DRAFT

REVIEW OF ASPECTS OF THE SUPPORT AVAILABLE TO PATIENTS INFECTED BY CONTAMINATED BLOOD/BLOOD PRODUCTS AND THEIR DEPENDANTS

1. In the 1970s and 1980s, approximately 4,675 haemophilia patients and 23,500 non-haemophilia patients were infected with HIV and/or hepatitis C by NHS supplied contaminated blood products or blood transfusions, until tests for HIV and hepatitis C were introduced in 1985 and 1991 respectively.[1] Successive Governments set up the Macfarlane and Eileen Trusts and MFET Ltd to provide ex-gratia financial relief to help those infected with HIV and their dependants; and the Skipton Fund to provide ex-gratia financial relief to those infected with hepatitis C.

2. HIV infected individuals currently receive fixed annual payments of £12,800, paid through MFET Ltd. These size of these payments was set by Ministers in 2009. Some also receive additional discretionary payments through the Macfarlane Trust (for haemophilia patients) and the Eileen Trust (for patients without haemophilia). These payments are decided by the Trustees, within the overall financial resources available to the Trusts. In 2009/10, the combined annual payment to an infected individual averaged £17,400. However, it is understood that this average figure will be lower in 2010/11, because certain one-off payments formerly made by the Trust will cease. Dependants of those with HIV are eligible for discretionary payments through the Macfarlane and Eileen Trusts both while the infected individual is alive and following bereavement. For the first six months following bereavement the dependant receives the same rate of payment as the infected registrant whilst they were alive. For the second 6 months they receive £100 per week, plus an additional £250 for a dependant child and £100 for each additional dependant child.

3. In 1988, a group of haemophilia patients who had been infected with HIV by contaminated blood/blood products brought litigation against the Government. Their chances of succeeding with this litigation were

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[1] A note of how these figures were arrived, together with the other assumptions used in modelling the costs of the review, is attached at **Annex A**.

estimated by their own legal counsel at "around 20%". On their own legal advice, the litigants settled the case out of court in 1991. The Government paid out £42 million through the Macfarlane Trust in this settlement, without accepting liability. To date, HIV infected individuals who have been in the scheme since the outset, will have received between £150,311 and £189,311 each[2].

4. In contrast, individuals who develop chronic hepatitis C receive a one-off lump sum payment of £20,000, and those who go on to develop severe liver disease (cirrhosis) receive an additional one-off lump sum £25,000. No recurrent payments are made, and nor is there any financial support for dependants. Only those infected and still alive on 29 August 2003 are eligible for payments. Where the claimant died after August 2003, but before payment was made, the payment was made into the estate.

5. The latest available figures from the three ex-gratia payment schemes report that they have paid out £206 million since their establishment, (including the £42 million in settlement of the HIV litigation).

6. Evidence gathered during the course of this review shows a wide range of views on the level of payments that this diverse patient group should receive, (see **Annex D**). The sums that have been paid out to HIV infected individuals to date, coupled with the level of payments going forward, means that HIV payments fall roughly in the low to middle end of the range. In contrast, current provision for hepatitis C payments is less than the minimum proposal being suggested.

7. In 2007, Lord Archer of Sandwell set up an independent inquiry into NHS supplied contaminated blood and blood products, which reported on 23 February 2009. The report did not seek to apportion blame but made a number of recommendations about financial and other support, focusing on haemophilia patients. A full list of the recommendations are at **Annex B**.

8. Some of Lord Archer's recommendations were already in place. These were:

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[2] Data supplied by the Macfarlane Trust.

- Free access to GP visits, counselling, physiotherapy, home nursing and support services.
- Testing haemophilia patients and blood donations for specified infectious agents.
- Ex-gratia payments to those infected with both HIV and hepatitis C, (although not at the levels recommended by Lord Archer). These payments are tax-free and are disregarded for the purposes of calculating means tested benefits. Entitlements are payable if infection is established within the appropriate timeframe, and there is also an appeals mechanism.

9. The previous Government's response to Lord Archer's report was published on 20 May 2009. The following changes were implemented as a result:
    - Flat rate payments of £12,800/year were introduced for HIV-infected individuals (at that time, the average payment was around £6,400), and there were also increased discretionary payments to both those affected and their dependants, through the charities;
    - A review of the Skipton Fund in 2014 (Later brought forward to 2010);
    - £100,000 annual grant to the Haemophilia Society from 2010/11to 2014/15.
    - Twice-yearly meetings between the Department of Health and the Haemophilia Alliance (as opposed to the statutory Haemophilia Committee proposed by Lord Archer); and
    - funding for a lookback exercise to identify individuals with bleeding disorders who might have been infected by hepatitis C but were still unaware of the fact.

