MS(PH)

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Date: 17 March 2010
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Contaminated Blood: Further advice requested on options for bringing forward a review of the Skipton Fund and the possibility of providing personalised health budgets for haemophilia patients

Issue

1. Further to Rowena Jecock's submission of 3 March 2010 (attached at **Annex A** for ease of reference), you have asked for:

   - further advice on options for bringing forward a review of the Skipton Fund (SKF)
   - more detail on the possibility of personalised budgets for haemophilia patients.

Advice on SKF options

2. Advice, including pros and cons, on the following SKF review options is contained in **Annex B**.

   A. Maintaining the existing position of reviewing the SKF in 2014, as per the Government's response to Lord Archer's report
   B. Bringing forward the full review (which has significant financial implications)
   C. Bringing forward the review with pre-identified finite non-recurrent funding in 2010/11
   D. Addressing certain anomalies with the existing scheme outside of a formal review (based on Annex B of 3 March submission)

Summary of SKF options including financial implications

3. Here is a summary of the options advice contained in **Annex B**.

   A. Although this will continue to dissatisfy campaigners, it would signal Ministers' determination not to bow to pressure. **It would also incur no additional cost**.
   B. While it is feasible to undertake the full review in the absence of allocated funding, this is likely to raise significant future funding problems when the review reports, given the expectations of those affected and the financial position from 2011/12 onwards. It is not possible to give an estimate of potential costs without an economist's input, but is likely to run into **many tens, or possibly hundreds, of millions pounds (possibly with a**

recurrent aspect). We recommend seeking Treasury advice on this, given that we are committed to a review in 2014 in any case.

C. It would be extremely challenging to complete a full, properly conducted review by the end of the financial year 2010/11, with only specific in-year funding, assuming that such funds can be identified. We would need to seek confirmation from Finance colleagues as to what funding could be available and it is likely that they in turn will need to seek Ministerial agreement on this, and **therefore we do not recommend this**.

D. It may be possible to address a particular anomaly in-year, assuming the Devolved Administrations agree and funding can be found, but there would be significant difficulties with this. For example, there will be personal/privacy issues around identifying those who died before August 2003 and we are likely to incur additional costs in dealing with deceased's solicitors. **Our cost estimate for just addressing the anomaly of the widows of those who died prior to August 2003 is in the region of £62.5m (without legal costs)**.

4. In considering option B, the advice from Finance is that our financial position in the next SR is already extremely tight and further pressures would require identification of other areas to be de-prioritised and this will be increasingly difficult.

5. The situation in relation to options C and D is that the DH budget for 2010/11 remains over-committed, and the financial position going forward will remain very tight. This means that we cannot commit any new expenditure to this work without stopping other programmes to release funding for this.

Recommendations

6. Due to the complexity of this review, the potential legal repercussions, and the far reaching implications for other Government Departments, we strongly advise not to rush any review – especially having decided so far to maintain the existing position. There will be many legal and policy requirements we will have to address and we think it is highly risky to promise something in a hurried way now that may prove to be difficult, or not possible, to achieve. We also run the risk of exposing the Department to further legal challenge by way of Judicial Reviews.

7. We therefore recommend that you hold the existing line, and do not change the current commitment to review the SKF in 2014.

8. If, however, you do wish to bring forward the review date, a great deal of care will be required from the beginning to manage campaigners' expectations. We would recommend the two-stage process detailed in option B of **Annex B**. This would allow a properly managed review to be undertaken and would significantly reduce any risk of wrong footing

other Government Departments (including the Devolved Administrations). It would also allow sufficient time to properly identify and recruit suitable people to participate in the review. There are likely to be clinical as well as significant operational considerations to take into account as well as financial and wider Government policy implications. However, this is likely to have financial implications that we cannot yet quantify, which will impact on the likely extremely tight next SR period.

9. Any such commitment would need to be cleared in advance with HM Treasury because it could set an expensive precedent and may be viewed as contentious. In addition, to ensure the Department's Accounting Officer (Hugh Taylor) is not exposed, there would need to be clear plans for delivering offsetting savings on other programmes in advance of any announcement.

