To: PS(PH)		
	From:	Naomi Balabanoff, ID&EH
	Clearance:	Ailsa Wight, ID&EH
	Date:	24 June 2015
	Copy:	SofS, MS(CS)
		Others – see end

CONSULTATION ON REFORM OF BLOOD PAYMENT SCHEMES

Purpose

1. To recommend that you seek Home Affairs Committee (HAC) clearance to consult in England, Wales and Northern Ireland on reforming the system of financial assistance for those infected with HIV and/or hepatitis C via treatment with NHS-supplied blood products prior to 1991. Scottish ministers have recently advised that they do not wish to join the consultation.

Recommendation

2. We recommend that you:
    a. Consider how the consultation will be received (para 4);
    b. Agree the content of the consultation document, including the equality impact assessment (**Annex A)**;
    c. Consider and agree the Equality Impact Assessment to be published alongside the consultation (**Annex B**); and
    d. Note the Impact Assessment, to be published with the consultation (**Annex C).**

And, subject to your decision on how you wish to proceed:

   e. Write to Home Affairs Committee (**Annex D**);
   f. Write to the Health Ministers in Wales and Northern Ireland asking them the agree to the consultation (**Annex E**);
   g. Write separately to the Scottish Health Minister, Shona Robison (**Annex F**) to express your disappointment that Scotland is not joining the consultation;
   h. Agree the recommended pre-consultation stakeholder engagement (**Annex G**); and
   i. Agree the draft Written Ministerial Statement announcing the Consultation and responding to the Penrose Inquiry (**Annex H**).

Timing

3. **Urgent.** In order to publish the Consultation Document before summer recess we need to submit the Consultation Document to the HA committee as soon as possible and <u>by 26 June 2015 at the latest</u>.

Key points about the consultation proposals, and how they are likely to be received

4. The consultation highlights the grounds for reforming the existing system and demonstrates that the Department of Health has listened to the views of campaigners. The document sets out proposed principles for a new system, agreed at official level in England, Wales and NI, and shows how these principles could be met in practice by introducing individual assessment of the impact of infection on health to inform future payment levels (see **Annex A**). A summary of the key proposals and likely reaction to them is in the table below.

Our proposals	**Likely reaction**
Retarget long-term financial assistance so that *all* those who are infected, or suffering residual side effects from treatment, become eligible for assessment for regular payments.	Likely to be welcomed by MPs, and those with hepatitis C who do not currently receive regular payments. May not be welcomed by those likely to lose out.
Highest payment levels would be directed to those whose health is most affected, based on individual assessment.	Principle of individual assessment likely to be well-received by MPs/campaigners.
Health reviewed periodically to ensure assistance linked to impact on health over time.	Mixed. Principle of periodic review likely to be opposed by those who want financial certainty, or think their health could improve, leading to lower payments.
New system not charitable	Likely to be well-received by MPs/campaigners.
Replace existing 5 bodies with a single new body to run assessment process/administer payments	Likely to be well-received by MPs campaigners, but may be opposed by some of the existing schemes and beneficiaries who are satisfied with the current system.
Regular payments to uninfected family members phased out in the new system, although we invite proposals for some form of assistance to this group, subject to affordability	Mixed reaction expected, but with vocal opposition from many. Devolved Health Ministers are not keen on this proposal.

5. You will wish to consider the impact of the proposals in terms of your public sector equality duty (PSED). The most relevant protected characteristics for those infected are disability, sex (because the largest patient group infected have inherited bleeding disorders, which are more prevalent in men), and age (because the majority fit the 40-70 age profile, having been infected pre-1991).

6. The Equality Impact Assessment (**Annex B**), which will be published alongside the consultation, sets out our current view of how the proposals impact on groups within

the schemes who share protected characteristics. The impacts are largely positive for the proposed changes to the system for those infected, although there is likely to be a negative impact for people at either end of the age distribution, who cannot make up lost income through earnings.

