

**Scottish Review of Financial Support Schemes:
minutes of second meeting, 28 July 2015,
10.00-14.00, Atlantic Quay**

Attendees

Ian Welsh, Chair – Alliance Scotland.
Alice Mackie - Campaigner, HIV.
Bruce Norval – Campaigner.
Bill Wright - Chair, Haemophilia Scotland.
Dan Farthing-Sykes - CEO, Haemophilia Scotland.
Jeff Frew - Campaigner, blood transfusion.
Petra Wright - The Hepatitis C Trust (Scotland).
Philip Dolan – Convenor, Scottish Infected Blood Forum (SIBF).
Tommy Leggate – SIBF/independent consultant.
Liz Ferguson – SIBF.
Mary McCluskey – SIBF.
Patrick McGuire – Thompsons solicitors.
Susan Murray – Central Legal Office.
Norma Shippin – Central Legal Office.
Gareth Brown – Scottish Government.
Robert Girvan – Scottish Government.
Naureen Ahmad – Scottish Government.
Sarah Manson – Scottish Government.
Marion Cairns – Scottish Government.

1. Welcome, introductions and apologies

No apologies were recorded. The following people were welcomed who were attending for the first time:

- Sarah Manson – from Scottish Government, who was supporting the work of the Group.
- Naureen Ahmad – from Scottish Government, again supporting the work of the Group.
- Susan Murray and Norma Shippin from the NHS Central Legal Office, who were attending to present on court damages/compensation; and
- Patrick McGuire from Thompson’s Solicitors who was attending to present on other possible payments schemes.

2. Chair and membership

It was noted that a request had been received from another individual to join the group. DF commented that it may be useful for this person to join, given that they were not affiliated with the historic campaigners. IW said that he would meet with them to discuss their membership.

It was agreed that Patrick McGuire, Susan Murray and Norma Shippin would join the Group as expert witnesses.

BN suggested that ideally a bereaved person would also be represented on the Group. PD noted that some of the SIBF members were bereaved and would feed into the exercise.

3. Action Points

Draft Terms of Reference - the amended TOR was agreed as accurate. It would be adopted as the working ToR.

Statistics – at the previous meeting additional stats were requested by members. RG had updated the statistics paper to reflect these requests as far as possible. Information related to the age of infection and Stage 1 extra-hepatic deaths was not routinely collected – the Funds did not see copies of Death Certificates. GB advised that modelling work would be undertaken by Health Protection Scotland on these matters as far as was possible given the data available.

Infectious disease specialist – GB noted that an ID specialist (Dr Morgan Evans) would attend the next meeting to provide advice on any medical issues. It would be useful if any specific questions could be fed to GB in advance.

4. History and Context

GB gave a brief presentation setting out the high-level background/overview of relevant events to date. SM commented that 20 Burton Judgement analogous court payments had been made in Scotland. Around 6 cases were still live.

With regard to the Ross report (2003), JF and PD commented that the rejection of the recommendations may have been due to the influence of the UK Government. They had both served as witnesses for the expert group.

With regard to the Ross report recommendations A & B on financial support, PM said that the solatium (pain and suffering) payment recommendations had clearly not been implemented. With regard to fault and liability, BN said that there were outstanding issues with regard to Crown Immunity and the regulation of the Protein Fractionation Centre.

JF noted that many people may have been deterred or prevented from applying to the Skipton Fund as their medical records had been destroyed. RG commented that the Funds did accept anecdotal evidence in some cases.

On the Penrose Inquiry report, BW commented that this was an individual's view of the events. DF said that there was an in-depth narrative but little analysis or recommendation. PM noted that the TOR of the Inquiry steered clear of assessing negligence and liability.

BN noted that there was no concrete proof of a 'cure' for HCV. The correct term would be 'sustained viral response'.

It was agreed that the presentations would be shared with the Group.

5. Understanding needs

TL gave a presentation on the findings of the Scottish Infected Blood Forum scoping exercise, focusing on what was known about the needs of infected people and their families.

BN asked if there was a method of calculating loss of income opportunity for a person infected as a child. SM clarified that there was – this would be based on the family context, careers of parents etc. BN commented that there was an additional issue around loss of physical capability. Many infected people could not carry out basic household tasks.

The problem of inflated travel and life insurance premiums for infected people was also raised. JF said that there had been a historic meeting with the Association of Insurers on this subject and he would try to find the note of it.

