Philip Dolan – I am the Convener of the SIBF

I have haemophilia and Hepatitis C. I belong to a generation that was not expected to live beyond middle age.

For about sixty years I have been actively involved as a member of the Haemophilia Society in Scotland and a Trustee and Vice-chairman of the UK Society.

Initially the Haemophilia Society was campaigning for improved treatment for haemophilia. During my early days very little treatment was available over the decades various forms of treatment were tried such bed rest then snake venom; Fresh Frozen Plasma; Cryoprecipitate; Factor Reconstitution; Recombinant Factor VIII etc.

In the mid-eighties factor products were introduced from American pharmaceutical companies which subsequently these resulted in patients becoming infected with HIV.

In the mid-eighties there were 4000 people with haemophilia about 1400 were infected with HIV by the year 2000 only about 300 were still alive.

During the 1980s another concern came to light that people with haemophilia were being identified as having Non A Non B Hepatitis which subsequently became known as Hepatitis C. (HCV) Sadly it was not until the 1990s that these patients were informed.

In my case, because of my involvement with the Haemophilia Community, I was becoming more aware of the consequences of HVC. In 1991 I asked the Haemophilia Consultant if I had HCV only to be told it nothing to be concerned about. However I persisted and when he look up my medical records he noted that in 1978 it was known that I had non A non B hepatitis. This raise a number of questions; why were doctors testing patients for non A non B hepatitis there must have been some concerns? why were patients not asked to give consent? why were patients not told the outcome, given that hepatitis can be transmitted to partners?

In the Penrose Report it states that doctors were being paternalistic by not telling patients. This is ethically wrong.

Penrose Inquiry – About 160 people submitted statements to the Inquiry and eighty indicated they wish to be Core Participants (in other words provide oral evidence) despite this Lord Penrose decided he would only allow sixteen core participants. In the end only six were permitted. The legal advisers for victims appealed against this ruling however, the appealed against Lord Penrose's decision. The appeal was then heard by Lord Penrose regards his own decision which goes against natural justice.
In the course of the Appeal the QC for me when speaking about HCV state that Mr Dolan had the “Sword of Damascus” hanging over him but Lord Penrose response you mean a feather duster.

The outcome of the Report has been well documented an seen as a “Whitewash” as I had predicted on the First day of the Inquiry when in his opening remarks Lord Penrose stated; “This Inquiry is funded by NHS Scotland every pound spent is money away from patient care – every doctor attending is time away from patient care”. These remarks caused upset to many of the families sitting in the public benches.

After about seven years and 1800 pages costing about £12 million pounds the report was published making only one recommendation that there should be a lookback to trace those who had received blood transfusion this had also been recommended by Lord Ross who chaired the Expert Group (2002 – 2003) set up by Malcolm Chisholm. Some years previously the Blood transfusion service had been requested to undertake such an investigation but little is known if this had taken place. Following the Penrose Report the Cabinet Secretary set up a Group to review this but to date it has only met on one occasion and no date has yet been set for future meetings.

Scottish Haemophilia Forum was formed by people with haemophilia living in Scotland who were members of Haemophilia Society’s Local Groups from Tayside, West of Scotland, Perth, South East Scotland and Grampian. Some individual members of these Groups had been campaigning individually for improved treatment for haemophilia and Non-A, Non-B hepatitis. In 1997 a meeting of representatives from these Groups took place and the Scottish Haemophilia Forum was formed. The Forum remained associated with the UK Haemophilia Society but focused on Scotland and was successful in achieving improved treatment for people with haemophilia in Scotland. In some cases as the result of our representation Scotland was ahead of other parts of UK.

In September 1999 Robert Brown MSP (Liberal) hosted a lunch meeting in the First Scottish Parliament, building regards haemophilia and Hepatitis C. Several MSPs attended and during the meeting the late Brian Adam MSP organised a petition in support of our campaign this was signed by about 80 MSPs. Perhaps, the petition that has had the support of all parties in the Scottish Parliament.

Subsequently the Government of the day set up an Inquiry that was dismissed by Parliament given that evidence was obtained from the civil service and doctors but the voice of patients was not sought. Later Malcolm Chisholm set up an Expert Group chaired by Lord Ross. The Expert Group after a year recommended that all those infected should receive £50.000 under the terms of “Solation”. While those who had developed cirrhosis or cancer should have a fast track legal route to determine their compensation.

The Heath Minister of the day some time later decided to award an ex- gratia of £20,000. As a result, less than an hour later John Reid MP, Westminster Health Minister announced that he would follow the decision of the Scottish Parliament.

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During this period we had good contact with Scottish MPs. Such as Donald Dewar, Teddy Taylor, Malcolm Chisholm, Tom Clarke, Norman Godman and many others. On 4th March 1998 an adjournment debate in respect of Synthetic Factor VIII, took place in the House of Commons Raise by Roseanna Cunningham, John Swinney and John McAllion, regarding the introduction of improved treatment for haemophilia, Sam Galbraith the Scottish Health Minister at Westminster.

Many of the original members have since died. The Forum were able to represent the need of members to the Chief Medical Officers for Scotland through regular meetings and with the Haemophilia Centre Directors.

Scottish Infected Blood Forum arose like the Phoenix from the ashes of the Scottish Haemophilia Forum. It was formed to meet the wider group of patients who had developed Hepatitis C from NHS Scotland blood transfusions or blood products. During the period as a member of the Scottish Governments Expert Group it became apparent that there were many people infected with HCV, not just those with haemophilia, but those who had received blood transfusions.

This Group had never met any other person with hepatitis C resulting from NHS treatment. Many were afraid to speak about their situation due to the fear of stigma and being branded as a drug addict. Thus they did not have an umbrella organisation although were registered with lawyers.

Arrangements were made by Frank Macquire, Solicitor Advocate, who represented many people who were infected with HCV. He provided accommodation thus allowing individuals anonymously to meet and discuss issues about HCV. Following a few meetings it was agreed to form a committee and subsequently become a registered charity in 2010.

Scottish Infected Blood Forum meets regularly and provides support for those infected and families affected. We have campaigned to get answers why this tragedy described by, Professor Lord Robert Winston as the “worst treatment disaster in the history of the NHS was allowed to occur and the secrecy by various governments officials.

Even after the Penrose Inquiry we are no further forward. There is no reference to the missing records such as Ministerial minutes of Lord David Owen and Lord Jenkins both former Health Ministers, for the Labour in the 1970s and Conservatives during the 1990. What happened to patients whose batch numbers are missing from their records?

The Financial Review Group – set up by the Cabinet Secretary for Health to consider the need of those infected by Hepatitis C resulting from their NHS treatment. There were delays in the Group getting started due to difficulties in finding a chairperson.

There were representatives from Scottish Infected Blood Forum, Haemophilia
Scotland and from the Hepatitis C Organisation.

During the various meetings several of the aforesaid seem to speak about Haemophilia while those from SIBF believed that the purpose of the Group was to consider Hepatitis C irrespective of the route that caused the infection. Although I have haemophilia I felt my purpose like the other two member of SIBF on the Group was specifically about Hepatitis C.

According to Lord Penrose’s statistics there are 3000 people in Scotland who were infected with HCV as the result of Blood Transfusions or blood products. While I have some reservations regard these figures (I think the number is too high). According to the civil servants one third are from the haemophilia community thus two thirds have been infected as the result of blood transfusions.

Given what I have previously stated those of us from SIBF felt that haemophilia needs seem to dominate all the meetings.

The major concerns was the emphasis that dominated most the meetings was demand for those who are currently receiving the Skipton Fund - Stage 2 payment of about £14,000 a year while those in Skipton Stage-2 like those of stage 1 received £20,000 about 10-12 ago.

Many people in Stage 1 are very ill, while others are unable to work, or as the result of their health have reduced earnings. Irrespective of what stage people are in they will encounter similar difficulties with heating cost (people with HCV are affected with the cold), they have the same difficulties obtaining insurance such travel.

