1. PS(PH)

2. SofS

From: Ben Cole Cleared: Ailsa Wight Date: 11 July 2013 Cc: see list at end.

OPTIONS FOR REVIEW OF THE UK CONTAMINATED BLOOD PAYMENT SCHEMES – INTERIM ADVICE

Issue

1. Following your 15 May meeting with officials to discuss the HIV and hepatitis C contaminated blood payment schemes, you requested advice on replacing the current system with a no fault Quantum damages-based compensation scheme. You also asked for advice on a tariff-based system. Since then, SofS has also asked for advice on a system of equal sized annual payments for all infected people, rising incrementally to £25k pa. This submission sets out our preliminary assessment of these options, to date.

Recommendation

- 2. We recommend that you:
 - Consider and agree, the success criteria identified at para 5;
 - consider the options against the success criteria, and within the overall funding envelope available, as summarised in **annexes A-C**;
 - advise on whether you wish us to work up further detail for any of the option(s);
 - note that as hepatitis C payments (but not HIV payments which DH historically provides) are funded by all four UK administrations, you therefore write to the Health Ministers of the Devolved Administrations (DAs) to agree a UK- wide approach to any further work to improve the current system, (a draft is at **annex D**).

Timing

3. An early response would enable us to begin more detailed work.

Success criteria for issue to be addressed

4. The schemes were set up in recognition of the special circumstances of these infections. The policy aim is therefore to establish a system of financial support that is fair, reasonable and affordable for all those affected, especially those currently suffering from chronic hepatitis C infection but who have not developed severe liver disease. This should be based on the scientific evidence as far as practicable, and able

to be delivered within affordable resources. Nevertheless, campaigners argue that the current system does not meet their needs, and want full compensation.

- 5. To enable us to evaluate options, we have identified the following success criteria:
 - i) Cost;
 - ii) Acceptability to affected individuals;
 - iii) Extent to which it addresses the spectrum of ill health and/or need, of those affected;
 - iv) Extent to which it minimises payments to people experiencing few/no ill health effects, or who have little/no need; and
 - v) Extent to which it can respond to changes in a person's state of health. (New, more effective treatments for hepatitis C are currently under development, which may enable some people to resume employment).

Options and costs

- 6. The current system will cost an estimated £820m over the remaining lifetime of the schemes, (approx 50 years). We have worked up a preliminary analysis of three options for change:
 - Option 1 A system of equal annual payments for all infected individuals rising to £25k pa, costing £2.1bn over lifetime of the schemes;
 - Option 2 A quantum based system, costing £2.3bn over lifetime of the schemes;
 - Option 3 A tariff based system, costing £1.4bn over lifetime of the schemes.
- 7. An overview of the options is at **annex A**; a summary of how each option scores against the success criteria is at **annex B**, and detailed analysis of each option is at **annex C**.

Limitations of the cost estimates

8. It is impossible to accurately determine the cost of options 2 and 3 because there are insufficient data available about the client group. As a result, the estimated costs are based on a number of assumptions, for example, option 3 is likely to be a maximum cost because it assumes that no hepatitis C infectees who are suffering moderate/severe ill health is able to work. The assumptions are more fully set out in **annex E**.

Finance issues

9. Options 1 and 2 are unaffordable within DH budgets to the end of 2015/16. A business case could be made to Treasury if Ministers wanted to pursue these options, but within the context of recent spending round discussions and the wider picture on

Government-wide finances it seems unlikely that HMT would grant any request for additional funding.

10. Option 3 could potentially be funded from within existing DH budgets, but further work would need to be done to determine detailed costings. To fund it, Ministers would need to re-prioritise existing budgets to 2015/16, within the context of a tight spending review settlement. If there are higher costs in the longer term, then HMT agreement would be needed.