The current Review

10. On 14 October 2010, the Government announced that it would be conducting a review of a number of aspects of the support available to those who had been affected by contaminated blood. This would cover the following issues:

    - the level of ex-gratia payments made to those affected by hepatitis C, including financial support for their spouses and dependants, and taking account of the level of payments made to those infected with HIV in the UK and via schemes in other countries;

- the mechanisms by which all ex-gratia payments are made;
- access to insurance;
- prescription charges;
- access to nursing and other care services in the community.

11. A copy of the Written Ministerial Statement announcing the review and the terms of reference for the review are attached at **Annex C.**

12. In addition, it has been decided to look again at a few other issues, which are outwith the terms of reference of the review, but which were raised during the House of Commons backbench debate on contaminated blood that took place on 14 October 2010. These issues, which are addressed in a separate section at the end of the report, are:
    - Exempting this patient group from DWP Work Capability Assessments; and
    - Access to dentistry.

13. This review covers support for both haemophilia and non-haemophilia patients who were infected by NHS supplied blood/blood products, and makes no distinctions between patients based on where the contaminated blood or blood product which infected them was sourced.

The review process

14. The review was conducted by a team of Department of Health (DH) officials, and the Health Protection Agency's Centre for Infections.

15. This team was supported by input from relevant external experts, including the Chairs of the Macfarlane and Eileen Trusts and the Skipton Fund.

16. Scientific advice on hepatitis C and HIV was obtained from a joint working group of the Advisory Group on Hepatitis (AGH), the Expert Advisory Group on AIDS (EAGA), the UK Haemophilia Centre Doctors Organisation (UKHCDO) and the Hepatitis C Trust.

17. Advice on insurance was obtained from the Association of British Insurers (ABI) and Hanover Re (a re-insurance company).

18. There has also been liaison with the following Government Departments: HM Treasury (HMT); the Department for Work and Pensions (DWP); and HM Revenue and Customs (HMRC), and the Blood and Tissue Policy Unit of the Department of Health and Children in the Republic of Ireland.

19. Representatives of the affected community and members of Parliament were consulted throughout the process. Anne Milton MP, the Under secretary of State for Public Health, met representatives of the main campaign groups (the Haemophilia Society, Tainted Blood, Contaminated Blood Campaign Coalition, Manor House Group and the Hepatitis C Trust), and others, at meetings in July and November. Written submissions and correspondence were also received from these groups and affected individuals. There has also been contact between officials and some of those representatives.

20. This enabled officials to identify a comprehensive list of proposals, see **Annex D**.

21. The conduct of the review was based on the following principles:
    - It focused on the anomalies with the hepatitis C payment scheme, taking payments for HIV as a reference point;
    - The current anomalies between the HIV and hepatitis C payment schemes should be reduced and the creation of new ones avoided;
    - The review was evidence based, wherever evidence was available;
    - Payments are not compensation, they are financial relief which will primarily be needs based;

Payments for hepatitis C infection

22. There are some clear discrepancies between the provision of ex-gratia payments to those who have been infected with hepatitis C, compared to those infected with HIV. There are no annual payments for those infected with hepatitis C and there are no discretionary payments to

those infected or their dependants. Removing these discrepancies is a key objective of the campaigners.

23. The campaigners base their case for parity between HIV and hepatitis C payments on the argument that the impact of quality of life of living with hepatitis C is as great as the impact of quality of life of living with HIV, and that those who are infected with hepatitis C are now actually more likely to die prematurely if they develop severe liver disease than those with HIV infection. In addition, there is currently no provision for payments to the dependants of those infected with hepatitis C (alive or deceased), whilst there is for HIV. Yet levels of financial need for bereaved dependants following death of the primary infectee can be the same, irrespective of whether the patient was infected with HIV or hepatitis C. Therefore, it is argued that those infected with hepatitis C and their dependants should receive payments that are equivalent to those paid in respect of HIV infection.

24. This part of the review assessed the scientific and other evidence for addressing the anomalies between the ex-gratia payments for hepatitis C and HIV infection, and identified potential options for doing so. The options are explained in greater detail in **Annex E**.

25. [HMRC and DWP have agreed that all ex-gratia payments will continue to be tax free and excluded for the purposes of calculating means tested benefits, whichever options in this paper might be chosen. **DN: to be confirmed]**.