The SIBF welcome the decision by Alex Neil the Cabinet Secretary for Health of the Scottish Government agreement to fund the Scoping exercise which has provided evidence of the impact that HCV has on individual and their families. We were pleased that on the completion the Exercise we were able to present a copy of the Scoping Exercise to the present Cabinet Secretary Shona Robinson last March her suggestion that we should consider making a presentation in the Scottish Parliament.

We acknowledge that by providing the Government this Scoping Exercise and its recommendations, does not mean that it will be part of Government policy. However it was suggested that the Scoping Exercise could be a starting point for the Review Group to consider in our deliberations. Unfortunately although at the second meeting of the Group there was a presentation by the author of the Exercise attempts to refer the exercise went unheard.

Copies of the recommendations of Scoping Exercise I understand are included in your papers for today.

There were six public meetings held during the Review Group deliberations I attended four of these meetings which were held in Dundee, Edinburgh,
Glasgow and Perth. I understand the meetings in Aberdeen and Inverness had very low number attending perhaps less than six at each those venues. The meeting in Glasgow attracted (46).

There was general support at all the meetings that the existence of various organisations such as the Skipton Fund, The Caxton Foundation and three trusts associated with the MacFarlane Trust some become the responsibility of a single trust set up in Scotland to meet the needs of those affected with HCV and or HIV.

Many of the people who attended these meeting expressed their disgust at failure of Lord Penrose to acknowledge the impact that HCV had had on them and their families. At all the meeting most people wanted compensation, many wanted a lump sum, suggestion £250,000. Others wanted a similar system of support such as was provided in Ireland.

While most people acknowledge the fact that the Scottish Government had given an apology. Most recognised that it was during the period that Westminster was responsible for health.

The recommendations from the Review Group leave several questions unanswered.

1 When the Scottish Government does propose to implement these recommendations?

2 When will the proposed £30,000 start?

3 Will this include payment to the families of deceased persons in the same way as the current Scottish system?

4 How quickly will the Scottish Government set up the New Charity or body to replace those controlled by London?

There still remains the need for an explanation why this tragedy occurred?

Scottish Infected Blood Forum
Hepatitis C Virus (HCV)
Contaminated Blood
Scoping Exercise
In respect of people infected with Hepatitis C as a result of NHS contaminated blood transfusions and blood products in Scotland

Final Report
Hepatitis C Virus (HCV)
Contaminated Blood
Scoping Exercise
Final Report

The Scottish Government, Scottish Infected Blood Forum and Insight Consultants gratefully acknowledge the participation in the Scoping Exercise of those Scottish citizens who have been infected and affected by HCV due to receiving contaminated blood or blood products from NHS treatment. Recognition is also given to the involvement of the various organisations that provide support to HCV infected people and their families.

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Disclaimer

The views expressed in this report are not necessarily the views shared by the Scottish Government, Scottish Government officials or the Scottish Infected Blood Forum.
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1. **Forward & Ministerial Introduction**

1.1 Convener’s Forward

In February 2013 a meeting was held at the Scottish Parliament with Alex Neil MSP, the then Cabinet Secretary for Health and Wellbeing. The meeting included representatives from the Scottish Infected Blood Forum and Scottish Government officials. The topic of conversation focused on the various impacts of Hepatitis C on the haemophilia and bleeding disorder community in Scotland as well as a group of other patients who had received blood transfusions. Their unique situation centred on the fact that their Hepatitis C infection had occurred as a result of being given contaminated blood or blood products as part of their NHS treatment; as opposed to being infected by other transmission routes.

A key outcome from the meeting was the decision to carry out a Scoping Exercise. The overall aim of the Scoping Exercise was to assist the Scottish Government to more clearly understand the scope and scale of the unmet needs resulting from Hepatitis C infection and to detail the supports required by those affected. It was acknowledged that aspects of the proposed study could have a bearing on those matters under consideration by the Penrose Inquiry. It was also acknowledged that the Penrose Inquiry was a separate and distinct activity which had not yet completed its work prior to issuing its report.

After a short period of liaison to develop the proposal, it was agreed that the Scoping Exercise would be undertaken by the Scottish Infected Blood Forum. Given the potential sensitivities for people concerning the matters to be addressed, there was a need to ensure compliance with good practice and policy requirements, and to initiate consultation to achieve appropriate stakeholder involvement. As part of this process letters were sent to all NHS Medical Directors, Consultant Haematologist and Hepatologists by the Cabinet Secretary advising them to inform their patients about the Scoping Exercise. From this initiation activity a Project Reference Group was established to inform the progress of the study. Due to these necessary preliminary activities the actual delivery of the Scoping Exercise was unable to start until May 2014. However from that time there was considerable engagement with infected and affected people whose participation was crucial to the success of the project.

This report is the tangible product of the Scoping Exercise. It is presented as a fair and independent output that is based on the life situations reported by real people and the experiences they willingly shared.

Finally, I would like to thank Tommy Leggate and his associates at Insight Consultants for the work that has been put into producing this report, which has exceeded our expectations in terms of its quality, reach and active participation. I would also like to thank Thompsons Solicitors for providing a Freephone telephone number and SCVO for providing a Post Office Box number for respondents to use and to allow a convenient collection point for postal responses.

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**Philip Dolan MBE**
Convener, Scottish Infected Blood Forum
1.2 Ministerial Introduction

My predecessor, Alex Neil, commissioned the Scottish Infected Blood Forum to carry out this Scoping Exercise to give us some more structured evidence on the specific support needs of those infected and their families.

Prior to this report, we have been to some extent reliant on anecdotal accounts. The Penrose Inquiry has of course taken considerable evidence from those affected regarding their experiences, but some issues such as financial support were largely outside the Terms of Reference.

This exercise has taken a wide-ranging and comprehensive approach to the issue of support that included historic experiences. The needs of those affected clearly go well beyond treatment of the diseases themselves, and I note that some treatments can in fact have serious side effects.

The enduring physical and psychological impacts of these infections are made very clear. There was huge fear, uncertainty and stigma caused by these diseases, particularly when they were poorly understood. Not only did the infected people and their families have to try to deal with these illnesses but often this meant a situation of financial hardship. In some cases serious illness may have made it impossible to work.

These matters have considerable sensitivity, so I know that great care had to be taken in the design of the survey. The impressive number of responses is testament to its effectiveness and I would like to thank all of those involved in creating and delivering it successfully to those affected. Hopefully the exercise may have also served to link some respondents into the SIBF network of peer support. The findings and recommendations will prove increasingly useful as we consider our next steps following the publication of the Penrose Inquiry report, and will certainly help inform our response.

Shona Robison MSP
Cabinet Secretary for Health & Wellbeing
2. Executive Summary

Purpose
The Scoping Exercise was commissioned by the Scottish Government to gain a more evidence-based understanding of the needs and issues faced by Scottish citizens who have been infected or affected by Hepatitis C Virus (HCV) as a result of receiving contaminated NHS blood or blood products. This would allow for a more effective targeting of resources to meet identified needs. It was acknowledged at the time of the commissioning that the same group of people were the subject of the Penrose Inquiry, but the Scoping Exercise was a completely separate activity which would allow the Scottish Government to be prepared to respond positively to the publication of the Penrose Inquiry Report and better meet patient needs.

Background
Since at least the 1980s, HCV infection through the administration of contaminated blood has affected some Scottish people either because of a need for plasma-based products to treat long-term chronic conditions such as haemophilia or other bleeding disorders, or simply by people receiving blood transfusions. This group of infected/affected people became identified as a specific cohort when there was a need for a collective patient voice, from the perspective of infected people, to the Penrose Inquiry. An early civic response was to see the establishment of the Scottish Infected Blood Forum which brought together HCV “victims” to facilitate Inquiry engagement. It soon became clear however that there were other issues for this community beyond just engaging with the Penrose Inquiry. There appeared to be particular needs and issues for this group that were distinct or additional to those of people whose HCV infection came as a result of other transmission routes.

