13 May 2024

TO: DEPUTY PRIME MINISTER, MINISTER FOR THE CABINET OFFICE

THE INFECTED BLOOD COMPENSATION SCHEME PROPOSAL FOLLOW UP ADVICE

Issue

- In response to advice on the Infected Blood Compensation Scheme ("the Scheme") sent to Ministers on 1 May 2024, Ministers requested further advice on a number of aspects on the scheme design. Decisions on the remaining aspects are listed in the table below.
- 2. In addition we have provided further advice on the issue of eligibility for parents and children as we understand the Chancellor wishes to see further options on this.
- 3. Under section 149 of the Equality Act 2010, you must have due regard to the need to achieve the objectives set out in that section. We have provided an initial equality impact assessment outlining the impacts currently identified for you to consider. Please see Annex A.

Remaining decisions for Ministers (MCO readout in blue, DPM notes in orange)

Section	Decision
1. Registration closure	 a. Do you agree that registration to people with an existing diagnosis should close after 6 years (target date 31 March 2031) with a review of the scheme closure date 3 years into the scheme's operation (before 31 March 2028)? Agreed b. Do you agree that for people newly diagnosed (after 1 April 2025) applications should be accepted up to 6 years following diagnosis? Agreed
2. Affected eligibility	 a. Do you agree that additional affected categories should be created for parents of someone who was infected when over the age of 18 Agreed children who were over 18 when their parent was infected? Agreed b. If yes, do you agree that the award level for these new categories should match that of siblings and carers? Agreed (DPM request to discuss on 16/05 on different rates- Agreed)
3. Injury and bereavement awards to the affected	a. Do you agree to uplift the affected injury award for infection severities most likely to result in death of the infected regardless of the affected person's bereavement status? Agreed (Option 1) (DPM request to discuss on 16/05 to understand benefits of option 1- Agreed)

4. Future Financial Loss payments to dependents of deceased infected persons	 a. Do you agree that where the infected person is deceased at the time of assessment, a 25% deduction should be made to financial loss that would have been paid to the infected person had they been alive, for the period between death and life expectancy? Agreed b. Do you agree dependency be calculated on the basis of the assumed working salary of the deceased for the full predicted healthy life expectancy of the deceased? Agreed c. Do you agree that evidence of dependency would only be required for dependents not in the position of a partner or child at the time of death? Agreed d. Do you agree that a tariff-based assessment of loss is applied to calculate dependency awards (option 1)? Agreed
5. Transition of Support Schemes	 a. Do you agree to the proposed transitional arrangements? Agreed b. Do you agree that top-up payments should be provided where a bereaved partner would receive less in compensation payments, either directly or as a beneficiary of an estate, than they would expect to receive in support payments? Agreed c. Do you agree that a discretionary fund should be established to mitigate individual cases not yet identified? Agreed d. Do you agree to write to DA ministers suggesting a meeting prior to any announcement? Agreed
6. Interim Payments	 a. Do you agree that the interim payment should be a fixed amount of £210,000 to both HCV and HIV applicants (option B)? Agreed b. Do you agree to include the request to deliver interim payments to infected persons registered with the Scottish, Welsh and Northern Irish IBSS when writing to DA ministers? Agreed
7. Validation with the community	a. Do you wish for officials to engage the community on the supplementary process, evidence requirements and support services? Agreed but wants to test with SRF should he agree to take on the role of interim chair.