The natural history of hepatitis C infection

26. To inform this element of the review, an expert review of the literature on the natural history of hepatitis, including its impact on quality of life, was conducted. Expert advice was sought from a joint working group of EAGA, AGH, UKHCDO and the Hepatitis C Trust. The following paragraphs are a summary of the review paper, which is attached at **Annex F**.

27. Most individuals experience few, if any, clinical symptoms during the acute phase of hepatitis C infections. Some patients clear the infection naturally in the acute phase. However, the majority of patients will progress to chronic infection.

28. Chronic hepatitis C infection is associated with a range of non-specific symptoms and a demonstrable loss in quality of life. In addition, chronic infection has been associated with a range of extra-hepatic symptoms, including neurocognitive effects that impact on daily life, but many of these are difficult to attribute to hepatitis C infection in an individual patient.

29. Drug therapy is able to achieve effective viral clearance, on average, in the majority of patients treated before cirrhosis has developed. However, therapy itself is associated with a range of side-effects, which may be significant. Following successful treatment, the prognosis for disease progression and quality of life largely improves. Within the next few years, more successful and better tolerated therapies are likely to become available.

30. A proportion of patients with chronic infection will progress to cirrhosis, decompensated cirrhosis, or hepatocellular carcinoma. This substantially reduces quality of life, which is liable to deteriorate over time, and has a substantial impact on life expectancy. Even if a sustained virological response can be achieved in cirrhotic patients, liver fibrosis is not completely reversed and the risk of decompensation or of developing hepatocellular cancer remains. Some patients will be eligible for liver transplantation but this in itself involves considerable morbidity and re-infection occurs in nearly all patients. Patients who develop life threatening hepatitis C-related tumours, specifically B-cell non-Hodgkin's lymphoma will experience ongoing hardship of a similar level to those who develop cirrhosis and severe liver disease.

31. Co-infection with HIV can increase the rate of progression to chronic hepatitis C infection and cirrhosis. However, the advent of more effective antiretroviral therapy has improved the quality of life of individuals with HIV, and is likely to improve the prognosis for their hepatitis C infection.

32. The following conclusions have been drawn from the review paper:

i) The lack of morbidity associated with acute hepatitis C infection supports the current position that individuals with acute infection should not receive financial support.

ii) Chronic hepatitis C infection has an impact on quality of life, but it is not as great as for those with severe liver disease (as described in paragraph 26). Skipton Fund stage 1 payments, for individuals in this stage of the infection are designed to take account of the range of symptoms caused by hepatitis C infection, as well as the side-effects of treatment. This suggests that there is not a strong case for making changes to the current Skipton Fund stage 1 payments for all patients. Nevertheless, some patients may experience financial hardship in this phase of the disease, particularly if they are unable to work during periods of treatment.

iii) The development of serious liver disease caused by chronic hepatitis C infection will substantially reduce quality of life, and have a substantial impact on life expectancy. Therefore, there is a strong case for improving the current provision for payments to this group, and for including those who deleop life-threatening extra-hepatic disease, specifically B-cell non-Hodgkins Lymphoma.

<u>Options for payments to infected individuals[3].</u>

33. Based on these conclusions, the review assessed the following five options:

Option	**Description**	**Estimated additional cost to DH budgets over SR period**
1	Do nothing. Keep Skipton Fund payments as they are.	£0.

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[3] Defined as primary infectees and infected intimates.

2	Introduce annual flat rate payments of £12,800 for those who develop any of the conditions identified in paragraph 26, i.e Skipton Fund stage 2 recipients. Plus access to payments from a discretionary fund, on same basis and at equivalent levels to those available for HIV.	£8.0m in year 1. Average £7.8m pa recurrent over next 10 years.
3	Introduce annual flat rate payments of £17,400 for those who develop any of the conditions identified in paragraph 26, i.e Skipton Fund stage 2 recipients. Plus access to small discretionary fund for exceptional hardship.	£9.4 million in year 1. Average £9m per annum (pa) recurrent, for the flat rate payments for the next 10 years. c£0.5million pa recurrent for the discretionary element.
4	Keep Skipton Fund stage 1 payments at current levels, but increase the stage 2 payment by £25k for those who develop any of the conditions identified in paragraph 26, i.e Skipton Fund stage 2 recipients. The options in brackets are for £40k, £50k and £75k.	Approx. £12.0m (£20.8m, £26m, £39.0m) in year 1. Additional average £1m pa recurrent over next 9 years.
5	Access to discretionary payments for Skipton Fund stage 1 patients, based on need. Through a new charity. (Assumes 5% of people have an average discretionary payment of £5,000/yr).	Approx. £0.2m pa recurrent

34. The evidence summarised in paragraph 28 supports the introduction for on-going financial relief for Skipton Fund stage 2 recipients and some provision for needs based payments for some Skipton Fund stage 1 recipients.

