To: PS(CMH)

From: Laurie Mousah
Clearance: Clara Swinson, Director General
Date: 23 June 2017
Copy: Samuel Beckwith
Private Office Submissions Copy List

INFECTED BLOOD PAYMENT SCHEMES – CONSULTATION RESPONSE 2017

Issue	Ministerial clearance is required to proceed with writing to the chair of the relevant Home Affairs Committee (HAC) to agree cross government clearance so that the Government consultation response on reform of the longstanding, ex gratia infected blood payment schemes can be published. HAC clearance normally takes 2 weeks to allow for comments from other government departments to be taken on board and clearance to be given.
Timing	Urgent (two working days) For all timing requests, please provide reason: HAC clearance must be secured before publication of the Government response before summer recess [redacted]
Recommendation	1. That you approve for cross government clearance publication of the following documents attached to this submission: • Draft consultation response • Impact assessment and Equality impact assessment • Draft letter to HAC 2. That you agree to seeking No10's views before proceeding with HAC clearance. 3. That you note the handling issues.

Discussion

Background

1. In January 2016 the Government consulted on proposed reforms to the existing payment schemes, to streamline the system and improve fairness. The response published in July 2016 introduced:

- an annual payment for those with non-severe (stage 1) hepatitis C (HCV) infection.
- uplifts in annual payments for those with HIV and/or severe HCV
- a new £10,000 one off payment to bereaved partners and
- steps to transition to a single scheme administrator (since named as NHS Business Service Authority (NHSBSA)).

The history and background to the reforms are set out in the introductory chapter of the accompanying consultation response document.

Judicial review

2. [redacted]

3. [redacted]

[redacted]

4. [redacted]

5. [redacted]

Consultation in 2017

6. The draft response to the 2017 consultation attached to this submission is based on the analysis of the 253 consultation responses (the affected population in England is circa 4,000). This is significantly fewer than responded to the initial 2016 consultation (1,558). The largest group of respondents (33% of the 253) were those with non-severe HCV.

7. [redacted]

Key ongoing issues

8. There is likely to be some disagreement among beneficiaries in the following areas:

Question	Response	Recommendation
Respondents were asked if they agreed with our proposals for the SCM process.	31% of respondents agreed. Those who did not agree commented on their concerns about the impact on the budget and the difficulties in ensuring assessments were fair.	Keep this proposal. [redacted]
Respondents were asked about our proposed allocation of funding. This included removing the uplifts planned for 2018/19 and keeping the £50,000 lump sum reserved for those who meet the criteria for severe (stage) HCV.	26% of respondents agreed. Those who did not agree commented on the need for a bigger budget, that those with HIV and those who are co-infected would be most impacted by the proposed allocation and the need to maintain the discretionary fund. No-one commented on the £50,000 lump sum being reserved for those who meet the stage 2 criteria.	Keep this proposal. The proposals ensure that nobody who receives an annual payment will see that annual payment decrease. It is also the fairest allocation of payments within the overall budget envelope.
Respondents were asked which elements of discretionary support they found most useful.	Respondents were supportive of all the suggestions (with at least 20% support for each).	Keep the proposal to reform discretionary support. This will create consistency and allow flexibility in the budget

		in the event a large number of people are eligible for the higher payments through the SCM.

Finance – cleared previously by Andrew Baigent

9. HMT has previously expressed concern about the long-term financial sustainability of the scheme beyond this SR period. Depending on future SR settlements, there is a risk the proposed reforms could then not be maintained. As the scheme is ex-gratia, it is not subject to the usual discussion on value for money (VFM). However, the proposals still aim to achieve the best VFM by benefiting the maximum number of beneficiaries. The DH Finance Director has previously confirmed that the scheme is affordable in the period of the SR.

10. It has been made clear that there would be a review of the workings of the scheme at the end of the current SR period in 2020/21, to inform the next government's discussions of affordability. Some respondents expressed concern that this meant support was not guaranteed for the remainder of their lives.

Legal – cleared by [redacted]

11. [redacted]

12. [redacted]

Legal duties

13. In considering policy, ministers must take into consideration the **Public Sector Equality Duty** (PSED) as set out in the Equality Act 2010 and the requirements of the **Family Test**. Details are at **Annex B**. In reaching your decision on the consultation, you must have due regard to the PSED which is to:
    - eliminate discrimination, harassment, victimisation and any other conduct that is prohibited by or under the Equality Act 2010;
    - advance equality of opportunity between persons who share a relevant protected characteristic and persons who do not share it; and
    - foster good relations between persons who share a relevant protected characteristic and persons who do not share it.

