, an additional £40,000 for those with chronic Hepatitis C, and full compensation calculated on the same basis as common law damages for those subsequently developing significant liver disease. This was rejected but the announcement of the creation of the Skipton Fund followed soon after publication.

## **Investigation by the Crown Office and Procurator Fiscal Service (2005)**

A number of applications for Fatal Accident Inquiries concerning hepatitis C infection by blood products were made to the Procurator Fiscal Service. The SNBTS was approached for information by the Procurator Fiscal Service and co-operated as fully as was possible without having access to all relevant medical records. None of the applications for a Fatal Accident Inquiry was approved by the Lord Advocate.



## Scottish Parliament Investigation into Hepatitis C (2006)

The HCCC returned to the topic of hepatitis C infection via blood products in 2006. The Scottish Haemophilia Forum, a number of individual patients and a Solicitor representing patients claiming to have been infected with hepatitis C via NHS treatment were invited by the HCCC to make written and oral submissions. The SNBTS was not invited to give evidence to the HCCC, either orally or in writing, nor was the SNBTS questioned by the HCCC on the issues raised.

At the conclusion of its hearings, the HCCC decided:

*“to ask the Scottish Executive to establish an independent judicial inquiry examining the treatment of people who were infected with hepatitis C through NHS treatment and examining the “look-back” procedure employed to trace them.”*

The Minister for Health & Community Care declined this request.

## Archer Inquiry (2009)

This independent (English non-statutory, funded by private donations) public inquiry was held to investigate the circumstances surrounding the supply to patients of contaminated NHS blood and blood products; its consequences for the Haemophilia community and others afflicted; and suggest further steps to address both their problems and needs and those of bereaved families. The Inquiry was led by former Solicitor General The Rt Hon (Peter) Archer of Sandwell QC and was published on 23 February 2009. The report contained 8 recommendations including:

Direct financial relief should be provided for those infected, and for carers who have been prevented from working (suggested that payments should be at least the equivalent of those payable under the Scheme which applies at any time in Ireland.)

There is a need for some provision to ensure to patients access to insurance. This could be done either by providing the premiums, or by establishing a separate scheme for the patients in question.

Increased funding was subsequently committed to the Macfarlane and Eileen Trusts and the Haemophilia Society. The Haemophilia Alliance was also invited to meet with the UK Department of Health twice yearly. The full report can be accessed by clicking on <http://www.archercbbp.com/report.php>.

## Contaminated Blood Review (2011)

A 2011 Government review examined the clinical evidence for further support for infected individuals, and also considered how best to provide support for families of those affected. Scientific and clinical advice on hepatitis C and HIV was obtained from a joint working group of the Advisory Group on Hepatitis (AGH), the Expert Advisory Group on AIDS (EAGA), the UK Haemophilia Centre Doctors Organisation (UKHCDO), the Hepatitis C Trust and the Health Protection Agency (HPA). The review resulted in additional financial support, particularly to those who are suffering most or who are experiencing financial hardship.

On 4 March 2011, then Cabinet Secretary for Health, Nicola Sturgeon, announced that she had accepted the recommendations of the Department of Health-led Contaminated Blood Review

which extended the scope of the existing financial support provisions for those affected by infected NHS blood and blood products to:

- Introduce an annual payment of £12,800 for those living with hepatitis C who qualify for Stage 2 payments from the Skipton Fund;
- Allow posthumous claims to be made on behalf of people who died before August 29 August, 2003;

- Increase the one-off payment made to those who qualify for Stage 2 payments from £25,000 to £50,000 (whether the patient is alive or dead);
- Give access to discretionary fund for patients and/or their dependants suffering financial hardship;
- Relevant patients who develop hepatitis C-related B cell lymphoma to be eligible to claim for Stage 2 payment;

Increase the annual payment for those with hepatitis C/HIV in line with then consumer price index.