35. Options 2 and 3 would be consistent with the scientific evidence, and remove an anomaly between HIV and hepatitis C payments, (£12,800 is the current flat rate payment for HIV infection, and £17,400 is proposed for option 3, should a decision be made to increase the HIV flat rate payment to that level). There is no worked-out rationale for either of these figures, but the £12,800 figure does bring parity between the two patient groups. Making the level of payments higher than to those with HIV would create a new anomaly, which may subsequently be challenged.

36. Consideration was also given to whether these payments should be index-linked (along with those for HIV). This would improve the level of financial certainty provided by these payments.

37. Under each of these options, it is proposed that Skipton Fund stage 2 payments will continue to be paid to those who meet the eligibility criteria, and the first of the recurrent annual payments will be made on the anniversary of the stage 2 payment.

38. The possibility of making an equivalent lump sum payment to infected individuals instead of recurrent annual payments was considered. However, this was rejected because of the difficulty in identifying any rational basis for calculating the lump sum payment and the possibility that new treatments might emerge which could significantly prolong life expectancy, leading to calls for further support from those who had taken lump sums.

39. The scientific advice at **Annex F** indicates that those with serious hepatitis C related illness are now suffering more than those with HIV, who have access to highly effective treatments. Therefore, there is a case for payment of a small additional lump sum to Stage 2 Skipton Fund recipients, as proposed in option 4, in conjunction with

flat rate recurrent payments. However, this could be perceived as "double compensation" and challenged on that basis.

40.The scientific evidence also suggests that the current Skipton Fund stage 1 payment is adequate for most of those with chronic infection, but that some of these patients might experience financial hardship, particularly if they lose their jobs during prolonged courses of treatment. The best way of addressing this issue, as proposed in option 5, is to make provision for discretionary needs based payments for this group. That would be the best way of targeting resources at those in greatest need.

41.A particular issue that will need to be addressed is payments to those who have been co-infected with both HIV and hepatitis C, and have developed severe liver disease. A number of patients with haemophilia were co-infected with HIV and hepatitis C, as were a small number of non-haemophilia patients. Around 360 these patients are still alive of whom less than 100 have developed severe liver disease (as assessed by receipt of a Skipton Fund stage 2 payment). The advice at **Annex F** is that the separate hardship payment should not be affected by hepatitis C-related payments. These patients would therefore receive recurrent annual payments that are twice the level of those who only have a single infection, in addition to the various lump sums payments. Although they would presumably have a lesser claim for discretionary payments from the Trusts. However, there is no clinical evidence to show that their suffering is twice as bad, although the double infection certainly does worsen their condition.

Payments for dependants.

42.As it is currently set up, the Skipton Fund only makes payments to infected individuals. When the Skipton Fund was set up, the decision was made not to make payments on behalf of those who had died prior to the announcement of the scheme on 29 August 2003. The campaigners have since argued that the dependants of those who would otherwise have been eligible to receive payments from the Skipton Fund, but who died prior to 29 August 2003, should receive the payments that their partners would otherwise have received. This has been one of their main representations to the Department of Health.

43. In addition, many infected individuals have expressed concern about the financial security of their dependants after they have died. Representations have been received for something to be done to provide some measure of financial certainty for dependants after the death of the primary infectee.

44. The following options were considered. In all cases it is proposed that payments will be made to dependants themselves, rather than the estate of the infected individual:

Option	**Description**	**Estimated additional cost to DH budgets over SR period**
1	Do nothing.	£0
2	One off lump sum of either £20,000 or £45,000 to widowed spouses/partners of otherwise eligible patients who died prior to 29 August 2003, using existing Skipton Fund eligibility criteria.	£29-59 million, non-recurrent.
3	One-off discretionary lump-sum payment, averaging £50k for primary bereaved family member on death of primary infectee, based on need. To be applied retrospectively. Plus access to discretionary payments, based on need.	Not costed because cannot be delivered.
4	One-off flat rate lump-sum payment of £50k for primary bereaved family member on death of primary infectee. To	£68m - £105m one off.

	be applied retrospectively.	Additional average £0.5m pa recurrent. (Includes HIV for UK & Hep C: for England).
5	Additional financial support to bereaved dependants in greatest need (on top of that provided for in option 4).	Negligible. Included in costs of option 4.
6	Small needs based annual payments for spouse/partner/dependant children[4] of hepatitis C infected people who are still alive. Average payments of £1,000 pa for spouse and £1,000 pa for children.	£0. 6m pa recurrent.
7	Make financial provision for cases of transfusion-acquired hepatitis C, where death before 2003 was not infection-related.	c£0.15m one-off payment.