Discussion

11. Only option 2 (a quantum based system) has the potential to end the campaign, but we estimate it could require at least £2.3bn plus administrative costs. Option 1 (equal annual payments to all those infected) has the advantage of treating all infected individuals the same, but would involve making significant payments to people who are experiencing little/no ill health, and who may never do so with the expected advent of effective new treatments. Option 3 (a tariff system) links payments for all those infected by hepatitis C to their state of health, for the first time. However, we judge that it would do little to reduce campaigning activity. The existing system should improve as the Caxton Foundation gains a better understanding of the needs of the hepatitis C community and makes appropriate discretionary payments, but we judge that this will not reduce campaigning activity.

The Devolved Administrations

12. 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 later this year. Scottish Ministers have committed to review hepatitis C payments as part of their response to Penrose, and this will provide an opportunity to assess less radical changes. In order to maintain a UK-wide approach, we recommend that you invite the DAs to participate in any further work. A draft letter is at **annex D**. The letter does not refer to the HIV schemes because DH is their sole funder.

Conclusion

13. You are invited to:

- Consider and agree, the success criteria identified at para 5;
- Consider the options against the success criteria, and within the overall funding envelope available, as summarised in **annexes A-C**;
- Advise on whether you wish us to work up further detail for any of the option(s);
- Note that as hepatitis C payments are funded by all four UK administrations, you therefore write to the Health Ministers of the Devolved Administrations (DAs) to

agree a UK- wide approach to this further work to improve the current system, (a draft is at **annex D**).

Ben Cole Blood Safety and Supply Team

Cc:

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ANNEX A

OVERVIEW OF OPTIONS FOR CONSIDERATION

Option	Title	Description (and comment)	Estimated	Indicative cost		
			cost in	over lifetime of		
			2014/15	scheme.		
Baseline	The current	Two bodies providing annual payments of £14,191 to people with HIV and those most	£29.1m	£820m		
	system.	severely affected by hepatitis C. Three discretionary bodies to provide support to all those				
		affected, depending on need.				
		[Targets resources at those in greatest need, but does not adequately address the position				
		of hepatitis C infectees who are suffering moderate/severe ill health. Could be improved				
		to some extent with changes at the Caxton Foundation, which makes discretionary				
		payments to people infected with hepatitis CJ.				
Option 1	Equal sized	Annual payments of £14,191, to all HIV and hepatitis C infected individuals, with real	£75.8m	£2.055bn		
	annual payments	terms incremental increases of £1,000 pa to £25k. The existing system of discretionary				
	to all infected	payments would continue as it is.				
	individuals.	[Would meet the campaigners' intermediate aim, but it would mean people infected with				
		Hepatitis C but with mild/no symptoms, who are in employment, would receive regular				
		payments for life. Also, the campaign for full compensation would continue].				
Option 2	A quantum-based	A panel to assess all infected individuals, and pay damages as stipulated in the Judicial	£2.285bn			
	system.	•		The bulk of this cost is likely		
		[This is what the campaigners want].	to fall in the first few years.			
Option 3	A tariff based	The Skipton Fund would make payments to people with hepatitis C infection, according to	£72.3m	£1.420bn		
	payment structure	a fixed tariff. 1 - £20k lump sum for chronic infection, as now. 2 - £5k p/a if capable of	[Maximum			
	for hepatitis C	limited work. 3 - £10k p/a if incapable of work. 4 – Lump sum of £50k, plus £14k p/a for	cost –			
	infected	the most severe disease, as now. People would move between tariffs 1-3 as their health	assumes no			
	individuals only.	deteriorates/improves. Other elements of the existing system would remain as they are.	Skipton			
		[Has the advantages of the current system, and will also provide regular support for	stage 1			
		people at stage 1 who are suffering severe ill health. However, it will not resolve the	recipient is			
		fundamental campaign issue regarding stage $1-2$, and the use of evidence from the	able to			
		DWPs Work Capability Assessment will be controversial].	work].			