The full report can be viewed here: [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/215828/dh\\_125977.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215828/dh_125977.pdf)

## Scoping study Scottish Infected Blood Forum (2014)

A survey was commissioned by the Scottish Government Health and Social Care Directorate on support needs for those infected with or affected by hepatitis C through NHS treatment in Scotland. The final report has been published by the Scottish Infected Blood Forum and can be found at <http://sibf.ninedesignstudio.co.uk/>

**The recommendations of the report were welcomed by the Scottish Government as additional evidence that would help inform the financial review, but were not accepted for implementation.**

- The Scoping Exercise took a holistic approach to identifying needs that would go beyond simply medical factors. It included looking at contexts for diagnosis and treatment, relationships, housing, financial matters, other aspects that affect the patient experience, quality of life indicators and general wellbeing. Some of the high level findings with regard to financial support were as follows:

- On the matter of financial recompense, HCV infection presents as a “double jeopardy”. Living costs go up at the very time when people’s capacity to be economically self-sustaining go down.
- However, many infected/affected people seem to want to avoid the appearance that they might be involved in campaigning just because there is the possibility of compensation in the future, or “ex-gratia” payments. Yet others have unashamedly called for fair and realistic compensation for what they claim to be genuine losses including their jobs, businesses, homes and savings.
- People know that they have been financially disadvantaged, and not by their own actions but by the state through one of its key public services.
- Affected people know that while money does not bring back full health (and certainly not a deceased relative), lack of money is a major issue for many HCV infected/affected people, in the most practical terms.

## APPG Inquiry report (2015)

The All-Party Parliamentary Group (APPG) on Haemophilia and Contaminated Blood investigated the quality and sufficiency of the current support arrangements. Their report can be accessed here: [http://www.haemophilia.org.uk/what\\_we\\_do/influencing\\_advocacy/appg\\_hcb\\_fr.pdf](http://www.haemophilia.org.uk/what_we_do/influencing_advocacy/appg_hcb_fr.pdf)

## ANNEX A - GROUP MEMBERSHIP

Ian Welsh – Chair, Health and Social Care Alliance Scotland (the ALLIANCE)

Alice Mackie - Campaigner, HIV

Bruce Norval – Campaigner

Bill Wright - Chair, Haemophilia Scotland.

Dan Farthing-Sykes - CEO, Haemophilia Scotland

**GRO-A** - Campaigner, blood transfusion.

Petra Wright - The Hepatitis C Trust (Scotland)

Philip Dolan – Convenor, Scottish Infected Blood Forum (SIBF)

**GRO-A** – SIBF

Mary McLuskey – SIBF

Andy Cowe – SIBF

Tommy Leggate – SIBF/independent consultant.

Patrick McGuire – Thompson solicitors

Susan Murray – Central Legal Office

Norma Shippin – Central Legal Office

Gareth Brown – Scottish Government.

Robert Girvan – Scottish Government

Naureen Ahmad – Scottish Government

Sarah Manson – Scottish Government

Marion Cairns – Scottish Government

## ANNEX B FINANCIAL REVIEW GROUP TERMS OF REFERENCE

To undertake a review of the existing UK-wide financial support schemes for individuals infected with hepatitis C and HIV through NHS blood and blood products, in respect of individuals and families receiving payments in Scotland.

To provide recommendations to Scottish Ministers on whether the current system should be changed and, if so, what changes should be made and whether any of these changes should be applied retrospectively.

### The review should

- Define and cost various options for future schemes and compare against the status quo, including parallel UK compensation and ex gratia schemes such as for those affected by vCJD, vaccine damage and Thalidomide.
- Agree general principles for a system of financial support.
- Consider the risks and benefits of the existing UK approach as versus a standalone Scottish approach, engaging with the other UK countries as part of this review to understand the current and historic UK context, including matters of

accountability, governance, cost, eligibility (tests of causation and disability) and any potential cross-border issues.