45. Option 2 would address the representations concerning the dependants of those who died before 29 August 2003. Given that the maximum sum currently paid out by the Skipton Fund at the time it was set up was £45,000, there is no case for making payments greater than £45,000 under this option. The initial presumption would be to make the payment to the bereaved spouse/partner. If the spouse/partner has also died, then the payment could be made to any dependant children. Alternatively, financial support for this group can be considered along with all of the other bereaved, under options 3 and 4, which would be administratively easier to manage, and would avoid the creation of any new anomalies.

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[4] For the purposes of this review, dependant children are classed as those below the age of 18 who are still in education.

46. A key consideration with implementing option 2 will be the medical evidence that individuals will be asked to produce in order to qualify for a payment. However, medical records may have been destroyed and there may be issues around whether deaths have been recorded as being due to hepatitis C. Therefore, there will be significant issues involved in implementing this option, and it is possible that some dependants may not be able to provide the necessary evidence. Relaxing a requirement to provide medical evidence to overcome such difficulties could invite fraud and would be unfair on those still alive if a dual standard of proof were introduced. It will be impossible to make payments to all genuine spouses, without introducing a significant risk of fraud.

47. Options 3 and 4 need to be considered together, and could be applied both retrospectively and prospectively. This would meet the campaigners representations for some measure of financial certainty for their dependants following death of the primary infectee. Option 3 would target resources at those in greatest need, but campaigners and the Trusts would not like the discretionary nature of the payments, and the Trusts have indicated that it would not be possible to justify needs-based discretionary payouts of £10s of thousands, as provided for in option 3. Therefore option 4 is the best option for making bereavement payments.

48. Options 5, 6 and 7 offer means of targeting additional resources at some of those in greatest need. However, it is recommended that these options should be given a lower priority than payments to infected individuals and bereavement payments. Focusing resources on payments to infected individuals and bereavement payments should address the needs of families and children.

Making all ex-gratia payments through the DWP benefits system

49. Evidence given to the Archer inquiry from affected individuals suggests that this request is that somehow applying to the existing charitable Trusts is tantamount to "begging" for hand-outs. Lord Archer argued in his independent report that making these payments through the Department for Work and Pensions benefit payment systems would give the Government direct responsibility for providing these resources.

50. However, it is not clear that there would be any tangible benefits to be gained from making these payments through the benefits systems administered by the Department for Work and Pensions. In addition, the written submission from the campaign groups stated that they wanted the existing ex-gratia Trusts to continue providing support.

51. It would be inappropriate for the Department for Work and Pensions to administer these ex-gratia payment schemes as they address health specific issues and are not consistent with that Departments business aims. In contrast, the mechanism for administering the schemes is well established in the Department of Health, which also holds the knowledge and expertise in this policy area and has had experience of dealing with the Trusts.

52. The Government, therefore, considers it entirely appropriate that these schemes continue to be administered by the Department of Health, as the Department that works most closely with the NHS.

Access to insurance

53. Insurers assess risk, taking into account the applicant's medical history, when deciding whether or not insurance can be offered and if so with what premium loading and/or exclusion. People who have been infected with HIV and/or hepatitis C by NHS supplied contaminated blood/blood products, may face difficulties in obtaining insurance that is assessed using medical history. Some people may be uninsurable for some risks. Other people may be offered a premium loading depending on their health. People with haemophilia who are co-infected with HIV and hepatitis C will not be able to obtain some forms of insurance. For people who are mono-infected with HIV or hepatitis C some insurance terms may be available.

54. The terms 'insurance' and 'assurance' are commonly used. Insurance is cover for an event that might happen, for example term-life insurance will payout if the policyholder dies within the term of the policy. Assurance is cover for an event that is certain to happen, for example whole-of-life will pay out whenever the policyholder dies. The following section will discuss different insurance cover. This has

been informed by the ABI. The insurance scheme set up in Ireland has also been investigated as a potential model.

