1. PS(PH)
2. SofS

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Cc: see list at end.

REVIEW OF THE UK CONTAMINATED BLOOD PAYMENT SCHEMES – FURTHER ADVICE

Purpose

1. To provide you, as requested, with indicative cost estimates for potential scenarios which offer choice of either a lump sum or annual payments to those infected with HIV and/or hepatitis C through treatment with contaminated blood, as a basis for your discussions with fellow Ministers. This is described and costed in paras 9 - 10.

2. Our analysis shows that the up-front costs of such a change could be anywhere between £61m - £410m, and under some scenarios an increase in the annual financial allocation for the system may also be required in future years. Such high upfront costs, or increases in the annual allocation for the scheme, could not be met from existing budgets. In the absence of additional money and given the severe pressure on central budgets, we will need to consider what might be done to reform the current system to address the key concerns of campaigners and MPs, within the current, or lower, budget envelope of the system.

Recommendation

3. We recommend that:
   - Officials provide further advice on options for reforming the current system, within its existing budget envelope;
   - You agree an early way forward with the other UK Health Ministers (as they fund the hepatitis C payments for their populations), in readiness for the report of the Penrose Inquiry;
   - You discuss the proposal with the APPG on Haemophilia and Contaminated Blood; and then
   - A wider stakeholder engagement, together with assessment of the evidence base be undertaken, to inform the detail of any changes to the system.

Timing

4. Routine. The Penrose Inquiry has been delayed until early summer, by which time we also expect to receive the report of the systematic review of the hepatitis C evidence base.

The purpose of the schemes

5. The system is ex-gratia in nature because all payments are made without any finding of fault or liability for negligence or any other wrongdoing on the part of DH. Although never described by DH as compensation, the system is clearly compensatory in nature. Some payments appear to be made in recognition of the fact of infection, while others provide on-going support, or to compensate for loss. Payment levels are for the most part arbitrary, and, with some exceptions, not based on any assessment of impact or need. As a result, there is scope for establishing a more coherent and rational basis for the system, which would serve as the basis for more effective targeting of spending.

The cost of the current system – and the impact of new treatments for hepatitis C

6. These payments are a significant long-term cost against central budgets. Since 1988, over £330m has been paid to date, with our current estimate of the total lifetime cost of the existing scheme now approximately £840m, based on a more realistic model recently constructed by DH analysts, which enables the remaining costs over the lifetime of the system (estimated to be until 2080) to be estimated with greater confidence than previously. The new model indicates that our estimated future provisions for the existing schemes with no changes, will need to increase from c£385m to c£510m. This increase is due to a range of factors including: more people coming forward; additional people qualifying for the Skipton Fund stage 2 payments; and CPI uprating of the annual payments.

7. This expenditure factors in the potential impact for those affected of the new hepatitis C treatments coming onstream. Expectations of the potential benefits are high, and the first NICE appraisal of one of the new treatments is now getting underway, but it is currently too early to know if these products will be recommended for use on the NHS and, if so, what the precise net impact on the schemes might be. Although we would expect that far fewer people would move from Skipton Fund stage 1 to stage 2 and their life expectancy would increase. Consequently, we recommend that any changes to the system to provide additional support to people at stage 1 should be flexible enough to adapt to improvements in a person's health. The benefits to patients could arguably be offset against the payments made currently, and should therefore be taken into account in any revision of the existing schemes.

Offering people a choice of either a lump sum or an annual payment.

8. You requested a cost estimate for a simple choice between regular payments or a lump sum. **These are provided in paras 9 - 10 and Annex A for 3 groupings:**
   - **all infected individuals, (para 9 and Table 1 in annex A);**
   - **only the infected individuals currently receiving annual payments, (para 9 and Table 2 in annex A)**
   - **bereaved spouses/partners (para 10).**

   (As Background: **Annex B** provides a more detailed assessment of their respective merits and disadvantages. **Annex C** explains the existing system. **Annex D** shows what different groups among the beneficiaries currently receive. **Annex E** is the summary table provided in my submission of 3 December for comparison).

9. **Annex A** contains cost estimates of a range of potential scenarios. **Table 1** assumes the level of annual payment remains as now, uprated annually by CPI, and the lump sum offered is £150k per infection. This could potentially bring closure for a number of people, but not all. It would not be best use of public money to make a similar offer at present to those with less severe hepatitis C infection (who currently receive no regular payments), given that many in this group should benefit from the more effective treatments which we expect to become available shortly. These figures assume that all eligible recipients will successfully be contacted, and are therefore probably an overestimate. These cost ranges in this table are based on an estimate of what could happen if the new hepatitis C therapies are introduced. There is therefore a significant degree of uncertainty about some of the assumptions that underpin these estimates. **Table 2** therefore shows the indicative costs

if the same choice is offered only to those currently receiving annual payments (currently about 25-30% of those affected). This would therefore not satisfy many of the campaigners.