- Consider evidence from affected patients, families and their representatives in relation to:
  - the strengths and weaknesses of current payment schemes; and
  - unmet need which could be addressed by an improved scheme.
- Consider evidence or practice in other relevant jurisdictions beyond the UK, such as the Republic of Ireland, for any lessons for Scotland.
- Consider any possible legal and tax issues, including legislative changes and transitional arrangements that may be required.
- Report to Scottish Ministers as soon as possible, but no later than November 2015.

The review will be supported by dedicated civil servant resource from the Scottish Government.



## ANNEX C

# OTHER SCHEME MODELS AND PRECEDENTS

### vCJD

In October 2000 the UK Government established a no-fault Compensation Scheme for the victims of variant Creutzfeldt-Jakob Disease (vCJD) and their families. This is a major no-fault compensation scheme by which the UK Government, without an admission of liability, accepted the responsibility for compensating those who have suffered. Payments are provided at a rate broadly comparable to common law damages.

vCJD is a rapidly progressive and rare (177 cases ever), fatal disease. The Government committed a total of £67.5m to the scheme, budgeting for 250 victims. The scheme does not preclude victims, their families, administrators or executors from taking proceedings against the Crown or any other body but, if they do, any sums paid under the Trust must be taken into account in any award of damages.

Payments are made under various headings, which include certain basic sums, sums for some expenses, sums for participation in care, loss of dependency claims, loss of earnings claims and sums payable as a result of psychiatric injury caused by the vCJD suffered by the victim.

vCJD compensation was initially paid through interim trusts, while the final trusts were established and set up. In reviewing the Fund a key message from trustees for any future schemes is the need to balance the sensitivity of the scheme with efficiency. A very sensitive, tailored scheme can take a long time to set up and is expensive to run. A cruder, more straightforward scheme can be established quickly and can operate efficiently, maximizing the level of funding that can go to recipients.

### Vaccine Damages

The Vaccine Damage Payments Act 1979 set up a no-fault liability scheme for the payment of a lump sum to people who suffer seriously adverse consequences (mental and/or physical) as a result of being vaccinated against a set list of diseases. The Act provides for a lump sum payment of £120,000 (tax free) to be made to those who have been severely disabled by vaccinations against specified diseases, in order to ease the present and future burdens associated with such disability.

There are clear, and tight, limitations on eligibility, both factual and judgmental. The Act is focused on diseases preventable through vaccinations offered as part of the routine childhood immunisation programmes that are administered by the United Kingdom Government and the Devolved Administrations.

The person must be severely disabled as a result of vaccination, with disablement assessed as at least 60%. The payment scheme also places less onus on the requirement of absolute proof of vaccine damage, to one based on probability. A Vaccine Damage Payment can affect other benefits and entitlements.

The assessment of disablement is based on the legislation pertaining to the Industrial Injuries Disablement Scheme. Under this scheme, 60% disablement equates to, for example, lower leg amputation, loss of one hand or deafness where the individual cannot hear a conversational voice beyond a distance of one metre. A vaccine-relevant example would be paralysis of a limb after oral poliomyelitis vaccine.

## Thalidomide Health Grant

In March 2010 the UK Departments of Health (DHs) agreed to make a UK-wide grant of £26.4 million to Thalidomide-impaired people, to help to address the exceptional health and health-related needs they are experiencing as they grow older. The pilot three year grant was distributed by the Thalidomide Trust (a charitable trust) over three years from April 2010, in the form of an annual lump sum to individual Thalidomiders.

The grant has a number of conditions:

- It must only be used to meet health-related needs
- It must not be used to meet needs that are already being met through NHS
- The Thalidomide Trust must account to the DHs for how the money is used.

The DHs agreed that individual Thalidomiders would not be expected to account to the DHs for their expenditure and would be free to spend it as they wished in order to meet their health and health-related needs, and a set of 'health-related needs' were developed to guide Thalidomiders in their expenditure. There are very varied levels of disability for each recipient, as well as recognition that each case is unique. Grants are awarded on a 'level of impairment banding'.