Methodology
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. The scope and scale of the study when considering the sensitivities for the defined target group meant that a very empathetic approach had to be taken since some people would be anxious or unsure about participating, while others were known to hold strong views and carry a sense of grievance. The main data gathering tool was a questionnaire. This was necessarily comprehensive since it had to capture responses across the different dimensions to be investigated. Great care had to be taken in its design and accessibility. It was important that the whole process was transparent, so a policy of full disclosure was adopted. A number of partner/stakeholders were involved in guiding the Scoping Exercise, including patient representatives, support providers, medical professionals and Scottish Government specialists. Recognised standards (such as for community engagement, social research, project management and quality assurance) were adopted and adapted to fit the needs of the invited participants. Certain risks were anticipated, including the potential of raising expectations simply by asking people what was needed and strategies were put in place to mitigate for these risks.
Community Engagement & Stakeholder Input

Given the perceived sensitivities for those invited to participate in the Scoping Exercise, trusted partners who were also stakeholders, including voluntary support organisations as well as specialist medical channels (such as local NHS hepatology departments and clinics), were used to invite people to be involved. More than 120 people responded to the questionnaire which was beyond not just the stated minimum quota but also the preferred target.

Results & Commentary

A large amount of data was collected which is an affirmation of the strength of feeling among those Scottish citizens who have been infected and affected with HCV due to receiving contaminated blood or blood products from their NHS. Findings included:

- People demonstrate responses to their infection that range from anger to resignation.
- HCV infection does not discriminate by age, social class, gender or any other measure when it was transmitted to people who came in good faith simply to access their NHS.
- Many people are hugely dissatisfied by the course of events over at least three decades. They have lost trust (perhaps irreconcilably) in both the medical profession and in governments who some perceive want to hide from the truth.
- Given that their infection came about through no fault of their own there is despair at the delays, misinformation, loss of documents and the apparent strain that existed between safety and savings considerations.
- Receiving a diagnosis (if patients were ever formally spoken to at all) was not generally a good experience. There were issues of feeling like guinea pigs, being kept in the dark, not being apprised of the real risks and then having to continue to engage with the very clinicians who brought about their infection with a life-limiting condition (however well-meaning their intentions were at the time).
- These perceived injustices have created a group of people who have become mobilised and determined to see some kind of just outcome.
- Infected people’s lives, and those of families, carers and in particular the bereaved, have been significantly impacted on, not just in terms of their health and wellbeing. For some, their lives have been “turned upside down” from being regular, happy and fulfilling, into circumstances of fear, uncertainty for the future, with greatly reduced quality of life, and a range of diverse health detriments.
- A significant number of people have died which, while it might conclusively resolve the problem for the “infected” person, does not relieve the pain felt by the “affected” who remain.
- Beyond immediate clinical interventions to address presenting medical issues, support for needs such as helping with strained relationships, understanding and accessing benefits, addressing mental health concerns, facing threats to employment, etc. have been largely unmet.
• 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 (however derisory these may be). 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.

• There seems to be great variability in people’s opportunities to self-manage their condition. Services tend to be concentrated on the centres of population for logistical reasons, but this excludes many others who are scattered across Scotland.

• There is a great deal of misunderstanding among the general public about HCV and this has resulted in distinct issues, including feeling stigmatised.

• Agencies that are meant to support people with needs are not always able to do so for people like those living with HCV due to its different manifestations and variability in health detriments.

• The picture in Scotland for those whose HCV infection arose from contaminated blood is one of distrust, disempowerment, emotional turmoil, personal and family tragedy, significant chronic health impairment and serious economic disadvantage. The sense is that for over 30 years the consequences have only been felt in one direction.

Condition Management Issues & Contributions

Respondents were invited to contribute to the collective wellbeing by sharing their experiences of what worked for them in terms of self-management of their HCV infection. HCV infection, and the associated anti-viral treatment programmes, come with a range of known (or in some cases suspected) health and wellbeing detriments or drug-induced side-effects. Responses covered a wide range of suggestions from the lifestyle change type (e.g. diet and exercise), to alternative therapies (e.g. reiki and meditation), spiritual outlets (e.g. prayer and church attendance), as well as other human response options (e.g. pets and gardening). Secondary (desk) research threw up suggested self-management responses to the various types of associated health difficulties people encounter as they live with HCV infection, covering issues such as depression and fatigue. It was recognised that as medical interventions develop, such as improved anti-viral treatment regimes, this will impact on those living with HCV, although for some they may be left with a legacy that is there for life.
Recommendations

1. Disclosure to patients about viral or other risks should, in the future, always be carried out by a consultant, by appointment, in a setting that ensures privacy and avoids interruptions, allows for unhurried discussion, provides printed information for later review, offers referral or signposting to support services, and offers the option of a return appointment to re-consider the matter once the implications of the discussion have been thought over.

2. Financial recompense for elevated living costs that are attributable to HCV infection from contaminated blood, as well as loss of potential earnings over the life course must be addressed. Recompense arrangements must be fair and comprehensive, and should be initiated as soon as possible, within the life of the current Scottish Parliament, to reflect the extended delays faced by HCV affected people and the serious chronic health impacts they have suffered.

3. The financial arrangements that applied in other countries should be reviewed as part of the consideration of financial recompense in Scotland.

4. Lord Ross’s Expert Group on financial and other support should be immediately reviewed and the relevant outstanding recommendations implemented. Similarly, the relevant outstanding recommendations of the Archer Inquiry should be revisited within the Scottish context.

5. Insurance/assurance products and services should be made available to people infected by HCV through contaminated blood at levels commensurate with those enjoyed by the general public, with government intervention to ensure this where necessary.

6. Counselling must be provided by an accredited counsellor, and when required or requested, counselling should be made available at no cost and at the time it is needed.

7. Benefits advice (tailored to the specific HCV situation) should be facilitated through Health and Social Work channels when required or requested.

8. Social work access should be facilitated through Health and Social Work channels when required or requested.

9. The Skipton Fund and the Caxton Foundation must become more accountable to and representative of the Scottish devolved context.

10. The Skipton Fund and the Caxton Foundation arrangements should be reviewed including opening negotiations to carry out a without prejudice cost/benefits analysis to test the feasibility of consolidating services into a single separate Scottish arrangement.

11. Trust between patients and clinicians should be rebuilt (where this is necessary) through a reaffirmation of the principles of mutual respect, transparency, honesty and informed consent.

12. Self-management opportunities to help people live with the HCV condition should be given greater emphasis with information on health and wellbeing improvement choices and tailored provision being more widely promoted and supported.
13. Stigmatisation sensitivities and perceptions for contaminated blood HCV infected patients should be acknowledged and addressed as a training need within the NHS.

14. The Penrose Inquiry Final Report should be cross-referenced (where relevant) with the Scoping Exercise findings to inform effective, efficient resource allocation decisions.

15. The recommendations of this report should be actioned within the life of the current Scottish Parliament.

16. The Scoping Exercise findings should be formally reviewed after one year to evaluate progress, with the review involving representation from patients, clinicians, voluntary sector support organisations and Government.

Appendices

A number of useful appendices are included either for information (in the spirit of the commitment to full disclosure), and in particular to achieve the desire to hear people’s voices individually and collectively.
9. Recommendations

Based on the results of the Scoping Exercise as contained within this report the following recommendations are submitted for consideration:

1. Disclosure to patients about viral or other risks should, in the future, always be carried out by a consultant, by appointment, in a setting that ensures privacy and avoids interruptions, allows for unhurried discussion, provides printed information for later review, offers referral or signposting to support services, and offers the option of a return appointment to re-consider the matter once the implications of the discussion have been thought over.

While this may be a case of shutting the door after the horse has bolted, and while there may well be updated clinical guidelines on these types of situations which have improved the protocols since people were finding out about their infection 20 years ago or more, it is nevertheless important to this group of patients that learning from the past is recognised and applied.

2. Financial recompense for elevated living costs that are attributable to HCV infection from contaminated blood, as well as loss of potential earnings over the life course must be addressed. Recompense arrangements must be fair and comprehensive, and should be initiated as soon as possible, within the life of the current Scottish Parliament, to reflect the extended delays faced by HCV affected people and the serious chronic health impacts they have suffered.

Despite apparent reluctance by some infected people to directly address the matter of the financial detriments caused by HCV infection, it is clearly a high priority for many respondents. There is a very real need to help people whose economic circumstances have been drastically affected by the actions (or inaction) of an organ of the state.