Section 1: Scheme registration closure

Decision in original submission: 1.C

Issue: Ministerial request to add a review point for closing the Scheme registration

- 4. In the interest of encouraging people to come forward to the scheme and enabling the ALB to scale back its assessment capability in the future, we recommend setting an expected scheme registration close date for people with an existing diagnosis. We recommended this is set at 6 years which is twice the limitation period for bringing a personal injury or fatal accidents claim. As we do not know for certain when registration will open, we suggest the 6 years runs from 1 April 2025, giving a target closure date of 31 March 2031. We also suggest that this closure date is reviewed before 31 March 2028 to ensure it remains appropriate given data on the Scheme operation such as number and rate of applications. The Scheme is expected to receive considerable pick up across media platforms and will be widely publicised through clinical networks to bring awareness of the Scheme to those with existing diagnoses, so we would expect the majority to come forward in the first few years of the Scheme.
- 5. The expert group has advised that whilst most people infected with HIV will be aware of their infections, there are still new cases of HCV being identified e.g. from transfusions received in childhood where infections only become symptomatic in adulthood. Recent BBC analysis has suggested that approximately 1,750 people in the UK are living with an undiagnosed HCV infection after being given a transfusion with contaminated blood. We will therefore need to retain some level of assessment capability within the ALB or handover organisation for the foreseeable future.
- 6. We would therefore recommend that:
 - a. The scheme launches with an expectation to <u>close registration</u> for people with an <u>existing diagnosis</u> (before 1 April 2025) on 31 March 2031, and that this is reviewed before 31 March 2028. The review will consider the trend in volume of new applicants coming forward to the scheme for each infection and processing times of existing cases for review (as it may be in the interest of the scheme not to force a rush of cases coming forward). Any decision to close the Scheme to registration of people with existing diagnosis (pre 1 April 2025) would be communicated at least 2 years in advance.
 - b. The scheme <u>remains open</u> to applications after this point for those whose infections were <u>newly diagnosed</u> (after 1 April 2025), with applications accepted up to 6 years following diagnosis: this would be publicised through clinical networks.
- 7. Do you agree that registration to people with an <u>existing diagnosis</u> should close after 6 years (target date 31 March 2031) with a review of the scheme closure date 3 years into the scheme's operation (before 31 March 2028)?
- 8. Do you agree that for people <u>newly diagnosed</u> (after 1 April 2025) applications should be accepted up to 6 years following diagnosis?

Section 2: Affected eligibility

Decision in original submission: 3a Issue:

- 9. We understand the Chancellor has asked for further advice regarding eligibility of parents and children. Under the eligibility criteria proposed in our advice of 1 May affected persons would qualify for awards as a parent where their child was infected while under the age of 18. Similarly to qualify for awards as a child, the infection of the parent must have occurred while the individual was under the age of 18. Parents and children where the infection occurred when the relevant person was over 18 would be eligible as a carer, provided they had provided care. The award levels for "parent" and "child" recommended by the Expert Group reflected the additional injury that would be expected where a child under 18 is concerned; for example a parent having responsibility for medical decisions and in some cases administration of medicines that may have caused the infection, and of the impact of adverse childhood experiences Annex B.
- 10. However, this may mean parents and children who do not qualify as a "parent" or "child" under the Scheme feel that their relationship is not being recognised. This could result in criticism of the Scheme. Ministers may, therefore, wish to consider creating additional categories within the Scheme which recognise this relationship, but at a different award level from parents/children where the relevant person was under 18. We would recommend that the award level matches that of siblings and carers. This would provide an award of up to £30,000 to a parent of someone whose first infection occurred when they were over 18, compared with £80,000 for a parent of someone infected as a child¹.
- 11. This would mean that parents of a person whose first infection was over the age of 18 and children who were adults at the time of their parent's infection would be admitted to the Scheme without having to establish that they provided care. Award levels would be the same for these additional categories as for carers, but there would be a quicker and simpler application process based simply on their relationship to the infected person. This would also have the advantage of having a category under the Scheme for affected persons who may have a dependency claim (see Section 3C). The number of people affected is very uncertain which means we cannot model the precise cost of this policy option. However, these additional parents/children were already counted as carers in the existing costs, meaning this uncertainty is accounted for in the current cost estimate range of the scheme (£8.1 to £21.9 billion).
- 12. Do you agree that additional affected categories should be created
 - a. for parents of someone who was infected when over the age of 18
 - b. children who were over 18 when their parent was infected?
- 13. If yes, do you agree that the award level for these new categories should match that of siblings and carers?