In early 2013, all four Departments of Health agreed to continue the Health Grant for another ten years. The new ten year Health Grant is distributed in the same way as the three year grant.

## Diffuse Mesothelioma Payment Scheme (DMPS) – Asbestos Exposure

The DMPS was introduced by Government in 2014 by the Mesothelioma Act 2014 as a Scheme of last resort for sufferers of diffuse mesothelioma who have been unable to trace either the employer who exposed them to asbestos or their employer's insurer. The Scheme makes payments to eligible people with diffuse mesothelioma diagnosed on or after 25 July 2012.

The legislation requires active insurers who pay employer's liability insurance to pay an annual levy based on their relative market share for the purpose of meeting the costs of the Scheme. The Scheme compensates individuals with a one-off lump sum payment, subject to the age of the individual. The older a person is at diagnosis, the smaller the lump sum. Changes to tariff rules introduced on 10 February 2015 mean that payments from the Diffuse Mesothelioma Payment Scheme increased to 100% of average civil claims, from the previous 80%, but only for those individuals diagnosed after 10 February 2015.

Where a person has already received government payments in respect of diffuse mesothelioma, this money is recovered from Scheme payments in accordance with the well-established principle that people should not receive money twice in respect of the same injury or disease.

Mesothelioma symptoms typically appear several decades after an exposure to asbestos. It takes 20-50 years for symptoms to develop. Although prognosis varies greatly, younger patients appear to have the most optimistic prognosis.

## **Armed Forces Compensation Scheme (AFCS)**

The AFCS provides financial compensation to service personnel or their dependants for injury, illness or death attributable to service, the cause of which occurred on or after 6 April 2005. It replaced the previous compensation arrangements provided by the War Pensions Scheme (WPS) and the attributable elements of the Armed Forces Pensions Scheme.

The AFCS provides a tax free lump sum for pain and suffering caused by the injury. Lump sum payments range from £1,200 to £570,000. All anticipated injuries are listed against a tariff level ranging from 1 to 15. The most serious injuries (tariff level 1) correspond to an award of £570,000. The maximum tariff payment for an infectious disease is £140k.

The more serious injuries – those in tariff levels 1 to 11 – are also compensated by regular tax-free and index-linked payments for life to be made once the individual leaves the Armed Forces (the Guaranteed Income Payment or GIP). This is designed to compensate them for the earnings and pensions they are now less likely to earn.

## **Irish Hep C And HIV Compensation Tribunal**

The Irish Tribunal system was first established in the mid-1990s after the Irish Government found that wrongful acts had been committed by the Irish Blood Transfusion Service Board. The Hepatitis-C Compensation Tribunal was established to operate on a non-statutory basis to review claims for compensation arising from the many civil actions pending in the courts. The Irish Government placed the Hepatitis-C Compensation Tribunal on a statutory footing in 1997 and its remit was then extended in 2002 to include infection with HIV.

Unlike in Scotland, a key driver for the Irish tribunal service was that over 1,000 pregnant women were infected with hepatitis C as a result of treatment with Anti-D (a product which

prevents rhesus disease in pregnant women) which had been manufactured and issued from a plasma pool which was infected with Hepatitis C. This included infections between 1991 and 1994, after the introduction of heat treatment and screening for the hepatitis C virus. These events led to specific criticisms of the Irish service made by two judicial inquiries (Finlay and Lindsay).

An award of the Tribunal to a claimant is made on the same basis as an award of the High Court calculated by reference to the principles which govern the measure of damages in the law of Civil Liability. Dependents can receive damages for pain and suffering, personal injury, and loss or diminution of expectation of life or happiness which the deceased suffered during his or her lifetime. This also includes payments for loss of consortium and post-traumatic stress.

## **Canadian HCV and HIV Compensation Settlements**

The Canadian settlements were a response to court cases against the Canadian Red Cross Society, which managed the blood supply. The Canadian Red Cross was ultimately found liable and was threatened with bankruptcy due to legal actions against it. Following a high-profile public inquiry into the blood system (Krever), the equivalent of almost £5 billion in legal claims and a criminal investigation into senior scientists, the Canadian Government admitted liability.