7. The proposal to cease regular payments to uninfected family members could have a negative impact on individuals with protected characteristics within that population, especially where they might not be able to work because of age, or pregnancy, and it could disproportionately affect females. We are seeking further information and views the impact on all groups with protected characteristics through the equality impact assessment which will be published with the consultation
8. Despite the expectation that reaction to the consultation will be mixed, we consider that it is necessary to consult now because:
   a. It is important to demonstrate to campaigners that Government is fulfilling its pre-election commitment to reforming the payment system; and
   b. There are major legal risks in reforming the current system without a consultation, and it could also mitigate the impact of one aspect of the current litigation threat.
9. If you agree the content of the consultation document and questionnaire (**Annex A**), the Equality Impact Assessment (**Annex B**), and the economic Impact Assessment (**Annex C**), you will need to write to the Home Affairs Committee for approval to publish the consultation. A draft letter is at **Annex D**.

Devolved Administrations

10. Officials in the Devolved Administrations (DAs) have had the opportunity to comment on the consultation document as it has been written. In 2014, Ministers in the Devolved Administrations agreed in principle to a UK-wide consultation. Their officials have indicated there was concern over the principle of cutting support to some, including uninfected family members. It could become increasingly costly to extend the regular payments made now to some uninfected family members to those who do not currently receive them, and in a new scheme it would be discriminatory not to do so. Assuming the budget envelope remains broadly the same as now, it would also result in less money available to assist those infected, whom you agreed should be the priority.
11. Scottish officials advised on 19 June that, following publication of the Penrose report, their ministers have made a commitment that no-one would be disadvantaged through the review of the schemes. As a result, Scotland does not now wish to join the consultation, although does not rule out the continuation of joint working on a UK-wide scheme. Scotland is undertaking its own scheme review process, and will share results with us. A draft letter to Shona Robison MSP, should you wish to write to her, is at **Annex E**.

12. Regardless of whether agreement to a UK-wide scheme is ultimately possible, our lawyers advise that it would be for the DAs to decide whether to set up schemes in respect of those people who were infected by NHS blood/blood products in their countries, as this power is devolved. That also means that responsibility for HIV-related payments in a new scheme(s), whether UK-wide or not, would transfer to the DAs. (At present HIV payments are fully funded by DH, and we do not recoup the money from the DAs). We have made DA officials aware of this.
13. We recommend that you write to Health Ministers in Wales and Northern Ireland, seeking their agreement to participate in the consultation. A draft letter is at **Annex F.**

Finance

14. We continue to plan on the basis that the budget envelope for the scheme in future years will be about the same as now (£22.3m), although you are considering whether additional funding could be identified. Whatever the outcome of that, we recommend that consultation proceeds now on the principles for a new scheme.

Handling

15. We suggest that you lay a Written Ministerial Statement to announce the consultation and respond to the Penrose Inquiry, as agreed following Naomi Balabanoff's submission of 28 May and Philippa Snape's submission of 12 June. A draft WMS is at **Annex G**.
16. It will be important to prepare the way with key stakeholders ahead of consultation. Stakeholder engagement recommendations are at **Annex H**.
17. In terms of the consultation process itself, we suggest promoting and advertising the consultation through the Government website, the existing payment schemes, MPs and the APPG, and stakeholder interest groups such as the Haemophilia Society and Hepatitis C Trust. This should maximise engagement with the consultation, which should advance equality of opportunity and foster good relations between those sharing protected characteristics (under the Equality Act) and those who do not.
18. A wider communications handling plan will follow once the timing of the consultation launch is confirmed.