The Scoping Exercise Terms of Reference did not include carrying out a detailed analysis of the financial costs to people of living with a HCV diagnosis to understand how this particular long-term condition impacts on people, but from the responses there is certainly an indication of the types of elevated costs that are being faced. Any assessment of financial losses should also include assigning an economic value to the reduced quality of life aspects, using existing tools to calculate these.

3. The financial arrangements that applied in other countries should be reviewed as part of the consideration of financial recompense in Scotland.

A key source in calculating financial recompense should be to review the approaches taken in other countries (and in this regard the Irish model is sometimes highlighted). It should be noted that campaigners and other HCV infected people are well aware of how previous references to the arrangements in other countries have been misrepresented by some government officials, and they have also seen how this wrong information has then been used as a pretext to unjustifiably dismiss such comparisons.
4. Lord Ross’s Expert Group on financial and other support should be immediately reviewed and the relevant outstanding recommendations implemented. Similarly, the relevant outstanding recommendations of the Archer Inquiry should be revisited within the Scottish context.

Lord Donald Ross’s Expert Group found that the financial support systems for infectees at the time of reporting were not fit for purpose (and, as is clear from this report, they still are not). There should be an immediate review of the Lord Ross Expert Group Recommendations with the aim of implementing those that have not yet been actioned. Similarly, with respect to the Archer Inquiry, there are highly relevant recommendations that remain to be adopted (and there seems to be no officially offered reason why they have not been).

This recommendation includes giving urgent consideration to the previous calls to extend Stage 2 payments from the Skipton Fund to all contaminated blood HCV infectees (or amounts at least equivalent to Skipton Stage 2 if that route is unavailable, at least as an interim measure). This approach would be much fairer and more inclusive, and would remove the unjustifiable distinctions around levels of impairment between individuals chronically infected by HCV. For example, changes made by the Westminster Government, apparently to address greater needs, actually only benefited approximately 20% of those infected, the consequence of which implies that around 80% of those who also experience documented serious health and financial difficulties are for some reason not eligible for the additional Stage 2 benefit, or anything else that might be put in place.

5. Insurance/assurance products and services should be made available to people infected by HCV through contaminated blood at levels commensurate with those enjoyed by the general public, with government intervention to ensure this where necessary.

This recommendation builds on those recommendations made by the Expert Group and the Archer Inquiry as referred to above. It is clear that without some form of intervention, providers of financial services such as life assurance, insurance, mortgages, etc. are unlikely on their own to make special provision for people living with HCV (and the additional health issues) unless it includes inflated premiums. Of course in some cases these products are not even offered, the result being that people cannot enjoy the normal benefits of travel or home ownership. This kind of situation is another example of how people are being denied (charged inflated rates for or ‘priced out’ of) services they would have otherwise had access to, were it not for their HCV infection status. Since they did not cause it themselves, and since the state did, there is a moral obligation on the state to redress the imbalance.

6. Counselling must be provided by an accredited counsellor, and when required or requested, counselling should be made available at no cost and at the time it is needed.

Clinicians should be advised that any conversation they have with patients, while that conversation may provide support and information in the form of “counsel”, should not
be confused with the distinct professional discipline of “counselling” which may separately be required by some people as a way of coming to terms with a diagnosis of a viral or other health concern.

Some people living with Hep C still struggle to come to terms with their diagnosis despite the support of medical staff. For a few, this has resulted in (or contributed to) specific mental health issues such as depression (and in extreme cases Post Traumatic Stress Disorder or Syndrome), or other less well defined emotional or other needs. These people should be considered for and offered referral to professional counselling services which should be available within the context of a “free at the point of delivery” NHS service to the patient.

7. Benefits advice (tailored to the specific HCV situation) should be facilitated through Health and Social Work channels when required or requested.

Some people living with Hep C suffer a level of detriment that materially reduces or even curtails entirely their capacity to work. The nature of the incapacity arising from Hep C infection can be intermittent, resulting in “good times and bad times”. People may be unfamiliar with the processes of the benefits system, or be unable to articulate their needs within the fairly rigid and uncompromising framework of the system. Practical means should be provided to this specific group of people to assist them access the financial and other supports to which they have a right. This may include resources to produce guidance materials on how to appropriately describe symptoms or conditions, as well as access to a specialist advice giving service (where the adviser understands the particular Hep C presentations), possibly provided through a third sector body (a charity or voluntary association).

8. Social work access should be facilitated through Health and Social Work channels when required or requested.

There are negative impacts of living with Hepatitis C that go beyond specific medical or general health factors. These relate to the more holistic concept of wellbeing and connect to wider issues in social contexts. These include housing, access to services, financial problems, and the need for advocacy or other specific supports. A system of social worker access, like the process for being supported as necessary by accredited counsellors, should be put in place to assist people living with Hepatitis C if they request or are considered in need of such a support. This should take into account the various geographic concentrations of people infected/affected with HCV due to their NHS treatment such that in more sparsely populated areas there should not be a lesser service as far as the patient experiences.

9. The Skipton Fund and the Caxton Foundation must become more accountable and representative of the Scottish devolved context.

The results of this study will be fed back to the respective organisations to inform their customer service development. It has been highlighted that while Scotland contributes to these pots, there is no Scottish representation on their governing bodies. This is seen
as a flaw in representativeness and accountability. This recommendation includes advocating for official Scottish Government governance participation, as well as patient representation under the devolved framework.

10. **The Skipton Fund and the Caxton Foundation arrangements should be reviewed including opening negotiations to carry out a without prejudice cost/benefits analysis to test the feasibility of consolidating services into a single separate Scottish arrangement.**

Several questions have been raised about the efficiency of having different bodies to deal with what is basically the same cohort of people. Following on from the previous recommendation, and without prejudice, this recommendation proposes a “best-value” type exercise to look at business models that would include the option of forming a separate single fund management body for Scotland with full powers to make changes to the criteria for disbursement based on Scottish priorities and needs.

11. **Trust between patients and clinicians should be rebuilt (where this is necessary) through a reaffirmation of the principles of mutual respect, transparency, honesty and informed consent.**

Even though there may no longer be the same issues over new cases of, specifically, HCV infection from contaminated blood or blood products, some of the more informed patients continue to have concerns over other infection issues. For example, and without being overly technical, there are questions around the use of the word “cleared” to describe someone who is declared to have demonstrated a “sustained viral response”. Patients want to be treated like the informed adults they could be if clinicians avoided the kind of minimisation they have previously been accused of by some. This would allow patients to share the responsibility for assessing and mitigating risk where such may exist in the course of their treatment. As before, certain areas will likely have moved forward in relation to policies and practices covering the interactions between clinicians and patients, but having this issue raised within the context of a patient engagement process such as the Scoping Exercise will allow the NHS to demonstrate that it remains willing to listen and respond.

12. **Self-management opportunities to help people live with the HCV condition should be given greater emphasis with information on health choices and tailored provision being more widely promoted and supported.**

This recommendation is at the heart of the concept of people taking responsibility for their own wellbeing either by acting alone for their own benefit, or by engaging with different healthcare providers to co-manage their conditions. It includes taking an approach that complements any medical intervention so as to maximise the positive outcomes for people’s health. A combination of health promotion, widening access and multi-agency coordinated provision could be required to realise the aim of empowering people to manage their own health in accordance with their own needs and circumstances.

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There is the factor of overcoming barriers to enhanced health and wellbeing that could be geographical, financial, psychological, or simply personality-driven. For some people a proactive approach may be required that involves providers and commissioners of services to work in partnership, for example on an outreach project basis around more localised communities.

13. **Stigmatisation sensitivities and perceptions for contaminated blood HCV infected patients should be acknowledged and addressed as a training need within the NHS.**

It may be unrealistic to expect special exclusive provision for contaminated blood HCV infected people when they need to access liver clinics etc., but there could be value in ensuring that NHS staff are aware of the real concerns people may have about being wrongly and prejudicially identified along with those whose liver issues are connected to, for example, alcoholism or drug use. Experience indicates that NHS staff are usually very good at improvising when they can if they recognise a need exists and can see how small changes will assist their patients’ experiences.