10. We would not recommend option C or option D because we consider neither will satisfy the lobby groups, and there is significant risk in both cases of not being able to spend the money in-year. The restriction with, and potential criticism of, option C could be that a valid review may not be able to be considered because we cannot afford it (e.g. providing a new element of on-going financial support like the Macfarlane and Eileen Trusts for those infected with HIV). Likewise, we would recommend not addressing other anomalies outside of the review at this time (option D), but could instead cite your desire to address these as the reason for bringing forward the review, as at para 8 above.

Personalised health budgets

11. Further information is provided at **Annex C**.

Recommendation – personalised health budgets

12. **We see no reason not to immediately pursue the option of personalised health budgets for haemophilia patients**. We suggest this is done via our formal meeting with the Haemophilia Alliance (the UK-wide partnership, which consists of patients, haemophilia doctors, and others involved in their care).

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Annex B

Advice on options

A. Maintaining the currently agreed review date of 2014

1. The decision not to review the SKF until 2014 has received criticism since it was announced in the Government's response to Lord Archer's report. Campaigners have said this is 'kicking it into the long grass' and it is realistic that a number of currently eligible people will have died before that date. It also delays the chance to correct the known anomalies that have existed with the scheme since it was set up.

2. Your predecessor decided the choice of the review date, outside of discussions with officials. Since then, the decision has remained that this line should be maintained – most recently during the House of Lords debate on 11 December during the second reading of Lord Morris's Private Members Bill.

3. There are pros and cons for maintaining the current position

   Pros:
   - Would maintain consistency of approach
   - Would signal that other aspects of the Government's response are not subject to re-negotiation
   - Would allow a properly managed review to be undertaken in 2014 – including full participation of the Devolved Administrations
   - Would allow Lord Penrose to report in Scotland first (we do not yet know if there are likely to be any resulting implications for the SKF)
   - Would not add further to resource pressures

   Cons:
   - Known existing anomalies remain unrectified
   - The choice of review date remains hard to defend
   - No change to existing payment levels for hepatitis C sufferers post-Archer report
   - More of the existing eligible people will have died before the review is undertaken and will therefore unlikely benefit from its findings

B. Bringing forward the full review

4. Paragraph 5 of Rowena Jecock's submission of 3 March 2010 identified that financial constraints meant that it was difficult to recommend that the review be brought forward as any decision would have a financial implication and we would need to carefully manage expectations.

5. We would also need to ensure the Devolved Administrations are properly involved from the outset as we could not make an announcement or any decision without their agreement as the fund is

UK-wide.

6. The review could be brought forward simply and we would recommend a two-stage approach to look at the scheme in its entirety and make recommendations for future considerations. It would:

   - Consider comments we have received from stakeholders about the structure of the existing scheme
   - Identify what anomalies exist and how they might be addressed
   - Consider whether aspects of the existing scheme should or could be reviewed (e.g. eligibility criteria or payment structure)
   - Scope what action would need to be taken to address the findings - for example, decisions may well impact on DWP (for benefits), HMRC (for tax implications), or require variations to the Skipton Fund Trust Deed.

7. We would expect there to be a report detailing the outcome of the scoping exercise. This could highlight what actions might be taken and which cannot (for example, we do not yet know if it is possible to interrogate medical records of deceased persons to confirm their eligibility if they died before the SKF was set up). This could help manage expectations from stakeholders.

8. The second stage would be to consider how the findings from the stage one report might be addressed and to identify a timescale and budget for taking it forward. This would need to be discussed with Finance and/or Treasury colleagues before we could commit to it.

9. Before announcing any review, we would need to agree how it would be conducted (internally or externally) and identify suitable resources to undertake the work. Once the review is set up, we think it would be realistic for an interim report to be presented in about six months. We would also need to consider the implications of the timing for the second stage. Expectations are likely to be that this would follow on immediately from the scoping report and we would need to be clear from the outset whether this is likely to happen.