Conclusion

19. You may wish to discuss with No. 10 before deciding how you would like to proceed. However, we recommend that, having considered PSED (see paras 5-6, 14, and the Equality Impact Assessment at Annex A) you:
    a. Consider how the consultation will be received (para. 4);
    b. Agree the content of the consultation document and questionnaire (**Annex A**);
    c. Consider and agree the Equality Impact Assessment to be published alongside the consultation (**Annex B**); and

d. Note the (economic) Impact Assessment, to be published with the consultation (**Annex C).**

And, subject to your decision on how you wish to proceed,

e. Write to Home Affairs Committee (**Annex D)**;

f. Write to the Scottish Health Minister (**Annex E**);

g. Write to the Welsh and Northern Irish Health Ministers (**Annex F**);

h. Agree the draft Written Ministerial Statement announcing the Consultation and responding to the Penrose Inquiry (**Annex G**); and

i. Agree the recommended pre-consultation stakeholder engagement (**Annex H**).

Copy List

Sophie Roscoe (PS PS(PH))
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Chris Collinson, HPAT
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Frank Brown, Accountability & Regulation
Alex McLaughlin, CMO PS
Iain Finlinson, PS DG SER
Susy Wootton, Digital comms
Phill Morrison, Parliamentary
Peter Bennett, HPAT
Onur Yelekci, Equality team

ANNEX A: Consultation Document

ANNEX B: Equality Impact Assessment

ANNEX C: Economic Impact Assessment

ANNEX D: DRAFT LETTER TO HOME AFFAIRS COMMITTEE

Oliver Letwin, MP

Chair, Home Affairs Committee

(Copied to the Prime Minister, members of HAC and XXX)

[Date xxxxx]

INFECTED BLOOD: REFORM OF FINANCIAL AND OTHER SUPPORT

What the Department would like to do

The Department of Health (DH) is seeking agreement to consult on reforming the current system of ex-gratia financial support for people infected with, or affected by, HIV and/or hepatitis C as a result of treatment with NHS supplied blood or blood products prior to September 1991. Of the five schemes within the current system, which operates on a UK-wide basis, each country funds its own share of schemes for hepatitis C, but DH funds the HIV scheme costs for all four countries. If a new system is established, responsibility for funding HIV payments (as well as hepatitis C payments) will lie with each country.

A copy of the consultation document and an impact assessment are attached to this letter.

Purpose of the policy

The purpose of the consultation is to inform proposals to reform the system of financial and other support. We are proposing that the reformed scheme should be focused on the provision of financial assistance to surviving infected individuals; based on the impact of these infections on the health of infected individuals. Individuals would receive payments on the basis of an individual health assessment which would be linked to the level of ill health they experience as a result of their infection, or as a residual side effect of treatment. We are also proposing to gradually phase out ongoing financial support to uninfected family members.

Health assessments would be undertaken at regular intervals to ensure that payments remain in line with health status. This would enable the system to respond where a person's health deteriorates, or improves, perhaps as a result of new treatment. It will also enable DH to review the overall financial allocation within the context of its other funding priorities.

The aim of reforming the current system of ex-gratia financial support is to introduce a scheme which is **focused** on the provision of support to surviving infected individuals; **evidence-based** through being informed by current scientific and medical knowledge of HIV and hepatitis C and the impact of these infections on the health of infected individuals; and **efficient and effective**, for example, by introducing a unified and transparent process administered by a single body. Such a body could operate on a UK-wide basis, subject to future discussion with the Devolved Administrations. My officials have been working with counterparts in Scotland, Wales and Northern Ireland. Scotland has recently decided not to participate in the consultation, but I expect it to include Wales and Northern Ireland and I shall be writing to the Health Ministers separately to seek their agreement.

Timing

Responses are requested by Friday 10 July so that we can publish the consultation before the Summer recess.

Background on the policy

Before heat treatment of blood products was introduced in 1985, and a test for hepatitis C for whole blood donors was developed and introduced in 1991, around 5,000 people with bleeding disorders (such as haemophilia) in the UK were exposed to hepatitis C as a result of NHS-supplied blood products during the 1970s and 1980s. Published epidemiological estimates suggest that up to around 28,000 other individuals might have been infected with hepatitis C through whole blood transfusions in the UK.