14. **The Penrose Inquiry Final Report should be cross-referenced (where relevant) with the Scoping Exercise findings to inform effective, efficient resource allocation decisions.**

The Scoping Exercise has no direct or indirect connection to the Penrose Inquiry, since they are completely separate pieces of work with distinctly different terms of reference, budgets and timescales. However, it is anticipated that the two reports may touch on some common ground. It would likely be welcomed by all concerned if early progress could be made on some aspects of the Inquiry report. It may be that the practical issues raised within the Scoping Exercise could inform a foresighted response and demonstrate that the Scottish Government, while it has not interfered or pre-empted the Inquiry report, has not been idle either. Rather, by engaging with patients in the interim it is better prepared to act, and to do so from an informed position.

15. **The recommendations of this report should be actioned within the life of the current Scottish Parliament.**

There is a strong sense that the cumulative delays experienced by sufferers, their carers or their bereaved families is unreasonably and wholly excessive. Some people have waited over 30 years for action. All of the recommendations arising from the Scoping Exercise are envisaged to be achievable within a 12 month period.

16. **The Scoping Exercise findings should be formally reviewed after one year to evaluate progress, with the review involving representation from patients, clinicians, voluntary sector support organisations and Government.**

With the aim of ensuring that there is a sustained partnership response, this recommendation will allow for the stakeholders to re-visit the Scoping Exercise Final
Report to evaluate progress, provide feedback and if necessary instigate new activity.

10. Appendices:

- Appendix A: SIBF Project Management Group
- Appendix B: Project Reference Group
- Appendix C: Key Contacts List (Support Organisations)
- Appendix D: Questionnaire
- Appendix E: Standards
- Appendix F: Penrose Inquiry Terms of Reference
- Appendix G: Health conditions associated with Hep C
- Appendix H: Questionnaire Responses
APPENDIX G - HEALTH CONDITIONS ASSOCIATED WITH HEP C

- Mixed cryoglobulinaemia (MC)
- Palpable purpura
- Vasculitis
- Arthralgia/myalgia
- Peripheral neuropathy
- Renal disease (e.g. MPGN or membranous GN)
- B cell non-Hodgkin’s lymphoma
- Monoclonal gammopathy
- Diabetes mellitus (or other related abnormalities)
- Porphyria cutanea tarda
- Lichen planus
- Psoriasis
- Other skin manifestations (e.g. vitiligo, alopecia)
- Pulmonary fibrosis
- Autoimmune thyroiditis
- Sicca syndrome or Sjogren’s syndrome
- Noncryoglobulinaemic nephropathy
- Aortic atherosclerosis
- Cardiomyopathy
- Chronic polyarthritis
- Polyarteritis nodosa
- Arthritis and arthralgia type conditions
- A neuro-psychiatric disorder (including dementia)
- Depression (professionally diagnosed)
- Chronic fatigue (beyond just occasional tiredness)
- Stigma (including actual or perceived discrimination affecting quality of life)

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18 Source: Advisory Group on Hepatitis: Review of the clinical consequences of hepatitis C infection: June 2013
A Commentary
on the
from the
Scottish Infected Blood Forum

1. Main Points of Divergence

- The first and preeminent issue we have with the report and recommendation is the retention of what we refer to as the ‘so-called’ Stage 1/Stage 2 distinction. We consider the distinction to be outdated, unfair and divisive. It is our view that this is a red line issue that must be thought of as a potential ‘deal-breaker’. We believe it is essential to see this as yet unresolved and fundamental issue as a line that cannot be crossed by the patient/victim representatives until it is made right. As such, the absolute need to see the removal of the Stage 1/Stage 2 distinction cannot be stressed too highly.

- The second main issue is the lack of acknowledgement in the proposals of the majority view as expressed by patient victims to see a substantive, full and fair lump sum payments scheme being proposed, at least as an option.

Since the matter of Stage 1/Stage 2 is so crucial it could be that this Commentary on the report stops at this point, but in good faith and following the course adopted at the Perth meeting (which was itself a matter for lively preliminary debate), we have continued to extend our Commentary to include the other elements of the document. However by providing this Commentary on the fuller content of draft report, this should in no way be seen as acquiescence to the proposals as they currently stand. The constant overriding principle is that the proposals are only worthy of consideration for support once the Stage 1/Stage 2 issue is resolved.

2. Name:

- We note that the name of the Review Group has reverted back to include the term "Infected Blood...". We must insist that the name go back to "Contaminated Blood".

3. Terms of Reference:

- We are very concerned that there is no mention of the broader Terms of Reference and guiding principles document that was tabled and was agreed (after some debate) as a guide to the process, while the highly edited/minimised ToR version as drafted by the Scottish Government representatives is included? We assert that if the fuller ToR document had been followed it would have helped to significantly aid the Group in reaching a more agreeable outcome than is currently being presented. We therefore must insist that for the sake of transparency these fuller ToR also be included as an appendix.

- We believe that the Group has not met one of the core tasks from the minimised ToR, specifically that in its considerations, “... [to include matters of] ... eligibility (tests of causation and disability)”. All that has been recommended is that this ‘should’ be looked at again at some unspecified time in the future (which may or may not happen before the other proposals are enacted, thus opening the door to unfairness and discrimination). The issue of extra-hepatic conditions, for example, has not been adequately addressed (even though it came up frequently in the consultation responses). It is now recognised that this ought to be a key component of the eligibility criteria, even based on already established and validated medical research on the subject.
• The Group has not met another of the core tasks from the minimised ToR, namely to, “Consider evidence from affected patients, families and their representatives in relation to ... unmet need which could be addressed by an improved scheme.” Despite assurances, infected/affected people have not had the opportunity to properly express the unmet need, in particular the very real financial losses resulting directly from infection.

3. Membership of the Review Group:
• Given that peoples’ names will be attached to this report for evermore, we pose the question, ‘do we want to be identified with these recommendations in full?’ and it is for this reason, as a membership organisation, we feel the need to formally present the concern expressed in this Commentary.

4. Executive Summary
• “… the Group recognises that one size does not fit all and there will be some people affected who are disappointed by the proposals”. We believe that if one size did fit all then at least the so-called Stage 1 people would be on par with the so-called Stage 2 people. We assert that this sentence is therefore misleading and could be seen as an attempt to manage expectations downwards. We must insist that it be removed/corrected.
• “(Concerning the proposals) … the Group considers that an effective system should meet all of them”. This establishes in the mind of the reader that there is a tacit endorsement of the proposals as apparently presented by the Group members individually and collectively. We cannot support the proposals as they currently stand for the reasons stated in this Commentary. We recognise that in some situations members of a body may be subject to ‘collective responsibility’, but we believe that this does not apply in this situation and that it is not in the interests of our members who are the infected/affected people to even appear to be endorsing in full what is currently being proposed. Were the key changes made (which we believe have been expressed by the vast majority of infected/affected people), then we certainly would want to see the complete set of proposals taken forward by the Scottish Government as part of a comprehensive, fair, full and ‘effective system’ of support.

5. Proposals (Introduction)
• “There was a divergence of views across the Group ...”. We believe that this statement is being used to justify not getting to where most infected/affected people wanted the Group to get to. On key issues such as the so-called Stage1/Stage 2 split, most if not all of the non-government representatives on the Group have publically asserted their individual efforts to remove this as far as possible. The divergence was therefore between the patient/victim representatives and the officials. This unclarified ‘divergence’ is a disingenuous representation of the reality of the situation. We contend that for the sake of the victim/patient representatives the true nature of the divergence must be explained. From the Perth event, attendees were given the distinct impression by all non-governmental representatives that there remained major differences of opinion when compared to the direction of travel being promoted by government representatives. Several non-government representatives highlighted their personal and collective efforts to effect a change of position but with little success. Their assertion was that many key points of discussion were still in the frame for debate and that they would be taking back to the Review Group table the overwhelming dissatisfaction of the Perth attendees with the proposals as presented, with a mandate to require a complete overhaul of the proposals as they then were being set forth. We are concerned that the proposals have hardly changed from those presented for consultation at the Perth event. We have sympathy with the views expressed by a number of people at the local meetings and the Perth event
that it was unfortunate (and ultimately unhelpful) that there were no government representatives at these events to see and hear for themselves the views of infected/affected people. We are concerned with the possibility of the patient representatives appearing to approve the Report and Recommendations document as it currently is drafted which could be detrimental to their personal integrity and the possibility that a massive disservice will then be done to the very people they have fought so hard to support for all these years. It is our contention that they should distance themselves from appearing to endorse this report as it currently stands since it does not represent a ‘fair and full’ settlement for all our memberships.

