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Royal College of Nursing (RCN) response to the Department of Health consultation on proposed reforms to the financial payment schemes for infected blood payment schemes. These schemes apply to those affected by HIV and/or hepatitis C through treatment with NHS-supplied blood or blood products.

Background

With a membership of around 430,000 registered nurses, midwives, health visitors, nursing students, health care assistants and nurse cadets, the RCN is the voice of nursing across the UK and the largest professional union of nursing staff in the world. RCN members work in a variety of hospital and community settings in both the NHS and the independent sector. The RCN promotes patient and nursing interests on a wide range of issues by working closely with the Government, the UK parliaments and other national and European political institutions, trade unions, professional bodies and voluntary organisations.

RCN members are employed in a wide array of roles and are involved with patients and clients affected by HIV and or Hepatitis C as a result of infection through treatment with blood or blood products. This response represents the views of RCN members who are involved with affected patients.

General Comments

- The consultation is open to anyone in the UK to respond. It is, however, predominantly aimed at the affected individuals. It is essential that their opinion is taken into account.
- Consideration must be given to the possible loss of corporate memory from the five existing payment schemes. Whilst one scheme would facilitate better consistency and a one stop shop, the benefits and best practice from each must not be lost.

- We feel that alongside this there should be a higher priority for hepatitis C treatment for those affected.
- There should also be a mechanism to consider stopping payment when sustained virological response is achieved in those affected by the hepatitis C Virus.

Responses to specific questions

Question 1: Would you prefer five separate schemes (as now) or one scheme?

We feel that consolidating the five schemes into one that cover all the infected blood conditions would facilitate consistency. However, there must not be loss of expertise and individual considerations. Any new scheme must ensure that the best practice from the five schemes is adopted.

Question 2: Do you have views on how the individual assessments should be undertaken?

The assessment process needs to be able to recognise and respond to the complexity of individual situations. This means that there needs to be a multi-agency approach to the assessment to include information from the individual alongside their doctors, carers, social, psychological and work assessments or any other relevant information.

Question 3: Should the reformed scheme include a lump sum payment of £20k when an infected individual joins the scheme?

Yes, as an initial payment with good advice. The individuals must be advised of the long term implications of their blood infection so that the initial lump sum can be utilised and/ or invested wisely to facilitate long term outcomes.

Question 4: 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, as they are paying for transport to appointments, and potentially will lose time from work, or be unable to work, it would appear prudent to retain the lump sum.

Question 5: 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?

We feel that this should be dependent on the overall assessment and individual circumstances.

Question 6: Should the scheme offer those already bereaved a final lump sum or continued access to discretionary support, or the choice between these two options?

As above this should be dependent on the overall assessment and individual circumstances.

Question 7: Should providing access to treatment for those with hepatitis C be part of the reformed scheme?

Access to treatment must always be based on clinical need and therefore needs to be part of the reformed scheme.

Question 8: 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?

We are concerned that this approach could imply that access to treatment is linked to the financial remuneration and could potentially deter some individuals from seeking treatment especially where the success of treatment is not guaranteed.

Question 9: Should discretionary payments be available for travel and accommodation relating to ill health?

Yes as the disease progresses to be chronic, many individuals need further assistance with their travel and accommodation. Therefore, discretionary payments should be considered on an individual basis. If the initial lump sum is meant to cover all or some of the cost, then this needs to be made very clear.

Question 10: Are you aware of any evidence that would show our policy proposals would negatively impact any particular groups of individuals?

Whenever there is a change it is very likely that there will be some individuals who will gain and other who will lose. It is therefore essential that any communication of the changes and how they will affected individuals is made clear and that they understand the rationale behind the changes.

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