Department of Health

SUBMISSION TEMPLATE

CLEARANCE CHECKLIST

Inclusion of this checklist is mandatory. A submission without it will be sent back. Please complete the whole list. Private office will remove before putting submission in the box.

Finance:
Does this involve any spending or affect existing budgets?
☑ If yes, named finance official: Andy McKinley

Legal:
Does this include legal risk, a court case or decisions that can be challenged in court?
☑ If yes, named official: Clare Martin

Communications:
Could this generate media coverage, or a response from the health sector?
☑ If yes, named official: Marc Masey

Analysis and data fact-checking:
Does this include complex data, statistics or analysis?
☐ If yes, named official: Click here to enter text.

Commercial:
Does this include commercial or contractual implications?
☐ If yes, named official: Click here to enter text.

Devolved Administrations:
Will this affect Scotland, Wales or Northern Ireland?
☐ If yes, named official: Click here to enter text.

Strategy Unit:
Does this relate to cross-cutting or longer-term implications for wider DH strategy?
☐ If yes, named official: Click here to enter text.

Implementation Unit:
Does this relate to one of the Secretary of State priorities?
☐ If yes, named official: Click here to enter text.

Duties, Tests and Appraisals:
The following tests apply and have been considered. The submission reflects our consideration (and/or confirms when we will provide detailed advice)

☑ Secretary of State Statutory Duties, including on health inequalities
☑ Public Sector Equalities Duty
☑ Family test
☐ Other(s) (please specify) Click here to enter text.

To: PS(CMH)

From: **Laurie Mousah**
Clearance: **Clara Swinson, Director General**
Date: **12 September 2017**
Copy: Georgina Johnson
Private Office Submissions Copy List

INFECTED BLOOD PAYMENT SCHEMES – CONSULTATION RESPONSE 2017

Issue	No 10 has responded saying that they want the uplifts to be funded from DH's existing budget without additional funding from HMT and to publish by 14 September.
Timing	Other For all timing requests, please provide reason: Urgent clearance is required so that the Government response to infected blood payment scheme reform is published by 14 September 2017 before conference recess at No10's request.
Recommendation	1. That you approve for cross government clearance and publication the following documents attached to this submission: • Draft consultation response • Equality impact assessment • GRO-D 2. That you confirm the handling issues.

Discussion

1. In response to a submission setting out reforms to the infected blood payment schemes you asked the infected blood team to consider options if the payment scheme funding envelope was increased.

2. You and SofS agreed that discussions should be held with No.10 to explore options to re-instate annual payment uplifts from 2018/19 (previously announced in 2016 but not yet implemented) and to increase the overall level of discretionary funding available. An additional £4-22 million per annum would be required from HMT as finance colleagues confirmed that DH does not have the money for this.

3. No10 confirmed they would like to see the additional funding from DH's existing budget. The DH Finance team are working to identify the funds in the existing budget.

4. The attached consultation response with the previously announced uplifts will therefore be published (Annex C summarises the changes).

5. Timing is a critical issue. No10 has asked that we publish by 14 September. The SCM element of the consultation response forms a key plank of our defence for our JR. Details of the SCM need to be provided to the claimant's solicitors when the consultation response is published with time for them to consider, a few weeks before DH's detailed defence is submitted on 29 September.

6. The consultation response package ideally needs to be published before conference recess on 14 September at No10's request. A draft WMS is attached at Annex A of the attached handling plan. This will enable Parliament to be updated

on the full response as we have done previously on infected blood matters. Alternatively the response could be published during recess but that risks Parliamentary and other criticism. We do not recommend simply submitting the SCM element to the claimant's solicitors because that risks further criticism that only one element would be made public.

7. We recommend that you call or meet with the Chair of the APPG (Diana Johnson) on contaminated blood and Haemophilia. We will proactively alert key stakeholders to the consultation response content at the same time that it becomes public knowledge.

8. We intend to point any interested media towards the wording of the WMS for the detail of the announcement, and a top line for reactive media enquiries is suggested in Annex B.

Finance – cleared by Andy McKinley

9. No.10's requirement to deliver all components of the 2016 scheme from within existing DH budgets results in unfunded costs from 2018/19 for the remainder of the Spending Review in which existing commitments outside of the NHS Mandate substantially exceed the funding available. Options will be presented to SofS on the options for cutting other budgets in order to support delivery of the No.10 Infected Blood commitment.