- “The group acknowledges that the final decision of Scottish Ministers will involve consideration of whether the proposals are proportionate, evidence-based and affordable.” We believe this statement is not representative of the situation it seeks to describe. It is not our understanding of what the Group ‘acknowledges’, certainly not the victim/patient representatives. At most, it was something that government officials referred to as a standard governmental process or protocol. But given the statements by the First Minister and the Cabinet Secretary, it would be for them to ensure the smooth passage of any statutory actions arising from the work of the Review Group since we would assume they already had Cabinet approval before publically making the commitments they did. “Proportionate” is possibly correct if it refers to truly “full and fair” support, but if it refers to a comparison with some other minimising criteria then the idea that it is acknowledged by the Group is wrong. “Evidence-based” again this might be correct but according to other parts of the document, that appears to be ‘acknowledged’ as part of the unfinished business. “Affordable” is the terms we have most concern about. Of course it is affordable if it is given the priority it deserves. Affordability is a matter of political will and choice. We retain the good faith that Ministers did make their public statements with real intent, and that latterly they would not suddenly come to the realisation that it might cost them money and so try to back out of their commitments by re-defining the criteria for making decisions and blaming it on Cabinet colleagues. We assert that this sentence appears to be more downwards expectation management.

- “Key suggestions involved …”. We are very concerned by how this paragraph in the document starts since we believe it fails to mention all, or at least certain more important ‘key suggestions’. The paragraph goes on to list those items that happen to fit with the proposals contained herein. However, we know from the victim/patient representatives that getting a fair deal for so-called Stage 1 victims, and also the overwhelming preference for a lump-sum payment were the two key “suggestions”, yet they are not even mentioned anywhere in the paragraph. We assert that this is very misleading and highly selective. We believe it could be seen as a conscious misrepresentation and therefore could call into question the whole consultation with infected/affected people; even though the report seeks to highlight what “a historic Scottish Government commitment” it is. We see this as an error that must be corrected for the sake of the credibility of the whole process.

- “(They agreed) … to build on the existing scheme parameters …”. We do not accept that there was any such agreement. (And in this vein we note, and it has been raised as an issue, that key contributions from Group members were not included in the minutes of meetings, which may have led to an assumption of collective agreement.) If this statement is allowed to remain in the report it could mean keeping the so-called Stage 1/Stage 2 criteria, even just for a while? We believe that this is not the view of the majority of infected/affected patient victims and that it is not supported by evidence. Thus we challenge the statement that this has been agreed, at least for the integrity of the victim/patient representatives, and more importantly for the unsuspecting patient victims.

- “The group acknowledges that some of those affected are likely to remain unhappy with the way they would be treated under these proposals. Such people are 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. This view was also reflected by a minority of group members. 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.” We are extremely concerned by this whole paragraph. We assert that it is a gross misrepresentation of the real situation. It automatically seeks to nullify any substantive increased support to all the so-called Stage 1 victims, and for that reason it must be challenged. The SIBF in particular cannot be associated with this for its own credibility sake with its members. We would ask how it can be said that the view to have a more even split was a view of “a minority of group members” those same group members have membership bases that would disagree this this view. For example, it is stated elsewhere in the report that half of the local meeting attendees were at the Glasgow meeting, and it is well known what the overwhelming majority view there was. We also assert that the only way this could potentially tend to lead to only “a nominal increase” for the “more serious impacts” is if the payments are derisory (as would be the case if the currently proposals stand). Also, we thought we had dealt with the unsustainable and unpalatable idea that one person’s suffering should be adjudged to be more or less than another’s. Further, we are deeply concerned by the phrase “any total budget identified”. We thought we had been told that there is no pre-conceived budgetary limit to provide financial support regardless of what the need is. Isn’t it about what is needed rather than what the government thinks it can afford? After all, the patient victims’ needs are real and rising (including past/outstanding losses) and they do not simply disappear because someone from the Finance Directorate wants to spend money on something else. We are looking for the fairness promised, and as part of that promise, for the Cabinet Secretary and the First Minister to stand up for state infected people against any pressure from colleagues who might have their own reasons for placing an unfair limit on adequate support.

- “… the survey responses support a simple, universal scheme.” We assert that this is an undeniable recognition that contradicts the quoted paragraph above. People have been asked and have responded with an unequivocal answer; ‘a simple, universal scheme’. We believe that this is not the only example of inconsistency in relation to the interpretation of consultation results within the report, but in particular this fundamental inconsistency cannot remain as it is. Similarly, for this reason we consider it was unreasonable to expect Group members to respond as if the document was "for final comments and approval" when in key areas it is imbalanced, inconsistent and not accurately representative of Group members’ views or consultation responses. There was also a deadline of 48 hours to respond which we believe was completely unfair and could be interpreted as an attempt to push through the report which appears to support Government preferences and may have the result of ‘bouncing’ the patient/victim representatives into accepting the resulting document without a fair time to consider it. We believe that it would be very unhelpful and inappropriate to allow the document to go to the Cabinet Secretary in its current form.

- “… there was some support for prioritisation based on health and disability.” We think this comment in the report is at best unnecessary. There was also ‘some support’ for financial support payments in lump sums of over £1million, but this is not mentioned. By mentioning only certain aspects where views were expressed, the document would appear to be seeking to justify elements of prioritisation (i.e. means testing) even though there is only ‘some support’ for this. We worry that this might demonstrate a tendency to ‘cherry-pick’ what a few people may have said when it supports a particular government preference as the way forward, while other factors raised in the consultation receive no mention at all, even if they were supported by many more people. We are left to question what was the point of asking people what they need and how they want that need met, (so raising expectations), and then just selectively focus on preferred responses, even if they are not the majority view? We believe that this does not describe or conform to being a competent or reliable consultation (even according to the Scottish Governments’ own standards for public consultations).

6. Key Principles

- “The scheme should recognise all types of loss and suffering including: Pain and suffering; Financial losses; Ongoing needs.” We assert that the proposals do not meet this stated key principle. For example, people have not even been asked to submit even the most basic of information about
financial losses. During the round of local meetings this lack of asking the basic questions about losses was raised, with the response being that we would be asked for that information later, because at the local meeting stage the aim was to establish the ‘key principles’. We note that this financial losses assessment never was followed through on, which means that the most basic data to assess need was never gathered. People were never asked, and some people have said that they were never asked because that information was not wanted or needed. People have expressed concerns (misgivings) that gathering knowledge about actual and estimated losses would be irrelevant to the outcome since they suspect the size of the pot to be distributed, or at least the maximum parameters, has already been decided (i.e. ‘any total budget identified’).

- “That nobody should be living in poverty as a result of the infections.” While this might appear to be a worthy assertion, in the context of the aim to achieve a full and fair settlement for patient victims we wonder if its inclusion is helpful. We believe it should be irrelevant to the matters under consideration. Too many infected/affected people are already experiencing poverty because of their infection – and we thought that was one of the main motivations for carrying out the Review to stop that happening. It is our understanding that the aim is for a full and fair settlement so that people can live comfortably and ensure their family’s future in spite of their infection; caused by no fault of their own. Just avoiding poverty shouldn’t come into it.

7. Proposal 1 (from Executive Summary and body of document)

- “Stage 2 (advanced) HCV”. We are concerned about this description as it appears in various parts of the document. Is this just an over-simplified explanation of the so-called Stage 2 distinction, or is it a further differentiation of people’s “level” of being infected/affected (a sub-set of a Stage). If it is the latter, where does it come from? We believe this must be clarified, and if the latter of the possible explanations then the “(advanced)” should be removed as it is spurious. As stated previously, we believe these distinctions are no longer useable since it is based on out-dated, over-simplified and unfair criteria.

