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Notes and actions following meeting held on Friday 15 July 2016

1. My apologies for the delay in getting this note to you since we last met on 15 July. Please see below a summary of discussion and actions to address these. Please note any actions for the group in bold.

Terms of reference

2. At the first meeting in May, I circulated the group's draft Terms of Reference. There were some comments from members of the group, which are captured in Annex A. Siobhain Butterworth had kindly agreed to take these comments away and look at providing a redraft that addresses these comments. Could I ask all members to please now take a look at the draft ToR document and let me have comments?

Update: Draft Terms of reference to be discussed under agenda item 3 of meeting on 22 August.

Process for Appeals

3. One of the decisions for scheme reform in response to what we heard in the consultation responses, is for a new special appeals mechanism to be set up from 2017/18, when the new scheme administrator is in place; for those with hepatitis C stage 1 who consider that the impact of their infection may mean they could qualify for stage 2 annual payments and the £50k lump sum payment. This replaces our initial proposal for individual health assessments.

4. The meeting on 15 July focused discussions on what this could look like and work has now started with Professors Thomas and Palmer on devising a model and process that is simple and is made up of a limited list of conditions associated to hepatitis C treatment and/or infection that could objectively be verified. **Work continues on this and a draft process will be tabled at the next Ref Group meeting in August for consideration.** The principle agreed by the group is that the process should consider those who have a condition caused, or strongly presumed to be caused by hepatitis C or its treatment and whose health is as badly affected as those currently receiving stage 2 payments.

5. The current application and appeals process for Skipton Fund eligibility works well:

    a. Individuals complete a form on the basis of evidence from their GP/hospital consultant and send it to the schemes;
    b. Two staff members at Skipton Fund consider an application and, if straightforward, refer it to any one of the four directors to review and approve their conclusion
    c. If it is not straightforward, they will review it with the professors and come to a decision

d. If the decision is not accepted by the applicant, he or she can then ask for it to be put before the Appeals Panel, supplying such additional evidence as might be available that is not relevant to answering the questions contained in the application form.

6. The new appeals process for alternative eligibility to stage 2 payments will build on this model.

7. Margaret suggested that mental health conditions might be measurable and that evidence on them could be submitted in an appeals process. In an early version of a model, aiming to address this, Professor Thomas commented that psychological diagnoses tend to be subjective (based only on symptoms) and difficult to attribute to hepatitis C with a high degree of confidence.

8. Use of the SF36 questionnaire has been discussed at length in the past, but measurement of 'softer' conditions such as low mood and anxiety would be very difficult to accomplish with consistency and fairness. It would therefore be difficult to deliver a properly validated assessment of such symptoms to include in an appeals process.

Action: Are the group in agreement that validation of psychological symptoms would be difficult to deliver? Jamie had helpfully suggested using NICE's EQ5D (level 5) form, which would provide both a measurable and objective method for assessing mental health attributed to hepatitis C treatment/infection. More work on this is required. I would be grateful if Jamie and anyone else on the group who is familiar with EQ5D would provide comments to reflect that on the draft model I will circulate later next week once Howard and Keith have commented on the current draft model?

Update

a) **Professor Palmer responded to say:** ***"I think the EQ5-D is no more objective than the SF-36, just shorter. No self-reported instrument of this kind is likely to be objective. It would be difficult to rule out the possibility that some appellants will exaggerate their symptoms for financial gain. More concerning, since mental health complaints are so very common in the general population, they will be common in claimants whether or not caused by infection; there is no reliable means of distinguishing those with a causal connection from those without. Potentially a high rate of claim could arise, using up the scheme's finite resources on matters that are hard to resolve.***

I would favour the line that these complaints (while undoubtedly real and important to affected people) are too hard to administer fairly: a higher level payment to all is a practical way of recognising this harm on the average, while accepting the practical barrier to going further case by case."

b) **Tabled for the meeting on 22 August is a copy of the EQ5D (Level 5) health questionnaire to help inform discussions on this point.**

c) **Further work on the inclusion of psychological symptoms is required and the DH are looking to field a psychologist to help advise on this issue.**

Principles for a new Discretionary Scheme

9. There was very little time for the group to discuss what they think a new discretionary scheme should look like. We know that the discretionary element of support is one most beneficiaries value and have come to rely on over time. There will be an expectation of continuity from those who currently use discretionary support. The group were asked to think about a new scheme that would address and reduce the expectations of current users reliance on such support, but at the same time differ from current practice. The group were asked to consider a scheme that was based around the following principles: ***sustainability + exceptionality + evidence of financial hardship.***