ANNEX B

ASSESSMENT OF OPTIONS AGAINST THE SUCCESS CRITERIA

Option	Title	Cost	Acceptability to infected individuals	Acceptability to other affected individuals	Responsive to extent of ill health/need	Minimises payments to those experiencing little ill health/need	Flexibility to adapt to changing individual circumstances.
Baseline	The current system.	Good	Poor	Poor	Intermediate	Good	Good
Option 1	Equal sized annual payments to all infected individuals.	Poor	Intermediate	Poor	Good	Poor	Poor
Option 2	A quantum- based system.	Poor	Good	Good	Good	Good	Good
Option 3	A tariff based payment structure for hepatitis C infected	Intermediate	Poor	Poor	Good	Good	Good

individuals			
only.			

ANNEX C DETAILED ANALYSIS OF THE OPTIONS

Option 1 - Equal sized annual payments to all infected individuals.

Annual payments of £14,191, rising by £1,000 in real terms to £25k per annum, and thereafter rising annually by CPI, to all infected individuals. Claimants would also be eligible for additional discretionary payments, as they are now.

Costs

• Estimated £2.055billion, over the remaining lifetime of the schemes.

Pros

- Addresses the stage 1- stage 2 issue. Treats all infected individuals the same.
- The mix of fixed and discretionary payments has flexibility to target additional resources at those in greatest need.
- Potential to significantly defuse political pressure.

Cons

- High cost.
- Not evidence based significant amounts of money would be paid to people with little/no ill health arising from Hep C infection.
- Builds dependency.
- Might take some of the political heat out of the issue, but it will not end the campaign because they want full compensation.
- Will still get complaints about discretionary mechanisms. There is a significant mismatch between the HIV and hepatitis C discretionary schemes.

Option 2 – A Quantum based system.

A no–fault compensation scheme that would pay damages at the same level as if the claimant had proven liability in court. A panel would assess claims for damages according to the Judicial College Guidelines (JCG).

Because of the progressive nature of the infections, particularly hepatitis C, the panel would need to operate over a period of time, and make additional payments to people if their health deteriorates.

Given that there is no legal obligation to pay such compensation, the system can operate in any way that the Department wishes.

What would it look like/how would it operate

- A panel of lawyers/medics/lay people to assess claims.
- A small admin team to support the panel.
- An appeals mechanism to consider appeals against decisions made by the panel.

The panel could make the assessment process a paper exercise only, but people may want the opportunity to address the panel. The Panel will not pay solicitors fees for claimants, but DH will fund a system of advocates to help claimants who might want support.

Who qualifies

Living infected people only, and the estates of people who had been infected with either hepatitis C and/or HIV and who have died.

Exclusions:

- People who have received compensation as a result of the Burton Judgement. (117 people).
- People who cleared hepatitis C in the acute phase.

How would damages be assessed

Damages would be assessed on the balance of probabilities. There are two sets of damages:

- 1. General damages for the infection and ill health effects arising from the infection.
- 2. Special damages for lost earnings, and on-going care needs etc. It is these damages which can potentially provide the biggest element of any award, depending on the claimant's personal circumstances.

Cost

• Estimated £2.285billion, over the lifetime of the scheme.

Pros

- Should largely draw a line under this. Although campaigners are also demanding an apology and admission of liability by the PM and a public inquiry.
- Fair and transparent.
- Evidence based will largely ensure that payments are proportional to ill health/ loss.

Cons

- Cost. Including increased administrative costs.
- Establishes a precedent for other things eg hepatitis B, people notified at risk of vCJD, and other BBVs.
- Will need to re-assess some people annually/as often as necessary.
- Potential risk that some individuals might exaggerate their symptoms to claim additional money, or claim that any ill health they experience is a result of hepatitis C. anecdotal evidence indicates that c80% of claimants in Ireland claim disabling fatigue, or else claim links between a range of extrahepatic conditions and their hepatitis C infection. This can be partly mitigated by setting clear boundaries on what the panel will pay, and having doctors on the panel who can rigorously scrutinise claims.
- Unless it covers those who have died, the campaign may continue in some form.
- Some people will be worse off than under the current system.
- Might disincentivise some people from moving back into employment, if their condition improves.