The key points to note **from Annex A** are:

a) The size of the initial lump sums for any of the scenarios: (ie c£61m - £410m), cannot be met from existing budgets given the severe pressure on central programme budgets, and would ultimately mean significant reprioritisation of other programmes of which the large majority are major policy commitments or legal/contractual commitments.
b) There might be scope for significant savings on future annual allocations to the schemes under the scenarios in table 2, compared to the current provision.
c) However, even if the lump sums are cheaper over the long term, they would not be affordable under any plausible scenario.
d) Only the scenarios in table 2 could offer cost savings over the lifetime of the system in all of these scenarios.
e) The potential cost savings accruing from the scenarios in table 2 will become increasingly marginal, the lower the % of people who take the offer of a lump sum. (We have no way of ascertaining how many people might take the offer, so it could well be less than 25%).

10. Finally, we have estimated the maximum cost of **a final payment of £20k to all existing bereaved spouses/partners now, to help support them in their remaining years to be £36m,** which will increase as further people are bereaved in future. These payments would be in addition to those identified in **annex A**.

Limitations of the cost estimates

11. We have had to make a number of assumptions to estimate the cost of the proposal , and so the figures have significant uncertainty around them. The key assumptions appear in **annex F**.

FINANCE

12. SofS has asked DH Finance to undertake a zero based review of all central programme budgets in 2015/16 in order to release savings to the front line. The savings needed to reach a balanced position in 2015/16 already look extremely challenging and it is of upmost importance to ensure any existing programmes provide value for money, taking account of future treatments and minimising disincentives to return to work. The costs presented in Annex A are unaffordable in the current financial climate and would require significant reprioritisation of other central programmes, of which the large majority are major policy commitments or legal/contractual commitments. Central programme budgets are coming under considerable pressure in both 2014/15 and 2015/16 in order to release savings to the front-line and to cover the high risk of the net provider position going into deficit. The view of DH Finance is that we should assess options for reforming the current system within its existing, or lower, budget envelope, ensuring value for money.

Possible way forward.

13. The preceding paragraphs identify major affordability issues associated with giving people a choice of either an annual payment or a lump sum. We know that there are two issues currently: the stage 1/stage 2 distinction for hepatitis C, which campaigners consider to be unfair, and the payments and

mode of operation of two of the three discretionary bodies, the Macfarlane Trust and the Caxton Foundation. As part of any review, a decision will be needed on whether a discretionary mechanism should remain, and whether it should continue to support bereaved spouses and dependants.

14. As you know, we have commissioned a systematic review of aspects of the evidence base on hepatitis C infection, which is due to report at about the same time as Penrose in the summer, which will inform decisions on further support for some of those at stage 1. The campaign groups are aware of the systematic review and have a legitimate procedural expectation that any policy changes will, at least, take account of the findings. Therefore, to offer the best chance of successfully withstanding judicial review, final decisions should await the outcome of the review of the systematic review and any consultation with MPs and the beneficiaries.

Requests for additional discretionary funding in 2014/15.

15. A matter on which we request your decision now, is whether you wish to provide additional discretionary funding in 14/15. The Caxton Foundation (hepatitis C) and the Macfarlane Trust (HIV) have both submitted business cases for uplifts in their financial allocations in 2014/15. Caxton is requesting additional funds in order to introduce a system of income top-ups, similar to that operated by Macfarlane. Caxton has assessed that many of its beneficiaries live on very low incomes. In contrast, Macfarlane is requesting additional funding largely in order to maintain its regular income top-ups at current levels, so that it can draw on its c£2m reserve to expand its system of grant payments.

16. The Macfarlane Trust is requesting an additional £1m pa, whilst Caxton is requesting an additional £500k in 2014/15 and a further £1m pa thereafter. While you are aware of the discontent about both bodies expressed by campaigners, they comprise a very small number of individuals amongst the beneficiaries of each body. In our judgment, the discretionary system provides support which is valued by many beneficiaries.

17. DH Finance are currently in the process of setting central programme budgets in 2014/15 which is extremely challenging given the need to find significant savings to release to the front line. Any additional pressures will need to be prioritised by Ministers against other pressures when considering the wider financial context.

We therefore do not recommend considering any uplift at the current time.