¹ Values quoted assumes recommendations in Section 3 are accepted.

Section 3: Injury and bereavement awards to the affected

Decision in original submission: 3.A **Issue**

- 14. Under common law, there is significant discrepancy across the four nations on the level of awards for bereavement following a wrongful death. In England and Wales (under the Fatal Accident Act 1976) and Northern Ireland (under the Fatal Accidents (Northern Ireland) Order 1977) a single bereavement sum of £15,120 and £17,200 respectively is available split between all those eligible. In Scotland (under the Damages (Scotland) Act 2011), loss of society awards (akin to bereavement) are often more generous and are calculated on an individualised uncapped basis available to a wider list of relatives. Approximately 13% of IBSS beneficiaries are based in Scotland.
- 15. The Infected Blood Inquiry ("IBI") recommended that an award for bereavement should form part of the affected Injury award and that in setting the appropriate award levels, the Scheme might consider the approach taken in Scotland.
- 16. In the courts, the right of the affected to claim a bereavement award only arises where an infected person's claim for the injury that caused the wrongful death has not been settled at the time of their death. Should the courts accept compensation under the Scheme as settling a living infected person's claim, affected individuals would not have a right to a bereavement award when the infected person dies, where caused by infected blood.

17. Option 1: Uplift affected injury award for infection severities most likely to result in death of the infected (recommended)

- 18. The new proposal for injury awards to the affected people would bring the total injury, social impact and autonomy award for those affected to a midpoint of what we estimate a relative may receive in Scotland as a loss of society award, see Annex B. We are unable to remove all risk of court action: persons based in Scotland could still pursue court action in an attempt to increase their payment amounts as the amount the court can award is uncapped and may be higher than that given under the Scheme. However, we consider this approach should reduce the likelihood that a person would pursue a court action. This is because the figure (for injury and awards overall) will be closer to what a person may receive in a court award and therefore it may be considered less worthwhile to pursue litigation given the stress and time involved and the uncertainty of outcome.
- 19. Given this award is meant to recognise the impact that loss of a loved one following wrongful death may have on an affected person, we recommend this increased award is only offered to the affected of infected people where their infection severity is likely to mean that the infection results or resulted in death i.e that the individual did or will die from the infection rather than die with the infection. Clinical advice from the Expert Group is that this applies to HCV/HBV Cirrhosis, HCV/HBV Decompensated cirrhosis, HIV and Co-infected. Affected for HCV/HBV chronic infections would receive a lower injury award as their loved ones' infection is less likely to have resulted in death, but still recognises the impact that the infected

person's disease may have had on them. It should be noted that this amount still exceeds the bereavement award amount for England and Wales, and Northern Ireland. This would replace the proposal to offer additional bereavement awards in the advice shared earlier this week.

We recommend it is made clear in the Scheme documents that the injury award to affected people recognises the death or likely death of a loved one in the future, as a result of infection, and the impacts which that may have on the affected person.	
result of infection, and the impacts which that may have of the affected person.	
GRO-D	
	7
GRO-D	
	affected people recognises the death or likely death of a loved one in the future, as a result of infection, and the impacts which that may have on the affected person. GRO-D

22. Increasing the injury awards as proposed would increase the cost of the scheme by a central estimate of approximately £0.87 billion (£0.34-£1.48bn). This would bring our estimated cost of the scheme to approximately £14.33 billion which consists of payments totaling £10.5 billion to the infected and £3.83 billion to the affected. This would replace the proposal to offer additional bereavement awards in the advice sent 1 May (discussed on 8 May) which we estimated to cost approximately £1.2 billion.