On 27 March 1998, the federal government announced a compensation package of £540 million for those who had contracted hepatitis C through the Canadian blood supply between 1986 and 1990. These were estimated to number as many as 10,000 individuals. This compensation arrangement had been forged with the provincial (arrangements can vary in different provinces/territories) and territorial governments and was made up of £149 million in provincial/ territorial funds and £397 million in federal funds.



On 18 December 1998, details of the package were revealed after much negotiation between a federal–provincial/territorial legal negotiating team and the counsel for the class action suits. In May 1999, a settlement valued at £550 million plus interest was reached; this included compensation for those individuals secondarily infected with HIV.

In November 2004, the Minister of Health announced that the government would enter into discussions regarding the options for compensating people who were infected outside of the 1986-1990 timeframe. In July 2006, the prime minister announced that an agreement had been reached on the elements of a settlement for this group. The package would be separate from the previous one established for those infected between 1986 and 1990, but would be similar in size, that is, approximately £500 million.

The Canadian Red Cross and Federal Government were also found negligent and held liable for haemophiliacs' HIV infection. In 1989 the Government offered a compensation package to anyone infected with HIV via blood/blood products.

A key element of the HCV compensation settlements in Canada relates to payments being made on the basis of assessment of disease levels.

# ANNEX D

## SCOTTISH INFECTED BLOOD FORUM

### Position Statement

#### **Note of Dissent to the Report and Recommendations of the Contaminated Blood Financial Support Review Group from the Scottish Infected Blood Forum**

We, the elected officers and management committee, acting on behalf of the Scottish Infected Blood Forum, do hereby express our dissent on behalf of our members to key elements of the Report and Recommendations arising from the Contaminated Blood Financial Support Review Group. This Note of Dissent embodies the unanimous view of all four SIBF representatives on the Financial Support Review Group (Philip Dolan, Mary McCluskey, **GRO-A**, Tommy Leggate) as well as the full management committee, and reflects the views expressed by all members at our recent Annual General Meeting. We have expressed our concerns in detail but in summary the main issues include:

- The retention of the distinction between so-called Stage 1 and so-called Stage 2 HCV patient victims.
- The apparent lack of recognition of the significant levels of health impacts on so-called Stage 1 patient victims compared to so-called Stage 2 people, as well as co-infected persons.
- The resulting differences in the support being proposed to so-called Stage 1 patient victims in comparison to so-called Stage 2 patient victims, as well as co-infected persons, where so-called Stage 2 patient victims are perceived to be given primacy, which we view as unjustified.
- The proposed financial settlement for so-called Stage 1 patient victims, amounting to £50,000 cumulatively, does not present any increase on the original recommendations laid

down by Lord Ross in his Expert Group dating back from 12 years ago and neither does it incorporate any inflationary impact dating back to that time or before.

- The apparent ceiling within the proposals to the total value of the support payments being proposed, believing that they do not represent full and fair levels in comparison to acknowledged losses (not least financial) that have resulted from people being state infected. We note that the consultation process did not include the opportunity for people to formally detail their losses, either actual or estimated.
- The lack of recognition of the clear majority view among patient victims to see lump-sum payments as preferable to just annual payments.
- The proposals still retain the possibility of resorting to a means testing regime (or prioritisation) if there is some reason to require restricting payment amounts. We believe this may result in clinicians making subjective judgements about health impacts as opposed to an objective assessment of a simple confirmation of chronic infection status.
- The apparent retention of the criteria to assess levels of health detriment that are still focused on liver factors, which we believe should be immediately extended to include extra-hepatic factors and other health impacts.
- The lack of an explicit commitment to a numerical equivalence of substantive patient victim representation on the assessment and appeals bodies.

**Philip Dolan MBE KHS, Convener  
For and on behalf of the Scottish Infected  
Blood Forum Management Committee**

