

The Hepatitis C Trust's response to the Department of Health consultation on 'Infected blood – reform of financial and other support', April 2016

Reformed Scheme

4. Would you prefer five separate schemes (as now) or one scheme?

One

Please specify: The Hepatitis C Trust supports the proposal to replace the current five schemes with a single body. All of our conversations with patients indicate that the existing payment scheme – whereby patients are required to engage with multiple different organisations to potentially secure a number of different payments – represents a source of confusion and often of additional stress for people living with hepatitis C. A simpler system for delivering payment is to be welcomed for this reason.

Individual Assessments

5. Do you have views on how the individual assessments should be undertaken?

Please provide any comments. : The Hepatitis C Trust has long campaigned for people infected with hepatitis C through contaminated blood products, whose health is affected as a result, to be recognised in the same way as those who contracted HIV by receiving annual payments. We thus support – in theory – the idea of enabling such payments by introducing assessments to determine the 'impact their infection is having on their health, or residual ill-health after treatment' against a set criteria based on 'current medical and scientific evidence'. In particular, we welcome the accompanying recognition that many people with 'stage 1' hepatitis C (without cirrhosis) may also experience severe symptoms as a result of the virus, which can restrict their ability to fully participate in society (including in some cases preventing them from working). However, more information must be provided on the criteria and evidence against which people's health will be assessed and how this will be measured, before a definitive answer can be provided as to whether individual assessments should be introduced. Without more information from an early stage about what the assessment criteria will include, there is a danger that regular assessments could be conducted too rigidly, acting as a burden for patients and perceived as a money-saving exercise on the part of the Government rather than as a system of support. There is also a risk that tests to assess the broader health impact of hepatitis C may be too difficult given the often vague, but debilitating, nature of the symptoms that can be hard to prove as being directly attributable to the virus. Such symptoms can include chronic fatigue; aches and pains, including persistent sharp pain around the liver for many; and 'brain fog' entailing difficulty concentrating and completing complex tasks. To ensure that assessments really do broaden access to annual payments for those with hepatitis C instead of functioning as a cost-saving initiative for the Department of Health, the assessment criteria would need to be carefully drawn up and developed in consultation with patients and other stakeholders, including The Hepatitis C Trust. In designing the assessment criteria, attention must also be paid to the results of the Scottish

Government's upcoming evidence-based review into the broader health impacts of hepatitis C, which is aimed at ascertaining whether new criteria should be established (to which it has recently committed).

Lump Sums

6. Should the reformed scheme include a lump sum payment of £20k when an infected individual joins the scheme?

Yes

Please provide any comments: So long as the assessments for annual payments for stage 1 hepatitis C are properly designed so as to facilitate ongoing support for as many people as possible, we support the reformed scheme continuing to include a lump sum payment of £20k. Indeed, when it comes to lump sum payments the Scottish Government has gone further so that infected individuals will receive a higher lump sum payment of £50k.

7. Should the reformed scheme maintain the difference between those with HIV and hepatitis C by retaining the lump sum payment of £50k for progression to cirrhosis in relation to hepatitis C?

Yes

Please provide comments: The Hepatitis C Trust is against the arbitrary distinction drawn between 'stage 1' and 'stage 2' ex gratia payments, given the fact that people infected with hepatitis C can experience severe symptoms before the onset of cirrhosis that make it difficult to get by on a daily basis (and conversely, some of those with cirrhosis may not experience many symptoms). However, we recognise the complexity of removing the distinction at this stage, and welcome the introduction of annual payments based on assessments for those with stage 1, which should go some way to addressing this arbitrary difference in support if properly administered. The Department of Health should also take note of the fact that in Scotland lump sum payments for those who progress to cirrhosis have been increased to total £70k, following from the proposed increase to lump sum payments for those with stage 1 hepatitis C, all of whom will now receive an initial extra lump sum payment of £30k (total £50k). We support a move to match the Scottish system here as far as possible.

Bereaved Individuals

8. Should the scheme offer the newly bereaved one final year of payment, or continued access to discretionary support, or the choice between these two options?

Choice of either

Please provide any comments: If left with no other option, we support a choice of either a lump sum or continued access to discretionary support. However, we believe that the newly bereaved should be provided with ongoing payments and that England should seek to match the Scottish system, where an annual payment (75% p.a. of the previous annual payment, for stage 2 recipients) will continue to be received by the spouse until death.

9. Should the scheme offer those already bereaved a final lump sum or continued access to discretionary support, or the choice between these two options?

Choice of either

Please provide any comments : Our answer is as above; we can identify no reason for a distinction to be drawn between newly bereaved and those already bereaved.