Communications – cleared by Naomi Stanley

14. Once HAC clearance is in hand, press office will produce a handling plan reflecting the current media climate at the time. Key messages will most likely focus on the benefit of the SCM for those with non-severe (stage 1) HCV, coupled with efforts to streamline the administration of the schemes. There is a very vocal group of campaigners who will likely criticise any Departmental activity as not going far enough. Press office will point media towards the Written Ministerial Statement or oral statement for the finer details of the announcement. A detailed Q&A will be provided nearer the time.

Parliamentary handling

15. If you are content with the attached documents it is recommended that you seek No.10 agreement before HAC write-round.

16. Increased parliamentary activity and correspondence will result when the consultation response is published. It is therefore recommended that you speak with the co-chairs of the relevant APPG (on haemophilia and contaminated blood) before publication.

Conclusion

17. In summary, you are asked to confirm that you are content with the:
    - package of reforms as per the draft consultation response and the IA/EqIA
    - draft HAC letter
    - proposed handling

18. If so, a detailed handling plan will be provided.

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Annex A

Elements of the consultation

1. We consulted on the following core elements of scheme reform:

   a. Addition of membranoproliferative glomerulonephritis (MPGN) to the current HCV stage 2 conditions. [*Q4 in consultation*]
   b. Introduction of the SCM [*Q5 in consultation*]
   c. Reformed discretionary support for the infected [*Q7 in consultation*]
   d. The proposed allocation of available funding [*Q6 in consultation*]

Addition of MPGN to the current HCV stage 2 conditions

2. Historically, those with chronic HCV stage 1 who develop advanced, cirrhotic HCV relative liver disease (stage 2) have been eligible for the higher level of annual payment and a one-off payment of £50,000. This has been based on the greater level of need of those with HCV at stage 2.

3. Based on advice from a reference group, including medical experts, we proposed the inclusion of type 2 or 3 cryoglobulinemia accompanied by MPGN, to the HCV stage 2 criteria. MPGN is a known complication of HCV which has comparable or even greater negative impact on life expectancy when compared to cirrhotic liver disease or its complications.

4. This means that HCV stage 1 beneficiaries who have been diagnosed with MPGN would be eligible to apply for the higher HCV stage 2 annual payment and will also receive the one-off £50,000 lump sum payment. Due to the low numbers of people with this condition, its inclusion in the HCV stage 2 criteria does not represent a risk to the overall affordability of the scheme.

Introduction of the Special Category Mechanism (SCM)

5. The SCM was first referenced in the July 2016 consultation response. Its original intention was to enable stage 1 beneficiaries to receive the same annual payment as stage 2 beneficiaries, where they were experiencing an equivalent impact on their health as a result of their HCV infection.

6. [redacted] we have now broadened the criteria for the SCM, to enable a wider group of stage 1 beneficiaries to benefit from it. The SCM will consider any significant and sustained adverse impact of HCV infection (or its treatment) on the ability of an individual to carry out routine day-to-day activities.

7. Stage 1 beneficiaries would complete a voluntary paper based application form and would be required to provide evidence against the above criteria. Their medical practitioner would also be required to provide evidence. If successful in their application, the beneficiary would receive an increased annual payment, equivalent to that of a stage 2 beneficiary (£15,500). Our proposal included the ability to appeal against a decision not to approve the application.

8. We have further developed our proposal to ensure that all appeals are considered by a relevant medical expert. An applicant who receives a final unsuccessful decision will be able to reapply for the SCM six months after their initial application if further or new evidence is provided.

9. Furthermore, as the reformed scheme and the SCM application process is scheduled to go live on 2 October 2017 when NHSBSA takes over the current arrangements. It is likely that a significant number of applications will be received in the early weeks of the new schemes operation. To help manage this and to manage beneficiaries' expectations, we propose that all SCM applications in this initial phase must be received within eight weeks. Successful applicants who apply within eight weeks will receive SCM payments backdated to 2 October 2017. Successful applicants who apply after this date will receive payments backdated to the date of application.

Reformed Discretionary support

10. The reformed scheme will also include a revised discretionary support system that provides additional financial and non-financial support to beneficiaries and their families beyond annual payments.

11. We know that discretionary support is valued by beneficiaries and their families and we are also aware that in some cases, beneficiaries have become accustomed to regular on-going financial support through the discretionary support system and have become reliant on it. This has never been the intention or purpose of the discretionary support system. We are also aware of inconsistencies in the level of financial support provided by the discretionary element of each of the support schemes.

12. To address and overcome these challenges in the new scheme we have set out a clear purpose statement for the new streamlined discretionary element of the single reformed payment scheme, reflecting the principles for the scheme that were set out in the consultation. We have also included a further principle of sustainability to ensure the on-going affordability of the scheme and to encourage financial independence wherever possible.