It was noted that benefits entitlement is gauged by how the illness affects you – not all are affected to the same extent. The guidance focuses on cirrhosis.

AM said that people with HIV may not want to reveal their infection to the benefits office due to the stigma.

6. Other UK schemes

RG presented a high level overview of other UK ex gratia, no-fault compensation and damages schemes including vCJD, Mesothelioma, Armed Forces, Thalidomide, Vaccine Damage and Industrial Injuries. The purpose was to encourage members to think about the various mechanisms and rationales that could drive a new scheme.

With regard to the Armed Forces scheme, RG agreed to seek further information on the appropriate Mental Health tariff and also the number of infectious disease claims related to HCV and HIV.

7. International comparisons

RG presented a high level overview of comparable international schemes: the Irish Tribunal and the Canadian settlements. RG agreed to seek additional information on the number of Irish claims from dependants as opposed to primary infected beneficiaries.

8. Court damages/compensation

SM and NS presented an overview of how Courts in Scotland award damages or compensation, and typical amounts. Solatium was the first element (pain and suffering) and was protected from claw-back if other payments had been made in the past. A net figure would be assessed over a period of years, taking into account life expectancy. Reduced life expectancy was calculated via a specific multiplier.

Payments for financial loss could also be calculated, including pension loss which was calculated by an actuary and could be a major factor. In the case of death, compensation for loss of support could also be paid to children and dependants.

Where someone was infected as a child, their family setup could be examined and their prospects extrapolated, although this was a less scientific process. Payments could also be made for loss of services such as actual care costs but these tended to be smaller amounts. Any relevant interest was paid at the judicial rate of 8% and legal expenses would also be included in the settlement.

SM said that court payments were made on a bespoke basis, rather than the thresholds applied by the ex gratia schemes. They were based on court precedents. The major infected blood HCV precedent was a 2001 case: A & Other vs NBA & Others. This was a class action that was still referred to, relating to product liability.

The Burton Judgement analogous payments were between £8K-£100K. There was a table setting out the relevant amounts payable – these were related to the severity of illness but also earning power. The highest earners such as Company Directors received the highest payments.

SM noted that there were no class actions in Scotland. Claims would be grouped however, with a lead legal firm. BW commented that there were issues around people knowing they had the virus and the timebarring on claims. SM said that there was some flexibility with regard to the interpretation of the time bar.

PM noted that there were essentially two bases to the claims – common law negligence which required evidence of a breach of duty of care; and the CPA criteria which had strict liability terms. For the CPA claim you did not need to establish negligence, it turned on whether the product was defective. With regard to the time bar there was a 10 year absolute barrier after manufacture.

PM presented his views on an alternative scheme. With regard to general principles, this could be an ex gratia or compensation scheme. A compensation scheme based on court principles would compensate for loss, injury and damage. It would aim to achieve restitution – that is to put the victim back in the position they would have been in without injury. Solatium related to non-financial losses. Financial loss compensation related to employability, insurance, pensions – basically all financial factors. Service or care costs were also payable but these were broad payments that did not strictly equate to the general level of care.

PM said that the compensation approach benefits the victim and compensator in terms of speed, certainty and fairness. It should involve some element of legal costs but this should be substantially less than in individual court cases. Another comparable scheme would be the contractual arrangement entered into with IRISC and then Capita to provide compensation for ex-miners respiratory conditions and vibration white finger. These featured interim payments and fast-tracked settlements.

It was noted that compensation could be affected by certain benefits received – these could be recovered in some instances. PM said that this relates to a 5-year period – there were ways of protecting compensation such as Personal Injury Trusts.

PM commented that the hallmarks of ex gratia schemes were generally smaller arbitrary sums, due to insufficient risk of litigation. He noted that in this case there still could be significant litigation dependent on the interpretation of the time bar. It could be argued that the publication of the Penrose Inquiry report was the starting point for timing. There was a court power to override time limits.

PM commented that a solatium payment would be protected from the recovery of previous payments. Everyone infected could immediately receive the £50K solatium payment recommended by Lord Ross. A quicker way to cover wage loss may be to look at the surveys of average earnings and create appropriate bands. A person could have the choice between a staged settlement featuring periodic payments, or a final settlement. There were various options and a scheme could be designed to reflect these. AM noted that some of the HIV beneficiaries may prefer ongoing, regular payments.