55. Travel insurance is a policy taken out by the individual to cover him for, among other things, cancellation and medical expenses incurred while abroad, including repatriation in the event of serious illness or death. It is usually available to this patient group from specialist providers but the premium loading may depend on the overall health of the individual, the length of stay and the holiday destination. Some holiday providers utilise group or multi-people plans and it is unlikely that this patient group would be disadvantaged or refused in such circumstances. Information from Ireland has indicated that take-up of their travel insurance policy has been low (17% of eligible people as at 2009). This is in part because most families appear to choose to take out a family (or group) policy. The decision whether and where to holiday, and the type and scope of travel insurance are a personal choice. The cost to Government of providing access to travel insurance, as set out above, for estimated low take up would be prohibitively expensive. Overseas travel is a personal choice, therefore it was considered that it would be more appropriate for resources to be focused on ex-gratia payments for those affected, and they can then choose whether to spend part of that money on an overseas holiday with travel insurance. Therefore the review did not consider this any further.

56. Mortgage payment protection insurance (MPPI) is a policy that pays towards the mortgage repayments should the holder be unable to work, for example due to ill health or unemployment. It is not required as a condition for obtaining a mortgage. Those who do choose such a policy will usually find benefits are available for a maximum period of 12 months, and some do not pay out for illnesses related to pre-existing medical conditions, or for redundancy , that could have been foreseen when the policy was taken out.

57. Term life insurance is a policy taken out for a fixed period of time that will pay out an agreed sum in the event of the policy holder's death. As with other insurances it does not accrue any form of maturity benefit or surrender value. This means that if the policyholder is still alive at the end of the fixed time period, there is no money returned to the policy holder. The biggest representation from the people infected

with contaminated blood is the desire to ensure that their dependants have a degree of financial security in the case of death.

58. There are a number of public policy issues which Government needs to consider when deciding how to proceed:
- Are the circumstances of this patient group sufficiently different to that of other patient groups to warrant making separate provision for life cover?
- What impact might the precedent of providing life cover for this patient group have on other equally deserving groups/individuals wanting similar assistance?
- People with haemophilia may have difficulty obtaining life cover, even if they were not infected with contaminated blood, purely as a consequence of their haemophilia.
- The issue for Government is limited to any additional detriment to accessing insurance, arising directly as a consequence of receiving contaminated blood. This includes people who have become uninsurable or those whose infection would result in higher premiums than they would otherwise have paid..
- Any options must represent value for money.

59. The review looked at 3 options. Full details are in the paper at **Annex G**:

Option	**Description**	**Estimated additional cost to DH budgets over SR period**
1	Do nothing.	£0
2	A state run life insurance scheme	N/k – would entirely depend on take up.

3	Travel insurance	N/k – would entirely depend on take up.

60. Option 2 would meet the campaigners requests, but evidence from the Republic of Ireland indicates that it would be costly to administer. Instead, the bereavement payments proposed earlier in this paper would provide an adequate substitute for life assurance.

61. Similarly, the case for option 3 is also weak. Travel insurance is currently available to this patient group. Premium loadings or policy exemptions might restrict the choice of holiday destination (e.g. the USA is prohibitively expensive for healthcare generally and it is not uncommon for a travel policy to exempt that destination) and duration for some patients, but there will nonetheless be other destinations for which travel insurance is more accessible. In addition, because take up of travel insurance among patients in the Republic of Ireland has been low, it is not considered to be value for money for Government to underwrite travel insurance services for this patient group. Instead, it would be better to focus resources on ex-gratia payments. This will help those who choose to holiday overseas to pay travel insurance premiums.

62. Where commercial insurance products are available, the increased ex-gratia payments proposed in other sections of this report will help individuals pay for premiums.

Prescription charges

63. A theme that emerged in the evidence gathered for this review was that patients who have been infected with HIV and hepatitis C by contaminated NHS supplied blood/blood products should be exempted from prescription charges. However, many of this patient group will already receive free prescriptions because they fall into one of the existing prescription charge exemption categories (primarily age related). It is estimated that there are around 500 infectees who

currently have to pay prescription charges[5]. The review looked at two options:

Option	Description	Estimated additional cost to DH budgets over SR period
1	Do nothing	£0
2	Make prescriptions free of charge for all.	£50k per annum recurrent.*

64.It does not make sense to tie this small group of individuals into a new exemption category under the existing exemption arrangements. This would be administratively complex and would require changes to secondary legislation. Instead, discretionary payments administered by the ex-gratia payment schemes could be made to those individuals affected. All beneficiaries of the Macfarlane and Eileen Trusts and the Skipton Fund who still pay prescription charges could be eligible for an annual discretionary payment that would cover the cost of an annual prescription pre-payment certificate (currently £104 a year) subject to making a declaration that they are liable to to pay prescription charges.