23. Option 2: Offer a bereavement to only currently bereaved affected individuals

- 24. An approach to ensuring a bereavement award is only paid to the affected where they would have a claim in common law would be to only offer a bereavement award to those already bereaved. This would involve a payment under the injury heads of loss to all currently bereaved partners, parents and children of infected persons where the infection was likely to have been the cause of death (HIV, Co-infection, HCV or HBV cirrhosis and HCV or HBV decompensated cirrhosis/liver cancer).
- 25. Affected people who are bereaved after compensation has been paid to the infected person would not be eligible for this award. Whilst reflecting the common law position, this approach is likely to not be well received by the community as it will be a difference in treatment between past and future bereavements. In the courts claimants may delay settling a case to increase the chances of their loved ones receiving a bereavement award. There is a small risk of a similar effect within the Scheme should the affected right to a bereavement award fall away with settlement of the infected claim. However we think this is mitigated as the infected person will be able to claim for future financial loss and make provision for any dependents in their will.

- 26. Adding a bereavement award to currently bereaved affected individuals would increase the cost by £20,400, £52,000, and £45,400 for each bereaved child, partner, and parent entering the Scheme respectively. The total number of affected coming forward is highly uncertain, but on current assumptions in our central scenario this would cost approximately £540m (this cost is already included in Option 1 above).
- 27. We would recommend Option 1 as this will likely be seen as most equitable by the community and ensures the Scheme recognises all bereavements where the infection is likely to have resulted in death of the infected person, without the need for affected persons to return to the Scheme at the point of bereavement.
- 28. Do you agree to uplift the affected injury award for infection severities most likely to result in death of the infected regardless of the affected person's bereavement status?

Section 4: Future Financial Loss payments to dependents of deceased infected persons

Decision in original submission: 3.C

Issue: Further advice on how to operationalise financial loss awards to the affected (akin to dependency awards) which Ministers have agreed to offer via the Scheme.

- 29. Under the England and Wales Fatal Accident Act 1976, Fatal Accidents (Northern Ireland) Order 1977 and the Damages (Scotland) Act 2011 in Scotland dependents are able to claim dependency awards. These cover the loss of dependency both in terms of the financial earnings of the deceased and the services they provided (for example childcare). Dependents have 3 years to come forward to bring a claim under the relevant legislation. In England and Wales (but not Scotland), a living infected or an estate of a deceased infected might be able to bring a claim for future financial loss (e.g. a lost years claim). If they were to do so, dependents would not also have a claim for dependency (as dependency claims on the one hand and future financial loss damages aim to compensate the same loss).
- 30. The Compensation Study sets out that Bereaved Family Financial Loss Award, akin to dependency claims, should be calculated in the same way as a loss of dependency claim under the Fatal Accidents Act. The IBI recommended this head of loss be replaced by a single category of financial loss award applicable to both infected and affected but did not advise how this should be paid out.
- 31. We recommend that where the infected person is deceased at the time compensation is assessed, past financial loss (based on the formula set out in our previous advice) from the point of infection to death is paid to the estate of the deceased to reflect the position at common law. We recommend that financial loss from death to the usual life expectancy of the infected person is paid directly to dependent affected persons. This would be akin to a common law dependency payment and aligns with the IBI recommendation that financial loss be paid direct to the affected, see Annex C.