9. Next meeting

The Group would reconvene on 29 July.

10.00-14.00, Atlantic Quay

Attendees

Ian Welsh, Chair – Alliance Scotland.
Alice Mackie - Campaigner, HIV.
Bruce Norval – Campaigner.
Bill Wright - Chair, Haemophilia Scotland.
Dan Farthing-Sykes - CEO, Haemophilia Scotland.
Jeff Frew - Campaigner, blood transfusion.
Petra Wright - The Hepatitis C Trust (Scotland).
Philip Dolan – Convenor, Scottish Infected Blood Forum (SIBF).
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Patrick McGuire – Thompsons solicitors.
Susan Murray – Central Legal Office.
Norma Shippin – Central Legal Office.
Gareth Brown – Scottish Government.
Robert Girvan – Scottish Government.
Naureen Ahmad – Scottish Government.
Sarah Manson – Scottish Government.
Jan Barlow – Caxton Foundation/Macfarlane Trust.

1. Welcome, introductions and apologies

IW welcomed Jan Barlow from the Caxton Foundation and MacFarlane Trust, who was attending to provide background information on the operation of the various UK-wide financial support schemes.

He noted that the meeting would provide an opportunity to consider the strengths and weaknesses of the current payment schemes. This would inform the thinking around how new schemes should/could operate and what they should aim to do. The meeting would also consider the terms of the consultation to be carried out with affected people in Scotland.

2. Existing support arrangements

JB provided a presentation that gave a strategic oversight of all of the current financial support schemes. BW commented that the schemes were primarily focused on the living rather than the bereaved.

JB explained that the charities (Caxton, Eileen, Macfarlane) could only act within the constraints of the budgets allocated to them by Government. Of these, the Eileen Trust was the least controversial because it had a very small number of beneficiaries with whom the charity could have close contact. The Macfarlane Trust was currently running at a deficit of around £600K a year. A number of business cases for additional funding had been rejected by the Department of Health in recent years.

JB noted that given their charitable status, the Trustees of the discretionary funds had a responsibility to assess financial need. PD raised the issue of accountability – he commented that from among the Trustees there was not a representative based in Scotland with knowledge of that specific context. JB said that the same support was provided regardless of a person's country of infection or residence. Payments were made according to need, not nationality. She noted that the Scottish allocation to the Caxton Foundation had recently been

increased in line with the higher proportion of Scottish registrants. She said that people from different jurisdictions were on the Boards, although there was not a mandatory appointment from each jurisdiction.

JF noted the issue of those who had historically been refused awards from the Skipton Fund due to medical records being destroyed. He considered that the current appeals process was not sufficiently open and transparent – those appealing were not allowed to attend in person and the reasons for rejection were not fully explained.

BN noted the issue of beneficiaries resident in remote rural areas – they could be subject to increased charges for services. JB agreed, commenting that this was also the case for those resident in London for example.

JB said that there was also the issue of new registrants/beneficiaries who could continue to come forward over the next 20 years. There had been a 57% increase in the number of Caxton beneficiaries in 2014/15. She clarified that the regular payments made by Caxton and Macfarlane were means.

JB advised that the schemes had a small core staff of 10 people supporting up to 4000 registrants/beneficiaries across the UK. Given those constraints they could not afford to carry out individual needs assessments under the current arrangements. She noted that with regard to reimbursement for the HCV schemes, the relevant Government funding was determined by the person's country of infection.

AM commented that of around 130 widows of those infected with HIV she was aware of, there were only 5 claiming support in Scotland. There appeared to be a discrepancy in the amount of widows claiming. JB said that many of the widows instruct the funds that they want no further contact. They may have remarried and started new families, for example.

JB noted the differing age profiles for beneficiaries of different schemes. For the MFT the majority were 40-60 year old, whereas for Caxton the majority were 30-69 years. JB listed the range of grants provided by the Caxton Foundation – this was primarily about tackling financial hardship. During treatment, time limited payments were provided to make up for loss of earnings.

It was noted that there was a question regarding what the lump sum payments were actually for – they were intended as some kind of financial recompense for infection but the principle behind the payments had never been defined. PD said that anecdotally he had heard that a Caxton recipient had been required to surrender their credit cards as a condition of payment. JB clarified that this had never happened – a charity could not make such a request.