13. In order to achieve this, and to continue to provide discretionary support that respondents value, we propose that the reformed scheme will provide all of the elements of discretionary support that were set out in the consultation. NHSBSA as the new scheme administrator will conduct a review of all regular on-going payments, such as income top-ups, assessed against overall need and income. On-going support will continue to be considered and provided through means tested income top ups, but to be fair, and give consistency and affordability, some individual payments are likely to be at a lower level than some of the existing payments and will be reappraised on an annual basis from the financial year 2018/19 to ensure a model with greater sustainability. Where payments will be discontinued or reduced, the move will be phased in over a period of time in order to avoid an immediate reduction in payments received.

Support for the bereaved

14. We propose that all bereaved partners/spouses continue to be able to apply for discretionary support under the new discretionary scheme described above. This would ensure those who are in most financial need continue to receive support under a reformed scheme. In recognition of the particular difficulties bereaved partners/spouses may have in adjusting to their new situation, and as they are not in receipt of regular annual payments, we propose that any reduction in regular discretionary payments be phased in over an extended timescale. Additionally, a new provision set out in the July 2016 consultation response has meant that newly bereaved partners or spouses are eligible to apply for a one-off £10,000 lump sum payment.

Allocation of available funding

15. In order to ensure that the overall scheme stays within the annual budget of £46.3m for the SR period, given the introduction of the SCM; the consultation proposed that the annual payment uplift that had been announced in July 2016 would no longer happen. It also proposed that the £50,000 lump sum payment would remain reserved for those who develop a with hepatitis C stage 2 condition.

16. In the consultation response we have retained both of these proposals.

Summary of responses

17. This proposal to include **MPGN** in the HCV stage 2 criteria is uncontroversial and was supported by 48% of respondents. Of the 35% who said they did not know whether they agreed with the proposal, the most common reason for their response was a lack of medical expertise.

18. 31% of respondents were supportive of the proposal for the **SCM**. Of the 46% of those who were not supportive common reasons for this were that an increased annual payment should be provided without the need to provide evidence and scepticism around the transparency and fairness of the application process.

19. The consultation proposed a number of different elements of **discretionary** support, all of which received support from beneficiaries. Although, some beneficiaries did comment that the annual payments should be higher to prevent the need for discretionary support.

20. 25% of respondents thought that the **proposed allocation of funding** would allow us to make best use of available funding. The most common themes amongst those expressing concerns were that more money should be made available to the scheme, that those infected with HIV and those who are co-infected would be the most impacted by the proposals and the discretionary fund needed to be maintained. There were no significant comments on the £50,000 payment remaining reserved for those who develop a with hepatitis C stage 2 condition.

21. There was some support for all proposals within the consultation. Analysis of the comments, including those who did not respond positively to the proposals, demonstrates that the main concern is about the fixed budget and the impact on those who already receive the higher annual payment amount.

Annex B

Statutory duties

1. The consultation proposals are designed to mitigate the potential risk that the reformed scheme is discriminatory towards those with protected characteristics and towards families. Our analysis of the proposals is set out in the draft Equality Analysis (attached separately). In brief:

- A key equality issue which underpins the consultation proposals is whether those who are disabled under the Equality Act as a result of stage-1 HCV infection are unlawfully treated differently from those with HIV. We developed the SCM to minimise the risk that the reformed scheme is discriminatory on disability grounds in respect of the HIV / HCV difference.
- A second issue concerns the loss of the annual payment uplift. This will impact the most on those with HIV and/or HCV stage 2 disease, who are disabled and also likely to represent the cohort of beneficiaries most sick. To mitigate any negative impact, the reformed discretionary scheme will be designed to be responsive to individuals' needs including those who are disabled and most in need.
- Regarding the impact on the proposals for the reformed discretionary scheme, we do not consider that there would be an unfair or negative impact on beneficiaries on the basis on the basis of gender, age, disability or any of the other protected characteristics.
- We consider our commitment to protect the discretionary scheme as far as possible is likely to impact positively on beneficiaries and their families.

2. In conclusion, we believe that our proposals are fair and reasonable, and necessary in order to preserve levels of support provided to all groups of beneficiaries including through the discretionary fund, which we know is valued by beneficiaries and their families.

3. Ministers also have a duty to comply with the **duties in the NHS Act 2006**. Of these, we have considered in particular:

- Duty to have regard to the NHS Constitution. This largely concerns the delivery of NHS services. However, in so far as it is a principle of the Constitution that "We value every person – whether patient, their families or carers, or staff – as an individual, respect their aspirations and commitments in life, and seek to understand their priorities, needs, abilities and limits", the consultation proposals are consistent with it.
- Duty to have regard to the need to reduce inequalities. This does not apply because the infected blood scheme is not intended to alter access to health service benefits for scheme beneficiaries.
- We consider that the other duties in the Act (duties to promote autonomy, research, and education and training, and to report and review treatment providers) are also not relevant in this context.