Legal Risk:	GRO-D	j
	GRO-D	
		1
		İ
	GRO-D	
	Legal Risk:	Legal Risk: GRO-D GRO-D

GRO-D

- 34. Do you agree that where the infected person is deceased at the time of assessment, a 25% deduction should be made to financial loss that would have been paid to the infected person for future financial loss, for the period between death and life expectancy?
- **35.** To avoid complexities of calculating when a dependency would have occurred in the deceased's earning lifetime, we would recommend calculating dependency on the basis of the assumed full working salary of the deceased (a rate of median +5% annual salary netted for tax and NI (£29,657)) for the healthy life expectancy of the deceased and not consider a pension rate.
- 36. Do you agree dependency be calculated on the basis of the assumed working salary of the deceased for the full predicted healthy life expectancy of the deceased?
- 37. There is then a question on how the financial loss award should be apportioned between dependent relatives. Under common law, dependency is assessed on a proportionality basis and divided among all relevant dependents and can include both financial dependency and loss of services (e.g. childcare provided by the deceased).
- 38. As not all affected individuals will have been dependent on the deceased at the time of death, we recommend that eligible affected individuals are asked to declare whether they had a dependency on the deceased infected person at the time of death, or would have expected to be dependent on the deceased were it not for their infection, when they make themselves known to the Scheme. In the interest of speed and reducing the burden on applicants we would not ask for evidence of dependency on the infected person for those in the position of a partner or a child under the age of 18 (e.g. a niece living with the infected person) at the time of the infected person's death. This is because it is considered likely that these groups would have been dependents of the infected at the time of death. If other affected persons declare that they were dependent on the deceased or the dependency of a child goes beyond the age of 18 (e.g. in the case of a child with a disability), they would be required to provide evidence of dependency via a supplementary route.
- 39. Do you agree that evidence of dependency would only be required for dependents not in the position of a partner or child under the age of 18 at the time of death?
- 40. Taking the 75% financial award of the deceased, there are two options on the approach the Scheme can take to apportionment between dependents:

Option 1: Tariff-based assessment of loss (recommended)

- 41. In the interest of speed, the Scheme could utilise a tariff based approach to assessing the financial loss of dependents by assigning fixed proportions of financial loss to affected individuals considered most likely to have a dependency, i.e. partners and children under the age of 18 at the time of death. This has the advantage that each application from an affected person can be assessed on its own merits, and as soon as it is received, regardless of whether the Scheme is considering applications from other affected persons with a relationship to the same deceased infected person. As a starting assumption we recommend using the conventional approach to apportionment proposed by case law² and current practices under the IBSS³. This sets out the assumption that there is an equal division of the dependency award (75% of net income) between partner, household (assumed to go to partner) and children (collectively). We would therefore recommend the following apportionment percentages:
 - Partners at time of infected persons death- 75% of total dependency award (56% of the infected person's financial loss): This reflects that under current UK IBSS, bereaved partners receive 75% of the infected person's award as a bereaved partner payment.
 - <u>Children under age of 18 at time of infected persons death- 25%</u> of total dependency award per child (18.8% of infected's financial loss). This is a more generous approach than that taken in the courts where the 25% would be divided between all eligible children. This does mean that where there are three or more dependent children, the amount paid out by the Scheme as financial loss to the affected would be more than would have been paid to the infected person if living. This may also be the case if there are other dependents accepted via the supplementary route. However this will be limited to the years for which those children are eligible, this would be until age 18, or longer where they could demonstrate dependency beyond this via the supplementary route. There is also an argument for this generosity in the apportionment percentage to children to reflect loss of services of the deceased e.g provision of childcare.

Financial loss award of deceased Award available to dependents (75% of net financial loss award)		Annual financial loss award to partner	Annual financial loss award to each child
£29,657	£22,243	£16,682	£5,561

42. Using this tariff based approach, the cohort we deem at highest risk of receiving a dependency payment less than the principles of the approach intended are children under the age of 18 who lost both parents to infected blood related infections. This is

² Harriss v Empress Motors (1984)

³ Under current IBSS schemes bereaved partners receive 100% of infected persons regular payment for first 12 month following bereavement then 75% of this payment after 12 months

because there will be no parent to bring a dependency claim in the 'position of a partner'. We would therefore recommend where a child has lost both parents to infected blood related infections whilst they were under 18, they are eligible to apply for the whole dependency award of £22,243 per annum for the period they were/will be under the age of 18 (i.e step into the shoes of a parent/partner as well as receiving the child payment).

- 43. This will treat children differently as between those with a parent and those without (as they would get more than if they received dependency for each parent based on the current model). We consider this justified because of the potential increased impacts on their financial position from the loss of both parents as compared to one. We recommend the higher amount settles both claims because of the increased amount that is paid to them. As this would be awarded per child it would result in paying out more than would be apportioned if the dependent group was assessed in full where there are more than two children orphaned as a result of two deceased infected parents. However, we expect the number of such people to be small and so we consider this to be justified given the specific circumstances and the benefit to those individuals.
- 44. The table below sets out example awards using this approach.

