

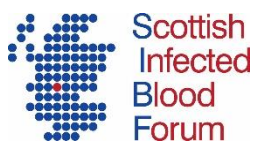
Hepatitis C Virus (HCV)

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



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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.

Contents	Page
1 Forward & Introduction	1
1.1 Convener’s Forward	1
1.2 Ministerial Introduction	2
2 Executive Summary	3
3 Purpose	8
3.1 Vision & Objectives	8
3.2 Learning from and using the results	8
4 Background	10
4.1 “The Worst Treatment Disaster”	10
4.2 Scotland responds	10
4.3 Victims voice	11
4.4 Penrose Inquiry overview	11
4.5 The Sexual Health & Blood Borne Virus Framework	13
4.6 The Scoping Exercise	14
5 Methodology	15
5.1 Scope & scale	15
5.2 Definitions	15
5.3 Techniques & approaches	16
5.4 The Questionnaire	16
5.5 Focus groups	18
5.6 Monitoring & quality assurance	19
5.7 Standards	20
5.8 Risk management	20
5.9 Potential for raising expectations	21
5.10 Success factors	21
6 Community Engagement & Stakeholder Input	22
6.1 Target participants	22
6.2 Stakeholders	23
6.3 Stakeholder roles & responsibilities	23
7 Results & Commentary	25
7.1 Section A: About you	25
7.2 Section B: Receiving a confirmed diagnosis	28
7.3 Section C: Medical matters	33
7.4 Section D: Living with a Hep C diagnosis	42

	Page
7.5 Section E: Experience of anti-viral treatment	48
7.6 Section F: Non-medical effects of having Hep C	53
7.7 Section G: Social work, counselling & psychological services	58
7.8 Section H: Support groups	59
7.9 Section I: Experiences with various agencies & organisations	63
7.10 Section J: Personal tips for coping better, living well & feeling good	72
7.11 Section K: Final comments	81
7.12 A picture of the situation	84
7.13 Common issues, unique issues	86
8 Condition Management Issues & Contributions	91
8.1 From questionnaire respondents	91
8.2 From desk research.	93
8.3 From a medical perspective (developments in anti-viral treatment).	96
9 Recommendations	98
10 Appendices:	103
• A: SIBF Project Management Group	104
• B: Project Reference Group	105
• C: Key Contacts List (Support Organisations)	106
• D: Questionnaire	107
• E: Standards	133
• F: Penrose Inquiry Terms of Reference	134
• G: Health Conditions Associated with Hep C	136
• H: Questionnaire Responses	137-273

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.



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.

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 C¹⁸

- 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)

¹⁸ Source- Advisory Group on Hepatitis: Review of the clinical consequences of hepatitis C infection: June 2013