With regard to eligibility, BN commented that the point of infection should remain the keypoint. There had to be evidence of a causal link. GB added that there was also the issue of place of residence – free prescriptions were administered on that basis. It was noted that a persons could have been infected twice with two different jurisdictions involved. There were also people living outside the UK who were infected in the UK and currently received payments.

3. Thinking about new schemes

GB gave a presentation on how a new scheme might operate and what its purpose might be. It was commented that a Scottish scheme would have more transparency, accountability and political control – currently all 4 jurisdictions had to sign off any revised funding arrangements. A smaller number of beneficiaries could mean that the organisation was more responsive to their needs. The Scottish historic context had been different with regard to the Protein Fractionation Centre, self-sufficiency and the introduction of heat treatment. It was pointed

out that the Eileen Trust recipients were generally content with the current arrangements – there was not the same appetite for change among them. RG advised that the current share of service delivery costs was small for Scotland – around £35K in total. This would increase significantly for a new Scottish scheme. It would have to operate on a cross-jurisdictional, cross-border basis which may cause eligibility issues. It was noted that the decision of the group would potentially influence the thinking in the other UK countries.

With regard to civil damages, PM advised that the key family members would be parents, grandparents, children, brothers, sisters, partners and widows. They could claim damages for loss of society and loss of support where the person was deceased. PM said that it was possible to claim for psychiatric injury as a secondary victim if the injury was considered foreseeable. The assessment was based on what would be considered ordinary mental fortitude and was difficult to achieve under Scots law.

AM commented that HIV and HCV were completely different diseases with different impacts that needed to be consulted on. It was noted that HCV also had extra-hepatic manifestations. The treatments for both viruses could cause severe hardship and long-term health impacts.

It was suggested that an existing agency could potentially be used to host a Scottish scheme. The Coal Board claims had been taken forward by Capita under contract, due to the high volume of claims. GB said that after the recommendations were made in November it would then be a practical question of designing a viable scheme.

The issue of self-directed support was raised which could be less restrictive on the beneficiary. This could involve respite care, furniture, mobility aids, home adaptations etc. Under the Thalidomide scheme recipients signed an undertaking to spend their grant on health needs, but were not actively monitored.

It was noted that a scheme could potentially feature a number of different components. There was a balance between complexity and accessibility. PM said that the key question would be whether the scheme was needs based or impact/consequence based. It could be a hybrid model. The level of autonomy in the person's spend and amount of application/bureaucracy required would also be important. BN said that it was desirable to empower the beneficiary so they do not have to continually ask for additional support.

PM said that an impact based scheme would cover loss of health, loss of society, loss of income etc. Individual factors would be taken into account. For a no-fault scheme, avoidability and fault would be put aside although causation must still be established. SM noted that solatium tariffs could be established from previous court cases. The Ogden tables allow for income based projections. A damages scheme could be individualised or tariff based. SM commented that a bespoke assessment would mean significant divergence in the amounts people would receive, given that this was earnings based. Such a scheme would mean a heavier workload and slower assessment.

The group agreed as a principle that nobody should receive less financial support due to the new arrangements. The same level of support should at least be maintained. It was noted that any new arrangements would have to be subject to future review. PD said that some group have not benefitted from the larger lump sums and regular payments – those with liver fibrosis for example.

It was noted that for a final settlement scheme the financial support that had already been received would probably have to be taken into account. If not, this would mean double or even triple compensation for the same injury if someone had already received ex gratia and court payments. The group agreed that the proposed scheme would have to be modelled and tested for individual cases.

4. Measures for standards of income

NA provided a presentation on various benchmarks for acceptable levels of income. This included data from the Joseph Rowntree Foundation and Treasury guidance on median income.

5. Consultation

DF gave a presentation on the proposals to engage with patient groups on behalf of the review group. It was agreed that the process should be as accessible as possible. It would feature two phases, with an initial survey at phase one and the draft recommendations consulted on in the second phase. The time constraints were noted – the first phase should have reported by the 7 September meeting.

It was agreed that the consultation would go out under a covering letter from the group rather than Scottish Government. The Alliance would host the electronic survey. There was a confidentiality issue – the hard copy surveys would have to be distributed by the schemes. DF would schedule times and venues for the regional meetings and a final national meeting in October.

It was agreed that the draft survey would be circulated to the group for final comments.

Item 6. Next meeting

The next meeting would take place on 28 August in Edinburgh.