Option 3 – A Tariff based approach for the Skipton Fund

Under this approach the Skipton Fund would be reformed by introducing a system of tariffs for those affected by hepatitis C. (The wider system of payments would remain unchanged). It would employ a panel of clinicians to make case by case decisions of people with chronic infection and make payments according to a fixed four point tariff. Ability to work would be used as a proxy for determining the extent of a person's ill health. Claimants would be asked to provide evidence that their hepatitis C infection restricts their ability to work, (eg the outcome of their DWP Work Capability Assessment), to enable the panel to make decisions against the following tariff.

Point 1 – Chronic infection – lump sum of £20k.

Point 2 – Assessed as being capable of only limited work - annual payment of £5k.

Point 3 – Assessed as being incapable of work – annual payment of £10k.

Point 4 – Cirrhosis/liver cancer/B-cell non-hodgkins lymphoma. – lump sum of £50k plus annual payment £14,191k (as now).

Annual payments from points 2-4 to be uprated annually by CPI.

Everyone starts at point 1. If their condition deteriorates they would progress through the points on the tariff. If it improves, and they move back into work, they will lose their annual payments.

Cost

- Estimated £1.420billion, over the remaining lifetime of the schemes. Pros
- Will make substantial payments to people at stage 1 who are most severely affected and cannot work as a result of their HCV infection.
- Evidence based, using ability to work as a proxy for ill health.
- Will focus additional resources on those who really need it.
- Is flexible, so if people are cured/improve and move back into work, will not continue making annual payments.
- Maintains the discretionary schemes to target additional resources at those in need. (Although could reduce their funding to take account of the fact that the worst affected will be receiving a lot more in regular payments).

Cons

- Will not completely resolve the stage 1- 2 issue. Those at points 2 and 3 will argue that they should receive what those at point 4 do. Campaigners will not like the fact that it can be reversed if their condition improves.
- Use of ATOS assessments will be controversial, but it will not be the only evidence that claimants can provide.
- Higher admin costs, because of need to appoint a medical panel and pay them appropriately.
- How will it deal with people at stage 1 who are now past statutory retirement age, and are experiencing severe ill health, but had been forced into ill health retirement age some years ago?

Annex D

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FINANCIAL SUPPORT FOR PEOPLE AFFECTED BY CONTAMINATED BLOOD

As you are aware, the four UK Health Departments fund two ex-gratia payment schemes which provide financial support to people infected with hepatitis C by contaminated NHS supplied blood and blood products, and their families. You will also be aware that there is some dissatisfaction among campaigners with these arrangements. I share some of their concerns, and have therefore asked my officials to consider what can be done to improve these arrangements.

I would like to maintain a consistent approach across the UK. I therefore recommend that our officials work together to develop some options, with a view to providing all four UK Health Ministers with advice. If you are in agreement, my officials will set up a meeting with yours to take this forward.

I am writing in similar terms to Mark Drakeford AM and Edwin Poots MLA.

ANNA SOUBRY

Mark Drakeford AM Minister for Health and Social Services. Welsh Government 5th Floor Tŷ Hywel Cardiff Bay. CF99 1NA

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ANNEX E

PRINCIPAL ASSUMPTIONS USED IN ESTIMATING COSTS

Due to data scarcity and uncertainty, the models used to estimate the costs of each option rely on a number of assumptions. The most important assumptions are listed below, in no particular order:

- a. We assume that all discretionary and non-discretionary payments are held at current levels, after adjusting for inflation.
- b. We assume that the increased mortality risk from HIV/HCV infection is independent of age, and that no one lives beyond 100.
- c. We assume 3% of the stage 1 population progress to stage 2 per year.
- d. For the quantum system, we assume all awards are single payments with no annual pay component. We also assume that the amount awarded is independent of the amount previously received by current beneficiaries.
- e. Our quantum model also assumes that stage 1 individuals receive the average salary and both stage 1 and stage 2 incur the average care costs for their age, gender and quality of life. Stage 2 individuals are assumed to be unable to work.
- f. We assume that all infected persons are equally likely to present symptoms related to their infection, and that there is no variation in the severity of these of symptoms between individuals.
- g. For the tariff option, we assume that all stage 1 individuals receive the maximum payment, to provide a maximum possible cost.