Legal – cleared by Clare Martin

10. The increase of funding for the discretionary pot reduces the risk of further legal challenge linked to reductions in the discretionary payments since most beneficiaries will see no reduction. But there remains a small risk that an individual could bring a legal challenge on the basis of legitimate expectation (that their payments would continue) or on failure to consult adequately (in not providing adequate notice). To mitigate this and give notice, the consultation and consultation response discuss the potential for reductions in discretionary support and also make it clear that no one will see a sudden reduction in their discretionary payments.

Legal duties

11. 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 were previously set out in Laurie Mousah's submission on 23 June.

Communications – cleared by Marc Massey

1. The attached WMS (Annex A) sets out key messages that focus on the benefit of the SCM for those with non-severe (stage 1) HCV and that all beneficiaries will see an increase in payments. There is a very vocal group of campaigners who will likely criticise any Departmental activity as not going far enough. The Guardian and The Mail have tended to splash on the story before. Press office will point media towards the Written Ministerial Statement for the finer details of the announcement. A detailed Q&A is included at Annex B.

Parliamentary handling

2. 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

3. In summary, you are asked to confirm that you are content with the:
   - package of reforms as per the draft consultation response and the EqIA
   - GRO-D
   - proposed handling

Laurie Mousah, Infected blood policy manager
Emergency preparedness and health protection policy directorate GRO-C

ANNEX A
DRAFT Written Ministerial Statement

Infected Blood: Special Category Mechanism (SCM) and financial and other support in England

The Government recognises the suffering experienced by people as a result of the infected blood tragedy and the Government apologised in March 2015.

This Government committed further funding of up to an additional £125m over the existing baseline budget. This additional money more than doubles the Department of Health's annual spend on the scheme over the Spending Review period to April 2021. This is significantly more than any previous Government has provided for those affected by this tragedy.

In response to beneficiaries' calls for more clarity about the special appeals mechanism, which is now called Special Category Mechanism, the Government launched a consultation on 6 March 2017, on the details of the new SCM and our proposals for ensuring the scheme remained within its budget as a result of the new SCM. The SCM is aimed at benefiting beneficiaries with hepatitis C stage 1 who consider their infection, or its treatment, as having a substantial and long-term impact on their ability to carry out routine daily activities. The consultation was open to all beneficiaries and other interested parties across the UK to comment on our proposals. The consultation closed on 17 April 2017.

We have listened carefully to the consultation responses, analysed pre- and post-consultation evidence from other sources, and reviewed consultation proposals in line with respondents' views and evidence. That is why post consultation we have identified additional funding so that uplifts to annual payments as originally proposed can be introduced from 2018/19 along with the originally proposed increase in the amount of discretionary funding available.

Our plans for reform are summarised below:

- Introduction of planned uplifts in annual payments from 2018/19. All beneficiaries will receive an increase in annual payments from 2018/19.
- A new Special Category Mechanism (SCM) for those with hepatitis C infection at stage 1 in November 2017.
- The introduction of a single programme of discretionary support for all – infected and bereaved.
- An increase in the overall level of funding for discretionary support from 2018/19.
- All annual payments will include the winter fuel payment.
- Addition of type 2 or 3 cryoglobulinemia accompanied by membranoproliferative glomerulonephritis, MPGN), to the current hepatitis C stage 2 conditions

The NHS Business Services Authority (NHSBSA) will become the new single scheme administrator effective from November 2017.

For the first time, all beneficiaries of any of the current five schemes will be receiving support from a single scheme. Until November, while this transition takes place, annual and discretionary payments and services will continue to be made by the current schemes to ensure a smooth transition to the new scheme with minimum impact on the beneficiaries.

ANNEX B

KEY MESSAGES AND MEDIA LINES

Reactive line to take

We have listened to a wide range of views on a revised measure allowing those most seriously affected to benefit from higher annual payments and the effects from reform of the scheme as a whole. That is why we are pleased to announce extra funding to introduce the Special Category Mechanism so that more people with hepatitis c stage 1 can benefit from higher annul payments. We are also introducing uplifts to annual payments from 2018/19 and increasing the amount of discretionary funding available. As a result of this extra funding and reform of the schemes more people affected by this tragedy will be receiving a higher level of financial support.