Access to nursing and care services

65.Evidence gathered for the review has shown that there are a number of issues related to the current provision for social care services and home nursing, that are of concern to this patient group. The main complaints are that patients cannot access sufficient nursing or social care, and that they often have to pay for it. Some individual

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[5] Estimate based on assumptions around the likely age distribution of this patient group plus overlap with other exemption crtiteria, which suggest that 90% of the group could be exempt (mostly on age grounds). It is assumed that for the remaining 10% (c. 500 people) prescriptions expenditure amounts to no more than the value of an annual prescription pre-payment certificate (£104) in any one year. This will diminish over time as increasing numbers of patients will become eligible for free prescriptions on age grounds.

campaigners have also highlighted that patients who develop terminal disease will require continuous nursing care in the period leading up to this stage, and that some have encountered problems accessing continuous home nursing care, forcing them to rely on unpaid informal carers. Concerns have also been raised about the level of knowledge about HIV and hepatitis C among nursing and care providers.

66. A common issue among the comments received during the review is the need for intermediate nursing care and improved access to counselling, for both patients and their families. There have been many complaints that patients and families have received no counselling at all on the NHS. Attached at **annex H** is a paper outlining the current position with regard to the provision of social and nursing care for this patient group.

67. The paper highlights that both social and nursing care are available free of charge, based on need. But whilst home nursing care is not means tested, social care services are. There can also be variation in how different Local Authorities charge for non-residential services.

68. The paper highlights one anomaly with respect to provision for this patient group. The first is that unlike payments from the other ex-gratia payment schemes, payments from MFET are not exempted from means testing for social care services.

69. The following options were considered:

Option	**Description**	**Additional estimated cost to DH budgets over SR period**
1	Do nothing.	£0
2	Make MFET payments (and any new payments arising from this review) exempt	

	from means testing for social care services.	To be met from within Local Authorities current provision for social care.
3	Write to Local Authorities asking them to use their discretionary powers to exempt all those infected with HIV and hepatitis C by contaminated blood, from any form of means testing for social care services.	
4	Make additional provision for counselling.	£100,000 pa over 3 years.

70. Option 2 is deliverable through an amendment to the National Assistance (Assessment of Resources) Regulations 1992. Its absence from the Regulations is due to an oversight rather than a deliberate decision.

71. Local Authorities have powers to exempt patients from means testing, therefore the easiest way of doing this would be to write to Local Authorities asking that they exempt this patient group from means testing. However, unless additional resources are provided to Local Authorities, this will put additional pressure on their social care budgets, which could lead to charges rising for others or a "postcode lottery" where some authorities do exempt this patient group but others do not. The exact consequences are difficult to quantify because it will vary from Authority to Authority. It is estimated that there could be 654 Skipton Fund stage 2 patients alive in 2011/12, but it is not known where they live, or how many of them are currently paying for social care services. Therefore the impact on charging for others could potentially be negligible. An additional difficulty is that this would set a precedent for all other individuals infected with hepatitis C (ie those not infected by contaminated blood and blood products).

72. Option 4 would meet a specific request that has made in many letters that the Department has received, and can be delivered with a minimum additional administrative burden through the Terence Higgins Trust and the Hepatitis C Trust.

Additional issues outside the Terms of reference

Payments for HIV infection

73. Comments received during the review have highlighted a desire among this patient group for the Macfarlane and Eileen Trusts to move away from receiving charitable discretionary payments, and for a greater emphasis to be put on fixed flat rate payments. Decisions in respect of payments to Skipton Fund stage 2 recipients could also create new anomalies with HIV patients. The following options are offered for consideration for those infected with HIV and their dependants, mirroring some of those made above in respect of hepatitis C:

Option	Description	Estimated additional cost to DH budgets over SR period.
1	Do nothing. The existing arrangements of flat rate payments of £12,800 for individuals infected with HIV, plus access to discretionary payments. This gave an average of £17,400 per infected person in 2009/10.	£0
2	Introduce flat rate payments of £17,400 for individuals infected with HIV. Plus access to small discretionary fund for exceptional hardship (assuming 5% of individuals receive average payment of £2,000 pa).	£1.6 million pa recurrent.
3	Small fixed annual payments for spouse/partner/dependent children of individuals infected with HIV. Average payments of £1,000pa for spouse and £1,000pa for children.	The estimated cost of these four

4	One-off flat rate payment of £50k for dependants of those infected with HIV on death of primary infectee. To be applied retrsopectively. Plus access to discretionary payments, based on need.	options have been rolled into the estimated cost of the equivalent options in respect of hepatitis C, that are cited earlier in the paper.
5	One-off discretionary lump-sum payment, averaging £50k for dependants on death of primary infectee, based on need. To be applied retrospectively.	