The Devolved Administrations

18. We could not change the payment system for hepatitis C without consulting the DAs, as we operate it on behalf of all four countries. The Penrose Inquiry, which is examining the circumstances surrounding these infections in Scotland, is due to report after March 2014. Scottish Ministers have committed to review hepatitis C payments as part of their response to Penrose. We recommend that you discuss the way forward with all of your counterparts in the Devolved Administrations. Your office has arranged a meeting with the Scottish Health Minister on 11 February, to discuss this.

Coalition Considerations

19. The Liberal Democrat manifesto at the last election contained a commitment to establish a working group involving patient groups to determine appropriate levels of financial assistance to those affected.

Conclusion and next steps

20. The high up-front costs of all the scenarios we have analysed cannot be met from existing budgets, even though there are some scenarios which would represent VFM over the longer term. Given the budget constraints, we are assessing options for reforming the current system within its existing, or lower, budget envelope. In the meantime, we recommend that you seek views from the other UK Health Ministers initially, and then Alistair Burt MP and the APPG on Haemophilia and Contaminated Blood.

21. Given pressures on central budgets we also recommend against the provision of additional funding for the system in 2014/15.

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ANNEX A

Table 1

% of people taking the lump sum	75%	50%	25%
2015/16	£400m (£390m - £410m)	£290m (£280m - £290m)	£170m (£167m - £176m)
2016/17	£21m (£21m - £22m)	£34m (£33m - £35m)	£46m (£44m - £48m)
2017/18	£19m (£18m - £19m)	£31m (£30m - £33m)	£44m (£42m - £46m)
2018/19	£17m (£16m-£18m)	£30m (£29m – £31m)	£42m (£41m - £44m)
2019/20	£16m (£16m - £17m)	£29m (£28m - £30m)	£41m (£40m - £43m)
Remaining cost over lifetime of scheme	£830m (£800m - £850m)	£950m (£920m - £990m)	£1080m (£1040m - £1130m)

This table includes all infected individuals.

Table 2

% of people taking the lump sum	75%	50%	25%
2015/16	£150m (£140m - £150m)	£110m (£100m - £110m)	£65m (£61m - £66m)
2016/17	£10m (£9m - £10m)	£14m (£13m - £15m)	£18m (£17m - £19m)
2017/18	£9m (£8 - £9m)	£13m (£12m - £14m)	£18m (£16m - £19m)
2018/19	£8m (£8m - £9m)	£13m (£12m - £14m)	£17m (£16m - £19m)
2019/20	£8m (£8m - £9m)	£12m (£11m - £14m)	£17m (£15m - £18m)
Cost over remaining lifetime of scheme	£410m (£390m - £430m)	£450m (£420m - £480m)	£490m (£460m - £530m)

This table includes people infected with HIV, and Skipton Fund stage 2 people only.

ANNEX B

A SYSTEM OFFERING EITHER A LUMP SUM OR ANNUAL PAYMENTS, BASED ON INFECTION

All infected individuals would be offered either a lump sum of £150,000 or an annual payment of £15k, uprated annually by CPI. The discretionary elements of the system would be abolished.

The 117 people who received compensation as a result of a court judgement against the Blood Service in 2001, would be excluded from these arrangements.

Pros

- Gives people choice.
- Offers potential for closure for a greater number of people, if the lump sums are big enough.
- Transparent and administratively easy to operate.
- Abolishes the discretionary elements of the system, which receive the greatest number of complaints.

Cons

- Cannot be afforded within existing budgets.
- People are unlikely to find the size of the lump sum acceptable.
- Approximately 350 people currently receive annual payments greater than £14,191, either because they receive annual payment from both Skipton Fund and MFET Ltd, or an income top-up from the Macfarlane or Eileen Trust. This choice may therefore appear coercive if it involves having to choose a lower annual payment.
- Abolishing the discretionary elements of the system means the system will become less flexible.
- Inconsistent with the evidence base, because people at Skipton Fund stage 1 who are experiencing no/few symptoms will receive an annual payment. The new therapies mean that fewer people should meet the stage 2 eligibility criteria in future.

ANNEX D

Group	Number of people	Payments per person
HIV with Skipton Fund stage 2	c50	£28k pa. Limited access to additional discretionary one-off payments.
HIV with Skipton Fund stage 1	c270	£14k - £19k pa.[1] Limited access to additional discretionary one-off payments.
HIV only	c55	£14k-£24k pa,[2] plus access to additional discretionary one-off payments.
Skipton Stage 2 only	c600	£14k pa, plus access to additional discretionary one-off payments.
Skipton Stage 1 only	c2,800	£20k one off lump sum, plus access to additional discretionary one-off payments.
Uninfected widows of people who died with HIV	c120	Income top up to £19k plus access to additional discretionary one-off payments.
Uninfected widows of people who died with HCV	c150	Access to discretionary one-off payments only.

