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## Haemophilia Scotland Response to Department of Health (England) Consultation on Infected Blood: reform of financial and other support

### **About Haemophilia Scotland**

Haemophilia Scotland is a Scottish registered charity, SC044298, established in 2012 and constituted as a Scottish Charitable Incorporated Organisation (SCIO) in 2015. We are based in Scotland and provide information, support, and advocacy services for individuals and families with bleeding disorders in Scotland.

We were a Core Participant in the Penrose Inquiry, served on the Scottish Infected Blood Financial Support Review Group and are currently members of the Scottish Penrose Short Life Working Group. We were not invited to take part in any of the Department of Health (England) pre-consultation engagement events.

Although the vast majority of our members were infected and reside in Scotland we also have members who are resident in Scotland but were infected with a blood borne virus but NHS treatment in England. We believe that there are 20 people resident in Scotland who were infected through NHS treatment with a contaminated blood transfusion or pooled plasma product in England. We also believe there are five bereaved families in this position.

### **Question 1: Would you prefer five separate schemes (as now) or one scheme?**

Haemophilia Scotland supports the simplification of the schemes. However, we believe that a single, UK-wide, scheme doesn't provide sufficient accountability to the Scottish Parliament and Scottish Government, and by extension the affected communities in Scotland. London based schemes also effectively exclude our members from the opportunity to meet with those administering the scheme face to face as the vast majority of those affected have significant joint damage and limited mobility as a result of their bleeding disorder. This has prevented significant numbers of Scottish beneficiaries taking part in engagement work such as the Partnership Groups run by the existing schemes.

Therefore, we are calling for a single Scottish scheme. The Department of Health (England) should cooperate with the Scottish Government to ensure the transfer to the new Scottish scheme is as smooth as possible, data is secure, and the amount of form filling required of beneficiaries is kept to an absolute minimum.

**Question 2: Do you have views on how the individual assessments should be undertaken? Please provide any comments.**

Haemophilia Scotland believes that regular health reassessments are inappropriate. One of the strongest criticisms we receive about the current discretionary grants schemes is that they are too intrusive and bureaucratic. Regular individual health assessments would exacerbate rather than address these problems. Individual health assessments might also be expensive to administer which would spend money which might otherwise be paid in financial support payments. The consultation document does not provide any indication of the level of ongoing payment for those in the current Skipton Fund stage 1 category. Neither does it provide any estimates of the cost of the assessments so it is difficult to know how cost efficient this approach might be.

Similarly, assessments of this sort would create a perverse disincentive in the scheme and could force some people to choose between their health and the financial support they require. Individuals may be forced to refuse treatment in order to preserve their income and provide for their family. If the Department of Health intended to assess the financial losses incurred by individuals as a result of the infections then an individualised process would be required. However, regular individual health assessments will only serve to create ongoing financial uncertainty.

We are also concerned that if individual health assessments are carried out by generalist clinicians then they will not have the required expertise in inherited bleeding disorders, conversely if they are carried out with input from specialist Haemophilia Centres that will place a burden on frontline services. Would the Haemophilia Centres receive additional funding to conduct this work? How would this work for beneficiaries living outside England? Would a Haemophilia Centre in Scotland receive payments from NHS England to conduct this work or would those infected in England but living in Scotland be asked to travel to England to be assessed? How would this work for people infected in England living abroad?

**Question 3: Should the reformed scheme include a lump sum payment of £20k when an infected individual joins the scheme?**

Haemophilia Scotland believes that it should be a fundamental principle of any reforms that nobody should be worse off as a result of them. Therefore, removing the current Skipton 1 payment of £20,000 would be unacceptable. As a minimum this should be increased to £50,000 to bring it into line with the Scottish proposals and the Lord Ross Expert Panel report upon which the Skipton Fund was based.

**Question 4: Should the reformed scheme maintain the difference between those with HIV and hepatitis C by retaining the lump sum payment of £50k for progression to cirrhosis in relation to hepatitis C?**

Haemophilia Scotland believes that being infected with both HIV and hepatitis C creates particular difficulties with the management and treatment of both viruses and that this should be recognised in any scheme. However, we believe the level of payments someone receive should be related to the impact of the infection rather than simply which virus was involved.

We believe one of the problems with the current arrangements is that there is no clarity about what each element of the payment is for. We consider that a fairer scheme would be clearer about which elements are acknowledged by a particular payment. The four main impacts which should give rise to financial support are,

1. Pain and suffering
2. Financial losses
3. Ongoing needs
4. Aggravating legal considerations (such as negligence or inappropriate use of crown immunity).

It would be helpful to have clarity from the Department of Health of which of these impacts is addressed by each of the proposals.

**Question 5: Should the scheme offer the newly bereaved one final year of payment, or continued access to discretionary support, or the choice between these two options?**

Whenever possible the affected individual should have the choice about how they receive their money. However, both of the options presented in this questions are inadequate to address the needs of bereaved families, in particular the losses experienced by widow(er)s in their own right. Many partners have had to give up work or follow less demanding careers to care for those infected by the state through NHS treatment. This is compounded as they are forced to take on a higher proportion of household costs. The resulting loss of disposable income means that many have been unable to make provision for their retirement. Any scheme which does not provide a secure future for widow(er)s who have been denied the opportunity to provide for themselves is inherently unfair.