10. It was proposed that a new discretionary scheme would:

    a. Provide a list of support payments tailored to individuals' needs;
    b. Have an emergency exceptions clause built in as a contingency, outside of the list of more general support, that considers any request for financial help as it arises and where unexpected 'immediate problems' are met;
    c. Offer discretionary income top-up on an annually reviewed basis;
    d. Introduce a 'phasing-out' over time of what has now come to be known, in some cases, by recipients as significant 'regular payments', bearing in mind that those who have come to rely on these payments for loans/mortgages etc should not be disadvantaged and their situations looked at to find a way forward within in the criteria of a new scheme (this will be for those who would not now meet any given eligibility criteria for any new income top-up within a new scheme);
    e. Consider proposals suggested by those who responded to the consultation (where lawful, affordable and fair).

Action: Reference Group members are invited to comment on this initial proposal and provide their views that consider equity, fairness and transparency.

Update

Professor Palmer responded to say: ***"I find it hard to know what 10a would like or what would qualify under 10b or 10c. Some examples from current practice would help me better understand the individual needs that current provisions support. Increased costs relating to the infection or its treatment would make perfect sense to me as an outsider, however. I think there should be a principle that the 'needs' are connected to the infection and not something that would arise irrespective of it."***

£10k Lump-sum payment to bereaved partners/spouses

11. Under the new arrangements, a one-off lump sum payment of £10,000 will be given to all those who are the bereaved partner or spouse of a primary beneficiary when they passed away and where infection with HIV and/or hepatitis C contributed to the death of their partner/spouse. This will apply to those already bereaved and newly bereaved from 2016/17 and beyond. They will also have access to a new discretionary support scheme that will be open to all bereaved family members.

12. When discussing eligibility of the £10k one-off lump sum payment to bereaved partners/spouses of those whose infection contributed to their death, the group asked what we meant by 'death contributed to HIV/HCV infections'? Our suggestion is that where the cause of death is taken from the death certificate and shows infection contributed to this, then the bereaved spouse/partner would be eligible for this payment if they were the partner/spouse at the time of the person's death.

    Action: Does the group agree with cause of death being taken from the death certificate as well as the deceased having been a registered as a primary beneficiary of the schemes as eligibility for their widows to receive the £10k? We can discuss further at the next meeting with a view to us drawing up criteria for your views soon after? Recognising some may not wish for cause of death to be certificated, the group are invited to provide any thoughts for resolving this.

    Update
    Professor Palmer responded to say: ***"Yes, I agree. I do sympathise though with the concern that families may not want HIV to appear on a death certificate (and perhaps not cirrhosis). Could spouses obtain evidence from the treating specialist? - I'm not sure how practical this is."***

Letter to beneficiaries and Stakeholders Q&A script – live document

13. When publishing our response to the consultation on 13 July, we undertook to write to every beneficiary currently registered with the 5 schemes.

14. This was completed a few days after the publication of the response document and the **Department wishes to express its gratitude to Jan and her team for assisting us in getting these letters sent out promptly.**

15. We produced a Q&A script for the schemes and third sector colleagues to use if contacted by anyone seeking clarity or further information about what these reforms actually mean.

16. The Q&A document, attached at the end of this document at **Annex A** is a live document and we are working with all recipients to update and amend accordingly, with any new concerns or issues being raised by correspondents. We have asked that all new queries, not covered in the Q&A

document, be directed to us so we can include to the document and then circulate, ensuring a consistent line is being used by all.

Action: Separately, do the group have a view on how we publicise our message about support more widely to capture those affected but not yet registered with any of the current support schemes? (eg bereaved partners/spouses?)

Update: No responses provided to this question.

Membership

17. I am pleased to inform the group that The Hepatitis C Trust has kindly agreed to join the group and I am delighted that the Trust's Chief Executive, Charles Gore will be joining us for all future meetings. In his absence, he has delegated this to his deputy Chief Executive, Rachel Halford and Neil Cowan from his Policy Team. We now have representation from key third sector colleagues to provide the group with a further dimension of challenge and input into our discussions that considers the needs of those our reforms will affect. **Thank you Charles.**

18. I look forward to hearing from you with comments to any of the above issues.

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