10. There are pros and cons in bringing forward the full review.

    Pros:
    - Would signal that you have listened to campaigners and moved your position accordingly
    - Would address the currently hard to defend position of a 2014 review date
    - It would allow a properly managed review and would avoid making on-going financial commitments this side of an election
    - Would allow us to address the known anomalies and consider Lord Archer's report in the context of hepatitis C sufferers

    Cons:

- We may be rushed into managing a review for ill defined reasons
- Campaigners would have an expectation of increased financial support that may not be deliverable in the current climate
- The potential for on-going financial implications
- Would need the agreement of the Devolved Administrations to take this forward on a UK-wide basis and this has not been discussed with them (they will probably need to consult their Ministers)

C. Bringing forward the review with finite funding in 2010/11

11. We have continually stated that the entire SKF would be reviewed in 2014 and that the review would consider comments received from stakeholders and campaigners on this issue. If we undertake a review with finite funding, it is likely that the review group may be precluded from reviewing some aspects of the scheme due to the fact that the outcome has recurrent financial implications.

12. There are likely to be some aspects of the review that could be considered and paid for in-year, but this in essence would mean only a partial review could be undertaken.

13. We would need to closely involve Devolved Administration colleagues if we want to take this forward on a UK-wide basis.

14. There are pros and cons for bringing forward the review with finite funding in 2010/11

    Pros:
    - Would enable some of the review issues to be considered earlier than 2014
    - Could prioritise addressing some of the known anomalies
    - Would not commit us to recurrent funding

    Cons:
    - Would receive criticism that it is only a partial review (if recurrent funded aspects cannot be considered)
    - Would require the identification of funds in 2010/11
    - May be operationally difficult to both conduct a review and take the necessary operational action to enable the money to be spent in-year (for example, we would have to identify potential eligible people who died before August 2003, verify their claims, make any necessary changes to DWP and/or HMRC legislation to recognise the award, and make actual payment within a tightly defined funding window)

D. Addressing certain anomalies now, outside of a full review

15. You have indicated that you would like to explore the possibility of addressing one of the anomalies – making a one-off payment to those

people who would have otherwise been eligible, but who died before the August 2003 cut-off date (option one of paragraph 9 in Annex B of the 3 March 2010 submission).

16. It is known that this is an anomaly that has been difficult to defend. Baroness Campbell of Surbiton is one of the widows whose otherwise eligible husband received nothing because he died before the August 2003 cut-off date.

17. There are pros and cons for addressing this outside of a full review

Pros:

- Would signal that you have listened to campaigners and moved your position accordingly
- Would address one of the most highlighted known anomalies
- Would incur a one-off cost with no recurrent financial pressure

Cons:

- We may be criticised for addressing just this one particular anomaly now and not others and will be considering one aspect of the full review in isolation
- Finance colleagues have confirmed the Department is over committed on funding for 2010/11 and the financial position in subsequent years will be tight
- Will also have financial and practical implications for the Devolved Administrations, which have not been discussed with them or their Ministers
- We would be rushed into having to agree eligibility criteria. We know it will be very hard to validate applications against any eligibility criteria as some of these people will have died many years ago and medical records may no longer be available
- We would need to understand the tax implications for making a retrospective payment to either the deceased's estate or his dependents.

Annex C

Personalised health budgets

1. You requested further advice on the use of personal health budgets by patients with haemophilia, to give patients more control over how money is spent on their healthcare. You proposed this at your recent meeting with Eddie O'Hara MP and Sylvia Heal MP from the APPG on Haemophilia. This could benefit all haemophilia patients, not only those affected by contaminated blood.

2. Individuals are able to use their budget in flexible, innovative ways to meet agreed health outcomes; they can use them on services and care not traditionally provided by the NHS. A personal health budget could be spent on any services, as long as it is legal and appropriate for government to fund, and agreed in a care plan as meeting the patient's health needs.

3. We are discussing with haemophilia care professional the suitability of elements of the care pathway for personal health budgets. Preliminary discussions with the UK Haemophilia Centre Doctors' Organisation indicate that personal health budgets are likely to be appropriate for some elements of an individual's care, but not for the purchase of clotting factors used for treatment and/or prophylaxis, which are procured through a national contracting process.

4. Around 70 PCTs in England are participating in the personal health budget pilot programme. This programme is voluntary and PCTs make their own choices about which health conditions they include. If you wish to take this further, and if experts think there are elements of the haemophilia pathway that are sensible to personalise, it will be important to determine whether there are one or more PCTs interested in developing proposals for a pilot for haemophilia patients. We can rapidly explore this with PCTs.