**Question 6: Should the scheme offer those already bereaved a final lump sum or continued access to discretionary support, or the choice between these two options?**

As with Question 5, affected individuals should be able to make their own financial choices wherever possible. It would be unjust to treat those who are bereaved after any changes differently from those who have been bereaved in the past. In both cases the pain, suffering, and financial losses are not altered by the changing policy of the Department of Health (England) in the intervening years.

**Question 7: Should providing access to treatment for those with hepatitis C be part of the reformed scheme?**

It is a basic tenant of justice that where harm is done those responsible for causing it do everything in their power to restore the damage caused. There is no dispute that the infections were a result of the actions of the state. Therefore, there should be no doubt that those infected should be automatically entitled to the best possible treatment and care. It is a red herring to seek to present this as an attack on the clinical prioritisation of resources within the NHS. The financing required to provide this potentially lifesaving treatment should not be taken from the fund available for providing people with financial support. This is akin to asking those infected to pay for their own

treatment from money which they are entitled for other purposes. The provision of treatment should be guaranteed through the NHS and not connected to these ex-gratia payments.

**Question 8: If you are a beneficiary of the current scheme, infected with hepatitis C would you be interested in being considered for access to treatment under the scheme?**

All those infected as a result of the contaminated blood disaster, for whom it would be clinically beneficial, should be offered the opportunity to be treated with Direct Acting Antivirals from a separate NHS budget. If, as Jane Ellison MP, asserted in parliament, that the treatment of those infected “has to be determined by clinical need rather than route of infection” then funding of treatment should be provided via normal clinical channels rather than being deducted from the extra £125 million proposed for financially supporting those affected by the disaster.

**Question 9: Should discretionary payments be available for travel and accommodation relating to ill health?**

Discretionary payments should be available to anyone who can demonstrate that they have needs related to the disaster not specifically catered for within the terms of the rest of the scheme. For example, there are no provisions in these recommendations for the children of infected people to be able to seek discretionary support to provide them with the training or development opportunities that a well parent might reasonably be expected to have assisted with. While this provision should include travel and accommodation related to ill health it shouldn't be limited to these narrow criteria.

**Question 10: Are you aware of any evidence that would show our policy proposals would negatively impact any particular groups of individuals?**

Haemophilia Scotland is extremely concerned that several aspects of the current proposals would negatively impact several groups.

In particular, breaking the index link for the maximum level of ongoing payments and capping it at £15,000pa will disadvantage those with the largest health impacts as a result of their infection(s). The current level of payment is £14,749pa. Even if the Consumer Price Index (CPI) remains at its historically low level of 0.2% then after five years of incremental rises the payment would have reached £15,046.13p. This amounts to giving these severely affected people £412 they would have been entitled to anyway in instalment over four years in exchange for year on year losses for the rest of their lives. They would also face the prospect of seeing their standard of living constantly falling year on year.

Similarly, the current Caxton Foundation, and to an extent the MacFarlane Trust, targets resources at those on the lowest incomes in order to make the best use of their limited finances. By proposing to abolish this support and replace it with ongoing payments based on an individual health assessment the proposals are likely to take money from some of those with the lowest incomes.

The current arrangements have been widely criticised for their failure to make proper provision for widow(er)s and bereaved families. The proposals are unclear in relation to these groups but appear

to suggest winding up the discretionary support which provides some within these groups with very limited support. If there were no discretionary support that what little safety net is currently being provided would be removed.

**Question 11: Do you have any other comments that you wish to make?**

It is welcome that the Department of Health (England) proposals tacitly acknowledge that there is significant ill health in the group who have currently received a Skipton 1 payment but have not qualified for ongoing support. In addition, we believe there are significant financial losses within this group which the Department of Health (England) proposals don't acknowledge. Indeed the lack of detail given on the amounts likely to be made for ongoing Stage 1 payments does not allow an informed evaluation to be made by those affected.

Under the new Scottish scheme Stage 1 is dealt with in 3 ways.

- 1 An extra £30k for all presently Stage 1 registered.
- 2 Ongoing access to the £1 million discretionary Support and Assistance Fund.
- 3 A review of the thresholds between Stage 1 and Stage 2 with a further review after two years to assess the effectiveness of any new scheme.

We are concerned that, taken as a package, the Department of Health (England) proposals appear to be approximately half as well funded as the package of measures currently being implemented in Scotland. As an absolute minimum would hope the Department of Health (England) would want our members who were infected in England to benefit from an equivalent level of support to our members infected in Scotland.

Haemophilia Scotland is also disappointed that the Department of Health have not adopted a co-production model to develop these proposals. The pre-consultation engagement seems to have been cursory and an opportunity has been missed to work closely with infected people to develop an approach which might have spent the notional budget more effectively.

Yours faithfully,



Dan Farthing-Sykes, CEO Haemophilia Scotland  
Signed on behalf of Haemophilia Scotland