Key messages:

On the consultation response:

- Having listened to the people affected, we believe the reformed scheme increases fairness by introducing a simple application to enable more people with stage 1 hepatitis C infection to apply for higher annual payments.
- We will introduce uplifts to annual payments from 2018/19 meaning that those who currently receive an annual payment will be better off than they are now.
- The overall level of discretionary financial support will be increased.

QUESTIONS AND ANSWERS FOR USE BY PRESS OFFICE AND KEY STAKEHOLDERS

1. **Why did you consult on not introducing annual payments payment uplifts and increases to the amount of discretionary funding if you were able to find additional funding?**

We wanted to consult with beneficiaries and other interested stakeholders on the details of the new SCM and our proposals for ensuring the scheme remains within its budget as a result of the SCM. We listened to the effect of not introducing the uplifts on beneficiaries and as a result more of those affected will be receiving a higher level of payment than currently.

2. **When will beneficiaries receive increases to their annual payments?**

The annual payment uplifts will be introduced from April 2018.

3. **What changes will be made?**

- The expansion of the current hepatitis C stage 2 criteria with an additional condition, type 2 or 3 cryoglobulinemia accompanied by membranoproliferative glomerulonephritis (MPGN).
- The new Special Category Mechanism (SCM) to identify hepatitis C stage 1 beneficiaries whose infection has a substantial and long term adverse impact on their ability to carry out normal daily activities. Those who make a successful application would receive the higher annual payments equivalent to the annual payment level for beneficiaries with HIV or hepatitis C stage 2 disease.
- Uplifts to annual payments and an increase in the overall level of discretionary support from 2018/19.
- The reformed discretionary rationalises payments

4. **Is this a government U-turn?**

No. We published a consultation and we have listened to the responses to that consultation. We will introduce the annual payment uplifts and increase the overall discretionary funding, which we know is valued by beneficiaries and their families.

5. **Why did you consult on infected blood reforms so soon after the publication in July 2016 of the government response to the January 2016 consultation?**

Our July consultation response announced a number of support measures for those affected by the infected blood tragedy of the 1970s and 80s. A completely new element that was proposed was the "special appeals mechanism".

We have now completed the work to develop the special appeals mechanism, which we now call Special Category Mechanism (SCM). The SCM will be a significant new element of the infected blood reforms. Therefore, we wished to consult with beneficiaries and other interested stakeholders on the details of the new SCM and our proposals for ensuring the scheme remains within its budget as a result of the SCM.

6. **Are you discriminating against disabled people?**

No, our plans for the SCM aim to recognise those infected with hepatitis C who may be suffer a substantial and long term adverse impact on their ability to go about their daily lives as a result of their hepatitis C infection.

Those with hepatitis C stage 1 will continue to receive the baseline payment of £3,500. If their circumstances change and they experience a substantial and long term adverse impact on their ability to go about their daily lives, they can apply for the higher annual payment of £15,500 as part of the SCM (in 2016/17).

7. Why are you not offering the £50,000 payment to hepatitis C stage 1 beneficiaries who apply for higher annual payments via the SCM?

It would be inconsistent with the rationale for the £50,000 lump sum payment based on reduced life expectancy: the lump sum is paid to those who develop hepatitis C stage 2 disease because, sadly, it reduces the quality of life but also substantially and negatively impacts on the life expectancy of those suffering from it. In contrast, the wider group of stage 1 beneficiaries who may apply for the higher annual payments under the SCM do not suffer from the same reduction in life expectancy as a result of their hepatitis C. Therefore, we consider it is fair to reserve the £50,000 lump sum for those who suffer from a stage 2 condition.

That said should a successful SCM applicant go on to develop one of the stage 2 indicators (including the new MPGN condition) they would qualify for £50,000 through the existing stage 2 process.

8. You say that beneficiaries should be aware that there is no guarantee of regular, fixed, non means tested support from the reformed discretionary fund going forward. What does this mean?

The overall funding available to provide discretionary support is being increased from 2018/19. The new scheme continues to provide all the types of help that people have been used to and more help with non-financial support.

On-going support will continue to be available and provided through means tested income top ups, however, such payments are likely to be at a lower level than existing payments and will be reappraised on an annual basis to ensure a model with greater consistency and 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.

We believe this will ensure discretionary support in the new, single, scheme is consistent and fair to all beneficiaries.

9. Why have you decided to appoint the NHS BSA as the new scheme administrator? What happened to the procurement exercise?