- “This should be payable in all co-infected HIV and HCV cases, including Stage 1 HCV, to reflect the additional health impacts and complications of co-infection.” We believe this demonstrates an acknowledgement of the fact that the so-called Stage 1 infection is recognised as sufficient to require ongoing annual payments for co-infected people. So the ‘one-size-fits-all principle’ should apply (if it really will) since it is assumed this cohort of people will also get the £30K increase as proposed later in the document. We insist that this inconsistency be acknowledge and addressed.

- “All co-infected who are currently at Skipton Stage 1 should also automatically receive the Stage 2 Skipton payment of a £50k lump sum.” As above, we assert that this demonstrates an unfair and unjustified distinction. If infected/affected people are all in this together and want to avoid being split into factions and pitted against each other by the prospect of a winners and losers scenario, we believe that the co-infected victims and the so-called Stage 2 victims should take a principled stance in favour of the whole cohort being treated fairly.

- “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.” We question why is this being used to describe co-infected people when the reality is that even victims who are only allowed to be designated at the so-called Stage 1 also suffer these exact same symptoms and detriments, and often to the same degree of severity. The inapplicability of this distinction in health impacts is also supported by the Penrose Report where there is no separation between the so-called Stages when it comes to detriments. We assert that retaining such untenable differences in how people are considered will result in pitting one patient against another. We see this as being divisive, distasteful and morally wrong. It completely highlights the fallacy of the so-called Stage1/Stage 2 distinction and must be challenged.
• We are unclear from the way the document currently reads if payments for those who fall into these proposed new arrangements will be back-dated to recognise the losses incurred since the time of infection? We believe that it would be important that this should be clarified since one role of the Group was to include in its recommendations those matter that relate to retrospective payments. For example, in relation to the proposal for annual payments, anyone who has not received these payments previously, when in light of improved recognition of health impacts they are assessed for payment, there is a strong case to see these back-dated to cover the whole period of being infected, not just from when the assessment system became fairer.

• We are unclear from the way the document currently reads if any annual payments scheme will be tied to annual increases “to reflect Scottish full-time gross median income” as that particular measure will presumably increase annually in line with the cost of living. All that is currently proposed is that it “… will reflect historic and future financial loss for those most affected by infections.” We assert that annual payments must be explicitly tied to a recognised annual increase arrangement.

8. Proposal 2 (from Executive Summary and body of document)
• “… or at HCV Stage 2 only.” We assert that this needs to be subject to the red line issue of removing the so-called Stage 1 and so-called Stage 2 distinction.
• “Widows of those who died at Skipton Stage 1 should also be able to apply for this payment where the virus contributed directly to the death of the primary recipient.” We believe that this would be a redundant/unnecessary clause when the so-called Stage 1/Stage 2 split is removed. However, even as it is it is we think it is too open to interpretation (particularly by a ‘hawkish’ clinician, as has been the experience already by some people who have sought Skipton support). We strongly believe that it would be very helpful for this be more specific (in particular when it comes to the possible flexibility of interpretation of the word ‘directly’, its scope and scale).
• “Payments are, in part, recognition of injury and harm …”. We believe this is a vital comment and strengthens the case for support as a result of injury/harm caused by the state. We insist that this stays in the report.

9. Proposal 3 (from Executive Summary and body of document)
• “The Ross report recommendation related to chronic infection with HCV should be fulfilled.” We have campaigned on the basis that the Lord Ross report recommendations should have been implemented in full back when they were published. We assert that the economic value of the financial elements of the Lord Ross recommendations are therefore outdated, and that they were ‘of their time’. Beyond that, we are deeply concerned that the Lord Ross recommendations may be being used to justify a greatly reduced payment structure (compared to one that is ‘full and fair’) such that it would be made to appear that the patient/victim representatives on the Group would be content with the proposed maximum settlement amounts being tied to the former Lord Ross recommendations. We are concerned that this could possibly be seen as another example of the Review Group discussions being selectively pursued to favour the state’s preferred outcome. We see this as falling into the same type of misuse of discussions and consultation responses as happened with the topic of interim payments where a letter was sent calling on Westminster to make an interim payment for a derisory amount when it was fully expected that it would never happen; and that the amount being mentioned in the letter was far removed from the level discussed at the consultation meetings. In our view, after the so-called Stage 1/Stage 2 split, the matter of lump-sum payments is the second biggest bone of contention. Firstly, the Ross recommendations are from 12 years ago. £50K then (or the as yet unpaid £30K top-up, for example) is worth a lot less today. Our view is that these amount are more in line with appropriate interim payments and a starting point for people to begin receiving full and fair support; but not to be considered ‘full and final’ amounts.
Similarly, we see no proposal which recognises that at the very least even these payments should be increased by an inflationary amount, or receive compound interest or be back-dated to a commensurate level to cover the entirety of the period of hurt and injury. More importantly, we assert that in the context of ‘full and fair’ then £20K, or £30K, or £50K or £70K for a life irreparably damaged or ended prematurely simply doesn’t go far enough.

- We would draw attention again to the objective as stated by the Cabinet Secretary to produce a ‘full and fair’ support arrangement. We assert that this Proposal 3 recommendation does not achieve that by any reasonable measure. People should justifiably expect full and fair to mean that at the very least their financial losses are covered. From consultation events it was clear that a majority of attendees were magnanimous enough to accept that a flat-rate lump-sum payment reflecting the collective losses which could then be divided evenly/equally should be put in place. Thus the higher earners appeared to be prepared not to receive a full settlement for their personal losses in recognition of those who had not had the opportunity to build up a career (maybe due to being infected at a young age), and who were no less worthy of a reasonable pay-out. But the actual losses they referred to were in the order of six-figure sums, for some it was seven-figures. (Had the consultation process included asking people to calculate even just financial losses this would have been understood.) It is our assertion that just because the current financial situation is poorer relatively than 10, 20 or 30 years ago this should not mean that victims are penalised. In fact the financial crisis and slow recovery has probably hit them more. The key here is that the sum to be distributed should be based on real losses distributed evenly to victims, not a government set “total budget identified” to be fought over by everyone trying to prove they are ‘more sick’ than the next person.

- It is our contention that almost everyone at the consultation meetings expressed a preference for a lump-sum payment. The discussion on this topic went so far down that line as to have move on to the need for an interim payment. We do not see this overwhelming preference for lump sum payments being properly or accurately reflected in the report or recommendations. It is our belief that if the Scottish Government really wants to be sympathetic to the needs of infected/affected people, but they genuinely cannot budget for lump-sum payments at the full and fair level of magnitude, then we ask why it cannot just be open enough to say that. We suggest that it would then be easier for people to accept a commitment to a combination of a reasonable (and ‘affordable’) lump sum payment scheme (for example £100,000 per infected or affected person), combined with the annual payment proposals that would properly cover the equivalent to a single large full and fair one-off 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 etc) …” We assert that this may be an empty promise since it is becoming clearer that the new treatments may increasingly render this transition redundant. Also, we see it as further evidence of clinging on to the old demarcation between the so-called Stage 1/Stage 2 without regard for the chronic extra-hepatic conditions arising from the infection and/or previous treatments (e.g. hypothyroidism, the likes of which become an additional chronic health burden with their own set of life-long, life-limiting detriments; and we know there are other specific physical and mental health impacts beyond liver damage).

- In good faith we are assuming that the reported lack of communication between the officials in Westminster and Holyrood is true. We therefore highlight that the announcement by the Chancellor of a significant increase to NHS funding in England within the Spending Review (£3.8bn, being an above inflation amount of 4%), which will include consequentials for Scotland, will have come as a pleasant surprise to the Scottish Government. It could reasonably be thought of as an unexpected windfall and so will not have been included in budgets. Thus we assert that it is reasonable for us to propose that some of this new consequentials money be used to better support (i.e. in a more full and fair way) contaminated blood HIV and HCV victims; assuming that lack of money is the reason
for the still inadequate support levels as proposed in the current version of the report and recommendations.