Approximately 1,200 people with bleeding disorders and 100 other individuals were infected with HIV by NHS-supplied blood products or blood transfusions in the UK before the introduction of heat treatment of blood products, and the development and introduction of a test for HIV, in 1985. Some people were co-infected with both hepatitis C and HIV.

Beginning in 1988, the UK government has established a number of schemes at different times to provide financial and other support, as set out below.

Schemes that currently support those affected by HIV

- The Macfarlane Trust
- This is a charity funded by the Department of Health which was established in 1988 to provide discretionary support to individuals with bleeding disorders who contracted HIV (including those co-infected with hepatitis C) as a result of treatment with plasma derived blood products, any person that they in turn may have inadvertently infected, and their families. It currently provides means-tested regular top up payments to primary beneficiaries and means-tested regular top up payments to bereaved spouses/partners. For both schemes the Macfarlane Trust take into account the household income (with the exception of any children over 25 living with an infected beneficiary or bereaved spouse/partner, where only 50% of their income is included). The Macfarlane Trust also provides a means tested winter payment, and a small number of individual grant payments. Its payments policies are set by its Trustees within the funds allocated by government. In addition to financial support it also provides benefits advice and in the past has hosted annual weekend events for its beneficiaries. Eileen Trust

  This is a charity funded by the Department of Health, which was established in 1993 to provide discretionary support to individuals who contracted HIV (including those co-infected with hepatitis C) as a result of a transfusion with whole blood, and for their families. The Trust provides financial support in the form of means tested regular payments to some beneficiaries, one-off grant payments, and a fixed rate winter payment. Its payment policies are set by its Trustees. In addition to financial support, the Trust also hosts an annual weekend event for its beneficiaries.
- MFET Ltd
- This is a company limited by guarantee, funded by the Department of Health and established in 2010 which provides non-discretionary annual payments (£14,749 in 2015/16) to all those infected with HIV as a result of treatment with NHS supplied blood or blood products, and any person that they in turn may have inadvertently

infected. The size of this payment is set by the Department of Health, and it is currently uprated annually in line with the Consumer Price Index (CPI).

- MFET Ltd also reimburses the cost of an annual prescription pre-payment certificate (PPC) to enable an individual living in England to receive free prescriptions.

Schemes that support those affected by hepatitis C

- Skipton Fund Ltd

  This is a company limited by guarantee, funded by the four UK Health Departments and established in 2004 which provides non-discretionary payments to individuals infected with hepatitis C as a result of treatment with NHS supplied blood or blood products. The fund makes payments in two stages:

  - Stage 1: a single lump sum of £20,000 for all individuals with chronic hepatitis C;
  - Stage 2: an additional non-discretionary lump sum of £50,000 and an annual payment (£14,749 in 2015/16, currently uprated annually by the Consumer Price Index (CPI)), for individuals with cirrhosis, primary liver cancer, B-cell non-Hodgkins Lymphoma or who have undergone, or are on the waiting list to undergo, a liver transplant.

The size of the annual stage 2 payment is set by the four UK Health Departments, and is currently uprated annually in line with the CPI.

The Skipton Fund also reimburses the cost of an annual prescription pre-payment certificate (PPC) to enable an individual living in England to receive free prescriptions.

- Caxton Foundation

This is a charity funded by the four UK Health Departments established in 2011 providing discretionary support to all individuals infected with hepatitis C through treatment with NHS-supplied blood or blood products, and their widows and dependents. It operates on the basis of providing means-tested grants and winter payments; the amount that a beneficiary receives is a set amount depending on the household composition, with households with more people in receiving a higher payment. Its payments policies are set by its Trustees. The Caxton Foundation now provides individual grants to top up the income of beneficiaries. In addition to financial support it also pays for referrals to debt and benefits advisors. The system lacks uniformity and there are inequities between some elements of the system. As time has gone by, our knowledge of the impacts of living with HIV and hepatitis C infection has also increased, and it has become increasingly apparent that the current payments do not adequately reflect the wide spectrum of ill health experienced by those affected.