[1] Comprises £14,191 from MFET Ltd plus up to a further £5,400 as a regular payment from the Macfarlane Trust, depending on household income.
[2] Comprises £14,191 from MFET Ltd plus up to a further £9,600 as a regular payment from the Eileen Trust, depending on household income.

ANNEX F

CONTAMINATED BLOOD COST ESTIMATES

This note provides more detail of the assumptions made to estimate the costs of the option presented.

Description of the approach

Under this approach , individuals are offered a choice of receiving *either* a single, one-off lump sum of £150,000, *or* regular payments until their death. We consider two alternatives: the first offers this choice to all individuals, regardless of their current Skipton classification, the second does not extend the offer to Stage 1 recipients. For both options, we assume that recipients who qualify for payment for infections with both HIV and Hepatitis C will receive twice the level of payment. We also assume that that the current payment of £50,000 to individuals at the time of registration to Stage 2, and the current discretionary payments will both stop, although we do provide a further set of estimates with the estimated costs of discretionary payments added back in.

We estimate the cost of making a single one-off payment of £50,000 to the widows or estates of deceased recipients, regardless of the original recipient's Skipton classification and whether they had one or two infections.

Impact of treatment

We are aware that some promising treatments for Hepatitis C are under consideration. We do not know when they will become available, and how many current recipients we will be able to contact and then treat without conflict with treatment for any other conditions. To provide an initial indication of what *might* be possible if treatment were to be highly-effective, we have assumed that we would be able to contact all current Stage 1 individuals who are also receiving payment for an HIV infection; all current Stage 1 recipients with haemophilia; and half the other current Stage 1 recipients. We have further assumed that all of these individuals will be able to receive treatment, and that this will be **95% effective in preventing progression to Stage 2**. However we assume that treatment will *not* affect the mortality rate of individuals whilst remaining at Stage 1 or after progressing to Stage 2 if this does occur.

We provide estimates of the resulting payments under both the current scheme and the suggested approach , assuming that the benefits of treatment will be realised from the beginning of the financial year 2014/15. The estimates do not include the cost of providing this treatment.

Uncertainties in estimating the cost

There are some uncertainties about the current and future status of recipients of funds, which lead to very great uncertainty in our cost estimates:

- There are major unknowns in rates of disease progression, especially in the numbers of people with Stage 1 HCV progressing to Stage 2. This is a major cost driver in the current scheme, and increasing availability of individual patient data has already led to significant increases in its estimated cost. Conversely, as indicated above, we also provide estimates for a scenario in which treatment will greatly reduce the rate of progression. We do not know how many current Stage 1 recipients will be traceable to offer the choice under the option involving payment to them. The figures provided represent a "worst case" scenario, where everyone is contacted. This is very likely to overestimate the cost.

Intelligent choice

Introducing choice further increases the uncertainty around the cost of the proposals. However, people do tend to act with some rationality, and so we have assumed that, among those who currently receive annual payments, those who will die in the first two years of a new system will have chosen to receive a lump sum. Where appropriate, we further assume that the proportion of Stage 1 only recipients accepting a lump sum will be the same as for current recipients of annual payments.

Behavioural research suggests that people tend to accept an immediate payment in preference to a slightly more advantageous scheme where some of the payment is deferred. This would tend to reduce the overall cost of a scheme, although also increasing the proportion of the cost that comes at the beginning. If substantial numbers were to accept the lump sum, this would reduce the uncertainty of the future costs by reducing the impact of uncertainties such as how long patients will survive.

At the moment, we have no indication of how likely a lump sum of £150,000 is to be accepted. We therefore provide estimates for illustrative scenarios in which 75%, 50% and 25% of recipients opt for a lump sum.

Other assumptions and requirements

We also assume the following:

- An individual with Stage 1 HCV who has chosen not to receive a new lump sum will receive a £50,000 lump sum and regular payments if they progress to Stage 2 (as now);

- Some new registrations will continue over the next few years. These individuals (and any who re-establish contact with the Fund) would be offered a choice of receiving a lump sum or the current regular payments and the lump sum;
- The system change would be implemented on 1 April 2015;
- Our costing should cover England rather than the whole of the UK; and
- No discretionary payments would be made under this proposal.

Health Protection Analytical Team 30 January 2014