- We are very concerned about the suggestion (or sub-text) that any proposals for support to contaminated blood patient victims will be scrutinised by Ministers as if they were not expecting or would not support a prior commitment by the First Minister and Cabinet Secretary to provide that support. We accept that there are good governance protocols in place, but we worry that the inclusion of such comments in the document might be overstating known governmental protocols. We are concerned that this may be a precursor to announcing that there is no money to provide full and fair support. As stated before, we do not believe and cannot accept any such response. We know that it is always a matter of political will. If any government really wants to find the money for what they set as a priority, then they will find that money. This was exactly the case when the UK Government introduced the ‘bedroom tax’ and immediately the Scottish Government ‘found’ the money to recompense everyone in Scotland who had been affected by it. Our view is that if the Scottish Government really wants to support infected/affected people (and we are told repeatedly they do) then they literally just need to put their money (our money) on the table.

10. Proposal 4 (from Executive Summary and body of document)

- As was discussed at the Perth event, this is potentially the most bureaucratic of the proposals (apart from the unfinished business within Proposal 5, potentially). We simply assert that this discretionary structure could be largely (or entirely) done away with by simply giving people a proper, full payment scheme so they can meet additional needs the way the rest of the population do.

- We are concerned to ensure that there should be an explicit recommendation for a totally separate Scottish body to administer lump-sums payments, annual payments and discretionary grants. We see how it could be interpreted that the proposals might only result in a Scottish body just to administer the support and assistance discretionary grants. Given the dissatisfaction that most people expressed with the current UK systems, we believe this needs to be clearer. An all-embracing Scottish body was certainly the majority view from the consultation events.

11. Proposal 5 (from Executive Summary and body of document)

- We believe this comes across to the reader as a catch-all for unfinished business. We think that it demonstrates how the timescales were ambitions (unrealistic); even though they were, we believe, part of a genuine desire to respond timeously. We believe it is very unfortunate that after all the delays, barriers, refusals, token gestures and promises encountered in the past 30 years, the need to complete the work of the Review Group in so short a time may have compromised the consultation process, and the Review Group’s ability to fully carry out its remit, and ultimately the achievement of the best outcomes for people by working with and not against the government (as it might appear in some ways).

- “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.” We wonder why this was not included (or at least referenced) in Proposal 1 related to annual payments. We see this, and the other Proposal 5 elements, as unfinished work that must mean the Review Group will need to continue to meet beyond the original November deadline. If it does not, we would be concerned about who else will deliberate and decide on the detail of these quite crucial items of unfinished business.

- “Access to insurance products, and additional loading of premiums due to infections, should be given further consideration.” We see this as just a re-stating of what was in the Lord Ross recommendations and the Scoping Exercise recommendations. We recall that at the Perth event it was proposed and apparently accepted that the word “should” must be strengthened by replacing it with something like the word “must”. Given that this minor change was specifically mentioned and
agreed as preferable in the Perth meeting but not actioned, we are concerned that if this small change was not followed up, there is clearly potential (and we would suggest more than the potential) for other weightier items that were apparently being recorded to take back to the Group, not actually getting back to the Group or not being taken on board when they were. We are concerned that the consultation process has been compromised by a lack of responsiveness to feedback given in good faith by infected and affected patient victims. We are further concerned that given the speed with which Ministers responded publicly (and admirably) to the publication of the Penrose Inquiry report, there may have been the temptation to move forward in a somewhat less than complete way after the Penrose spotlight was no longer shining.

- “The current thresholds for Stage 1 and Stage 2 of the Skipton Fund should be the subject of a specific, evidence-based review.” and “This review should also thoroughly evaluate the criteria for attributing HCV to the cause of death, including death certificate data.” As stated previously, we see these as fundamental to the whole process. We are left to reflect on why they were not adequately addressed during the eight meetings of the Review Group. The non-governmental representatives on the Review Group have all stressed publically the efforts they made individually and collectively in relation to this key topic, but no resolution has resulted. We recognise that some see reviewing thresholds/eligibility criteria/etc. as a strategically preferable alternative to forcing a climb-down on the so-called Stage 1/Stage 2 delineation. It would potentially open the door to so-called Stage 1 victims effectively becoming so-called Stage 2 people, by a completely different route to that of removing the stage designations. We acknowledge that this may be is a good strategy, but equally we worry that it could simply be a way to delay acting on this more challenging aspect. We would assert that there was already sufficiently robust evidence of the need for changing threshold criteria.

12. Operation of the Scheme

- “A new Scottish scheme should be established that is sensitive to the unique Scottish context.” As mentioned above, we would seek a more definite and clear description of how the entire support programme will operate in a fully independent way from the UK, or to know for the avoidance of doubt if anything was being left to London?

- “Payments should not be taken into account for the purposes of entitlement to benefits and should be exempt for taxation purposes.” We recognise that this will involve Westminster since these matters are reserved. We worry that this will delay the implementation of the Scottish scheme (since the preservation of these entitlements might require going through the UK parliament legislative process)? We fully support the spirit and intent of this operational statement, but would want to see a bolder assertion (not just ‘should’) and a plan to move forward if, while awaiting a London response, an interim arrangement needs to be put in place.

- “Appeals mechanism – a credible, transparent appeals mechanism should be established for all parts of the improved schemes.” Again, we do not see the bolder, more assertive commitment by replace ‘should’ with something stronger like ‘will’ or ‘must’ as was presented at the Perth event.

- “Accountability – the new structures established in Scotland should have affected patients involved in Governance/oversight.” Once again, we believe the strengthened wording was all meant to be fixed after Perth.

- “Any new arrangements should be subject to periodic future review to ensure they are fit for purpose.” While supporting this more genuinely designated ‘future’ work, we believe the current Scottish Government needs to build in cast-iron protections so that a future administration does not decide that the scheme needs to be scaled back as part of an overall cost-cutting exercise (e.g. which might be dressed up as a “review” in the event of another recession).

13. Other General Comments
• We are concerned that the specific remit issue of considering payments being applied retrospectively has not been fully addressed. We believe this could be vital at the point when fund administrators are following guidelines that may not have properly addressed this issue, resulting in people losing out or having to contend with an administrative process that has not adequately covered any retrospective-type eventuality.

• We recognise that there is an opportunity (potentially, at least) to head-off the consequences of the so-called Stage 1/Stage 2 split by boosting the relevance of extra-hepatic factors to be added to criteria that moves someone from one to the other. However, we are concerned that any threshold criteria change could still be open to unfairness in its application. We believe that it would be far simpler just to have someone designated as state infected and that would be sufficient to open the door to support, as opposed to a clinician making a relativistic judgement on impacts.

• We are concerned that there is little detail on those who have ostensibly been “cured” and so worry that some of our members could suffer a detriment by this matter not being adequately addressed in the recommendations.

• We are very concerned that the archetypes/case study exercise which was to look at specific cases has not been followed through. This would have looked at possible relationship situations people found themselves in, losses related to various livelihood scenarios, etc. and then it would have assessed them for likely need and possible unintended consequences arising from the proposals. This proofing or testing process would have included, for example: ‘cured’ people; dependents from different relationships; people demonstrably infected in Scotland but now resident elsewhere; separated or divorced people who have children who themselves have support needs but who no longer live with them; unmarried partners etc.

• We believe the Group needs to go back to the original statements by the Cabinet Secretary and the First Minister to pick out the no doubt sincerely meant words from our nation’s political leaders in the aftermath of the Penrose Report publication. Specifically this review should list commitments like ‘full and fair’, and then proof the draft recommendations against their aspirations.

• We are concerned that the Scoping Exercise is hardly mentioned in the report, even though it was meant to be a ‘starting point’ for the work of the Review Group. At the Perth event there was a difference of opinion about whether or not the Cabinet Secretary had accepted the recommendations of the Scoping Exercise in full (which would have implications for the report and recommendations). We maintain our assertion that she did.

• We recall how our members were encouraged during the consultation process to complete the questionnaire not only with their responses to the questions, but also with comments about the process, including the questionnaire itself. There was a big debate at the time. We wish to know what happened to these process related responses. They don’t appear to be reflected in the report. In our view, at the very least it is bad practice in social research and in community engagement (if the report document aspires to be seen as such) not to see some reference to the methodology and it’s acknowledged shortcomings/limitations/assumptions.

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