Initially the government intended to appoint the new scheme administrator through open competition. A pre-engagement with interested bidders was held in the autumn of 2016; however, the procurement exercise was not launched.

The government heard beneficiaries' feedback regarding the plans to procure for a new scheme administrator. As a result, ministers decided to appoint the NHS Business Services Authority as the new single scheme administrator. This will happen in November 2017. Until then, annual and discretionary payments and services will continue to be made by the current schemes to ensure a smooth transition to the new scheme administrator with minimum impact on the beneficiaries.

The NHS Business Services Authority (NHSBSA) is a Special Health Authority which already provides a range of critical central services to NHS organisations, NHS contractors, patients and the public.

10. How will my data be transferred?
Data will be transferred to NHSBSA by the current schemes. You should have received a letter from each of the schemes you are registered with about this. If you have not received this please contact the appropriate scheme.

11. Can I continue to receive my payments from Skipton/MFET/both?
At the end of October 2017 the Department of Health will replace the current schemes with the one administered by NHSBSA. Therefore annual payments will be received from NHSBSA.

12. How will you ensure my data is transferred smoothly and without mistake?
The current schemes and NHSBSA will work together to ensure that data is handled sensitively and in accordance with data protection rules.

13. Will my payment dates be affected by the move?
NHSBSA will work with the current schemes in relation to transfer of data to minimise any impact on payment dates however NHSBSA will be in touch nearer the time to confirm what the payment dates will be.

14. How does the decision to appoint NHSBSA as the new scheme administrator in England affect Wales and Northern Ireland?
Wales and Northern Ireland have announced that they will also be moving to separate, single scheme administrators. We are working with them to ensure that the new schemes can start at the same time.

15. Did the consultation cover the whole UK?
The consultation was for beneficiaries of the English scheme only.

The current schemes have already completed an exercise to identify which scheme each beneficiary was eligible for. This allowed them to write to only those who are eligible for the English scheme to make them aware of the consultation.

16. Why is the English scheme not following what Scotland, Wales and Northern Ireland are doing?
Health functions are devolved; responsibility for the infected blood payment schemes is therefore a matter for each devolved administration.

In England, we have committed up to £125m to provide additional funding to the reformed scheme. The budget allocation will more than double the department's annual spend on the scheme to April 2021. This is significantly more than any previous government has been able to provide for those affected by the tragedy.

17. How do I apply for SCM payments?
Beneficiaries who believe that their hepatitis C infection, or its treatment, complications, or a condition caused by the infection is affecting their ability to carry out everyday activities can apply for higher annual payments from November 2017.

The SCM is voluntary and is a largely paper-based application process. A sample of the application form is included in the consultation response for information. However, beneficiaries are advised not to complete this version of the form.

18. What information will I need to submit as part of my SCM application?
We expect that you will need to get a doctor who knows about your condition to help you fill in the form. In most cases this will be provided a hospital consultant or viral hepatitis nurse as they are likely to have a detailed understanding of your condition. The

commitment to reimburse any reasonable cost incurred in obtaining medical evidence remains.

19. How will SCM applications be assessed?
We have listened to consultation responses regarding the need for a medical expert to assist with the application process. Applications will be assessed by those with relevant experience and expertise. In addition, appeals will be heard by an independent group of experts.

20. When can I apply for SCM?
Applications for the SCM will open on 1 November 2017.

21. When will beneficiaries receive SCM payments from?
Any application received within 8 weeks of the SCM opening on 1 November 2017 date, if successful, will be eligible for higher payments backdated to 2 October 2017. This will ensure applicants do not lose any value in their annual payments whilst the new scheme administrator processes the anticipated high level of applications. After this period all payments linked to successful application for the SCM will be backdated to the date on which the application is received by the scheme administrator.

24. What is the appeals process?
A panel of independent experts with relevant medical expertise will review all applications and accompanying evidence. The decision made by the experts will be final and applicants cannot appeal against their decision. In such cases applicants will be eligible to reapply after a period of six months, taken from the date that the original application was received. It is expected that further applications will include additional evidence that was not provided in the original application.

ANNEX C

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. In order to respond to the claims in the JR about the Claimant's rights from 2017/18 onwards, 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 stayed 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 revised the proposal not to introduce uplifts to annual payments and this will now go ahead in 2018/19. The £50,000 lump sum payment will remain reserved for those who develop a with hepatitis C stage 2 condition.

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.