74. Options 2-5 mirror the key proposals in respect of hepatitis C, identified above. This will avoid the creation of new anomalies between HIV and hepatitis C payments. Increasing flat rate payments for HIV patients to £17,400 would be well received by the campaigners and MPs. The figure of £17,400 per annum is roughly equivalent to what Thalidomide patients receive and nearly equivalent to the national average wage of £21k, after tax.

Exemption from the DWP's Work Capability Assessments. **[DN: the following text is subject to change depending on response to PS(PH) letter to IDS].**

75. Some campaigners have asked that this patient group should be exempted from having to undergo the Government's new Work Capability Assessment. The Department of Health has not received any reports that individuals in this patient group who are unable to work for health reasons are now being assessed as being capable of work. Therefore, this demand does not seem to be derived from a tangible problem, just the inconvenience of having to go through the process.

76. Whilst the Government is committed to supporting those who cannot work because of a health condition or disability, and recognises that asking people to attend a face-to-face assessment unnecessarily is in

no-one's interests, there are currently no plans to exempt this patient group from the Work Capability Assessment.

77. Entitlement to Employment and Support Allowance (ESA) is based on an individual's functional capacity for work. It is important to recognise that a health condition will affect different people in different ways, and so we should not assume that a health condition is automatically a barrier to work. That is why we assess each case individually to determine if someone is entitled to benefit and whether it is appropriate to help them prepare for a return to work.

78. The Work Capability Assessment does not always include a face-to-face assessment. Where possible, decision makers may use the paper-based evidence available - information that the customer provides on their ESA50 questionnaire and information from their GP or consultant. However, in order to assess people fairly and accurately it is often necessary to assess them face-to-face, in order to understand how their condition affects them.

Access to dentistry for hepatitis C patients

79. During the backbench debate on 14 October, an MP suggested that hepatitis C sufferers often have significant problems with gum disease, and that there are issues around access to dentistry for that patient group. However, this issue has not been raised in correspondence, or any of the submissions received during the course of the review and we are unaware of this being a specific problem encountered by those with hepatitis C. The question is therefore whether there is a systemic problem around access to dentistry, or whether the issue that was highlighted was simply an example of local difficulties with access.

80. DH advice to the dental profession provides for hepatitis C and HIV patients to be treated safely in general (high street) dental practices. However, individual dentists have discretion over which patients to treat, and might refer a patient to the salaried service or a dental hospital. DH receives occasional complaints about dentists refusing to treat patients with HIV or hepatitis C, but generally, the dental profession are sympathetic and will treat these patients. If patients

have been denied access to treatment for whatever reason, they have recourse to the NHS complaints system.

81. Specialist/secondary dental care, like all other hospital services, is free of charge. In respect of charges for high street dental care, which also applies to the salaried services, it has been the policy of successive governments to base support for dental charges on income rather than medical conditions. Although people in the following groups are exempt from charges:
    - Aged under 18;
    - Aged under 19 in full time education;
    - Expectant mothers;
    - Women who have had a baby in the last 12 months.

82. In addition, the following groups have their dental charges remitted:
    - Those receiving income support, and their partners;
    - Holders of an NHS low income scheme HC2 certificate;
    - Holders of an NHS low income scheme HC3 certificate (partially remitted only);
    - Those receiving income based job seekers allowance, and their partners;
    - Those receiving child tax credit, and their partners (providing family income is below £15,276);
    - Those receiving working tax credit which includes a disability element or severe disability element, and their partners (providing family income is below £15,276).

83. Many recipients of disability living allowance, incapacity benefit, and other benefits would receive full or partial exemption on application for help from the NHS low income scheme.

84. In conclusion, there does not appear to be a systemic problem with access to dentistry for hepatitis C patients. Individual patients might experience problems locally, and they need to be resolved locally.

Conclusions

[DN: to be completed once ministers have made decisions.]