Treatment

10. Should providing access to treatment for those with hepatitis C be part of the reformed scheme?

No

Please provide any comments: The Hepatitis C Trust does not support a move to provide access to treatment as part of the payment scheme for those affected by contaminated blood. People with hepatitis C who meet the eligibility requirements – both those who contracted hepatitis C through contaminated blood products and those who contracted the virus through other means (often as a result of experiencing health inequalities themselves) have a right to NICE-approved treatments as part of the NHS Constitution. Given this already-existing entitlement to treatment, offering treatment access as a form of compensation within the financial support scheme would not be to the benefit of patients, particularly if treatment access is to be paid for out of the same pot of funds allocated for financial payments, thereby potentially diminishing other forms of support. Many of our conversations with patients, through our helpline and with other stakeholders representing this patient group, indicate that they would be left significantly worse off financially under the new proposals, and we are strongly of the opinion that this should not be the case. Therefore, as opposed to putting in place measures to facilitate treatment access, the Department of Health's focus should now be on freeing up as much of its resources as possible for improving financial support payments, including maintaining the discretionary payments that are so crucial for many patients.

Additionally, providing access to treatment as part of the scheme would potentially add a layer of confusion to the recently-established national system for delivering hepatitis C treatment, under which multi-disciplinary teams within regional Operational Delivery Networks are working towards 'run rates' for treatment set by NHS England. Whilst the basis for allocating 'run rates' in the first place is questionable, detailed questions would need to be answered about how a separate scheme to treat people infected with hepatitis C through contaminated blood would sit alongside the ODNs, and whether indeed the existence of such a separate scheme would impact on the run rates set for each ODN area.

11. If you are a beneficiary of the current scheme, infected with hepatitis C would you be interested in being considered for access to treatment under the scheme?

Not Answered

Please provide any comments below. : N/A

Other support

12. Should discretionary payments be available for travel and accommodation relating to ill health?

Yes

Please provide any comments below.: Yes, discretionary payments represent a vital source of additional support for people affected with hepatitis C through contaminated blood, and several patients we have spoken to are dismayed and upset by the prospect of having discretionary payments (including, for example, free prescription rights) taken away from them. As outlined below, the Scottish proposals include a new Support and Assistance Grants scheme which would see discretionary funds increase from a £300k to a £1m p.a. allocation from the Scottish Government. It would seem to be extremely unfair, and likely to cause a significant backlash from patients, if England were to take a backward step in this regard and fail to provide essential discretionary payments.

Impact

13. Are you aware of any evidence that would show our policy proposals would negatively impact any particular groups of individuals?

Please provide any comments below.: The comments we have provided in answer to many of the other questions within this consultation outline our views that these proposals; in particular those around prioritising treatment access and removing discretionary payments, are likely to negatively impact on the majority of those affected with hepatitis C through contaminated blood.

Other comments

14. Do you have any other comments that you wish to make?

Please provide comments below: The Hepatitis C Trust is opposed to the apparent decoupling of the English scheme for financial and other support for people with hepatitis C from that which exists in Scotland. We strongly support the proposals agreed by the Financial Review Group in Scotland 'Contaminated Blood: Financial Support – Conclusions and Recommendations'. Whilst some variation across the nations is to be expected given the differing health systems and governing arrangements in place, these new proposals for financial and other support in England should not leave those who happened to have been infected through contaminated blood in this part of the UK (pre-devolution) with a much worse deal comparatively, as would seem to be the case on comparing these proposals with those in Scotland. It is imperative that the Department of Health in England takes note of the recommendations being taken forward in Scotland to ensure that a postcode lottery of support is not created which leaves those affected with a strong sense of unfairness.

Unlike in England, where consultation with current recipients indicates that most will be worse off financially, the financial review group in Scotland has agreed as a principle that nobody should receive less financial support due to the new arrangements, and that the same level of support should at least be maintained. This should also be the case in England. Other arrangements in Scotland include a new Support and Assistance Grants scheme which would see discretionary funds increase from a £300k to

a £1m p.a. allocation from the Scottish Government, which sits in stark contrast to the English proposals to cut discretionary payments altogether.

Important questions will need to be answered and clarified as soon as possible around how the English system will relate to the new system being created in Scotland, and what this means for people infected in one part of the country and now living in another, who will arbitrarily receive an entirely different package of support.

We would also like to express our disappointment that – as the national charity advocating for and providing support to people with hepatitis C in the UK, and as the provider of a dedicated counselling and support service for people who contracted hepatitis C through contaminated blood - we were not involved by the Department of Health in developing its proposals for reform of the current schemes and plans. This is again in contrast to Scotland, where The Hepatitis C Trust has been a member of the Financial Review Group, established following the Penrose Inquiry to assess support arrangements.

We would like to be consulted during the development of any future revisions to these proposals and in designing the criteria for any assessments. We also wish to discuss further other forms of (non-financial) support – for example an extended counselling service and health days – which could be offered by third sector organisations such as ourselves.