Regulatory impact

'Infected blood: Reform of financial and other support' concerns the payment of money from the Department of Health to individuals. As a financial transaction, it does not concern the regulation of business and hence falls outside the scope of Regulatory Reform and the Business Impact Target. There are no impacts in business or civil society.

Devolution

The existing system is UK wide. DH is the sole funder of the HIV schemes, but the DAs pay a share of the administrative costs for the hepatitis C schemes and the full cost of payments to beneficiaries in their respective territories. Officials have liaised closely with the DAs in drafting the consultation document, and I will be writing separately to the other Health Ministers to request formal agreement to consult on a UK wide basis. DAs are aware that if a new payment scheme were to be set up the SofS for Health does not have the power to make payments in relation to those infected outside of England.

ANNEX E: DRAFT LETTER TO SHONA ROBISON

Shona Robison, MSP
Cabinet Secretary for Health and Well Being
Scottish Government House
Regent Road
Edinburgh
EH1 3DG

INFECTED BLOOD: PROPOSALS FOR REFORM OF EX-GRATIA PAYMENTS

You will be aware that our officials have been working closely together to develop some proposals for a public consultation on how we might reform the system of ex-gratia support for those infected with HIV and/or hepatitis C through treatment with NHS-supplied blood or blood products.

I was [disappointed/sorry] to hear that Scotland has withdrawn from the planned UK-wide consultation. I understand that since Lord Penrose reported, you have decided to institute a different consultation process, and have made commitments in Scotland.

England intends to proceed with a public consultation, and I shall be inviting Welsh and Northern Irish colleagues to join that process.

I am pleased that our officials have agreed to share the outputs of our two separate processes.

Cc:

Mark Drakeford AM

Simon Hamilton MLA

ANNEX F: DRAFT LETTER TO HEALTH MINISTERS OF THE DEVOLVED ADMINISTRATIONS

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

Simon Hamilton, MLA
Department of Health, Social Services and Public Safety
Castle Buildings
Stormont
Belfast
BT4 3SJ

INFECTED BLOOD: CONSULTATION ON REFORM OF THE SYSTEM OF EX-GRATIA FINANCIAL ASSISTANCE

I wrote to you last June to let you know that I had been giving some thought to how we might rationalise the system of financial support for people infected with HIV and hepatitis C by treatment with contaminated NHS supplied blood or blood products prior to 1991, and their families.

Our officials have been working closely together to develop some proposals for a consultation exercise. I am pleased to say that we have now reached the stage where we are ready to go to consultation with the beneficiary community and other stakeholders on our proposals. I have attached a final copy of the Consultation Document, together with a draft Impact Assessment.

It would be beneficial if the Consultation could be issued on a three-country basis with the endorsement of your Health Departments. I would therefore welcome your agreement that you are content to proceed on this basis. Our officials can then continue to work together to analyse the responses and identify a way ahead.

I am writing in similar terms to [ ]

Cc: Shona Robison MSP

ANNEX G: DRAFT WRITTEN MINISTERIAL STATEMENT – JULY 2015

INFECTED BLOOD AND PENROSE INQUIRY

[719 WORDS]

Made by: The Secretary of State for Health (Jeremy Hunt)

On 25 March 2015, the Prime Minister and I expressed how sorry we are to those infected with HIV or hepatitis C, or both, through treatment with NHS supplied blood or blood products before September 1991. I would like to say again on behalf of this Government, how sorry we are for what happened, and for the pain and grief caused by the consequences of treatments that were intended to save or improve people's lives. In March, we said we would consider the report of Lord Penrose's public inquiry in Scotland. In our view, the report represents a thorough and detailed investigation into the infection of individuals through treatment with blood and blood products in Scotland, which is also of relevance for the Westminster Government as the events in question occurred before devolution. The Inquiry did not identify any systemic failings and reflects on how clinical practice at the time was different to practice today. This report, together with over 5000 documents from the period from 1970-85 that we have already released into the public domain, and the further documents from 1986 – 1995 that we shall be releasing this Summer, provides a comprehensive picture of events and decisions made.

Lord Penrose's single recommendation was to take all reasonable steps to offer a hepatitis C test to everyone [in Scotland] who had a blood transfusion before September 1991 and who has not been tested for hepatitis C. In England, GP guidance[1] already recommends offering a hepatitis C test to patients who received a blood transfusion in the UK before 1991 or were treated with blood products before 1986. [DN – depending on option chosen: The Department will be acting to ensure that GPs are reminded of this guidance and that early diagnosis will help prevent patients from developing to more serious liver disease.]

Lord Penrose made no comment on financial support for those affected by infected blood. However, I, and other Health Ministers, have heard concerns about the existing arrangements and have been considering for some time how we might improve that support. These include issues, as highlighted by many Honourable Members in this House and the All Party Parliamentary Group on Haemophilia and Contaminated Blood's Inquiry report, such as the complexity of the different organisations, the criteria for payments and the charitable nature of some payments. Having considered these concerns and how we might address them, I am pleased to announce today a consultation in England, Wales and Northern Ireland, seeking views on reforming that support.

The focus of the consultation is on principles and structure rather than levels of payment. As I/we said in March, the challenge for Government is to identify the most appropriate

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[1] 'Guidance for the prevention, testing, treatment and management of hepatitis C in primary care' (2007) http://www.rcgp.org.uk/clinical-and-research/clinical-resources/~/media/Files/CIRC/Hepatitis-C-guidance-2008.ashx

way of targeting financial assistance, whilst ensuring that any system can be responsive to medical advances and is sustainable for Government in financial terms.

To create a new and fair system, we propose that it should be:

- focused on the provision of support to surviving infected individuals;
- evidence-based through being informed by current scientific and medical knowledge of HIV and hepatitis C, and the impact of these infections on the health of infected individuals; and
- efficient and effective, for example, by introducing a unified and transparent process administered by a single body across the UK.

We consider that, with limited funds available, this is the fairest approach to targeting support to those affected by this tragedy of modern healthcare.

Regarding the additional £25m that we announced in March 2015 to support transition to a reformed scheme, we will consider responses to the consultation before announcing plans for use of that money. However, I confirm that we do not intend to use it for the administrative costs that might be associated with closing down the existing schemes.

Finally, I would like to turn to the exciting advances in treatment for those with hepatitis C. Last month, I was very encouraged to see NHS England implement its Interim Commissioning Policy for the treatment of chronic hepatitis C in patients with cirrhosis with the new highly effective therapies. Thousands of patients in England with cirrhosis caused by the hepatitis C virus are now able to access new treatment options to prevent further damage to the liver, including the potential of end stage liver disease or cancer.

ANNEX H: RECOMMENDED CONSULTATION-RELATED STAKEHOLDER ENGAGEMENT

Critical Stakeholder Engagement for Consultation of Scheme Reform.			
Key Stakeholder group to be engaged	**Who Should Engage**	**How Should Engage**	**When should engage**
APPG on Haemophilia and Contaminated Blood Co-chairs (Diana Johnson and Peter Bottomley)	PS(PH)	Face to face meeting	Before consultation begins
Chairs and Company Directors of the current five schemes.	PS(PH)	Meeting with Chairs/ Directors (3 key people) to introduce concept of system-wide reform and reasoning behind it, without disclosing details.	Before consultation begins
Haemophilia Society	Officials	Meeting with Liz Carroll (Chief Executive)	Immediately before consultation begins
Haemophilia Society (Optional)	David Prior (PS(P))	Meeting with Baroness Meacher (President of Haemophilia Society)	Immediately before consultation begins
Hep C Trust	Officials	Meeting with Charles Gore	Immediately before consultation begins
All MPs	PS(PH)	Letter to all MPs explaining consultation and case for reform	On day of announcement / launch of consultation
Patient Groups	MPs in constituencies, APPG	Engagement activities, MP surgeries in constituencies, workshops/ focus groups	During consultation period – July to October