Financial loss award of deceased	Dependents	Annual financial loss award to dependents
Financial loss award of	Household with one	Partner: £16,682 pa
deceased: £29,657 per	partner	Total over 10 years: £166,820
Financial loss award available to dependents:	Household of one partner and child A aged 10	Partner: £16,682 pa Child A: £5,561 pa
£22,243 per annum	agou 10	Total over 10 years: £211,308
Total over 10 years: £222,430	Household of one partner, Child A aged 10, Child B aged 6	Partner: £16,682 pa Child A: £5,561 pa until 18 Child B: £5,561 pa until 18
	aged o	Total over 10 years: £278,040
	Household with one	Child A: £22,243 pa until 18
	child aged 8 (both parents infected deceased)	Total over 10 years: £222,430

45. As this proposal does not split the total financial loss of an infected person between a known group of dependents, there is a risk the Scheme could award more or less overall than what would be awarded to a known group of dependents. For example, a large family could receive higher compensation in aggregate than if their claims had been considered in the round. Meanwhile a partner with no children could receive a lower percentage than would be apportioned to them if the dependent group was

assessed in full. However, in the interest of simplicity and parity we consider this discrepancy to be reasonable. We do not hold any data on infected family size or structure, so cannot specifically cost this option. However, we are confident that this will cause a net reduction in the overall cost of the Scheme whilst still treating applicants fairly and equitably.

46. Please note decisions on the approach to dependency will impact on arrangements for the transition from the support schemes including the level of top up payments current bereaved partner currently registered with IBSS may require (see section 5).

Option 2: Assessed apportionment to dependents after period of time

- 47. This approach reflects the common law approach to dependency claims and would require all dependents of an infected deceased individual to register their dependency with the Scheme within a set time period. After this point an apportionment exercise would be undertaken by the Scheme to decide the percentage of the deceased infected person's financial loss award due to each dependent.
- 48. As the Scheme is proposed to be open for 6 years, with a 3 year review, it is fair for the affected (who are entitled to the dependency payment in their own right) to have the 6 years to bring their claim including for the financial loss award. This would have the benefit of ensuring a simple and accessible scheme as the same closure date would apply to all applicants.
- 49. Introducing a shorter time limit for declaring a dependency, for example 18 months after the eligibility of the deceased infected person was accepted by the Scheme, would have the advantage of being able to settle affected claims in full more quickly. However, this may be difficult to enforce given that dependents would likely be reliant on the estate representatives informing them of the registration to know about the deadline as actions the Scheme could take would be limited by confidentiality considerations and affected individuals not being known to the Government. Treating affected dependents differently from each other, or differently from the infected, without good reason, or failing to be transparent in terms of rules applied to each of the affected will increase legal risk as the scheme might successfully be challenged on the basis of lack of reasonableness, rationality and/or procedural fairness, for example.
- 50. Following the registration period for dependents, the value of the financial loss of the dependents on the deceased infected would be apportioned between dependents according to the assumptions set by *Harriss v Empress Motors (1984)* and the years where a dependency claim was valid (e.g. life expectancy of the deceased and the affected). The table below sets out example awards using this approach.

Financial loss award of deceased	Annual financial loss award to dependents

Financial loss award of deceased: £29,657 per annum.	One partner, child A aged 16, child B aged 10	Year 1-2: Partner: £14,829 Child A: £3,707 Child B: £3,707
Financial loss award available to dependents: £22,243 per annum (75% of £29,657)		Year 2-8: Partner: £14,829 Child A: £0 (over 18) Child B: £7,414 Year 8+: Partner: £22,243 Child A: £0 (over 18) Child B: £0 (over 18) Total over 10 years: £222,430
	One partner	Year 1+ Partner: £22,243
		Total over 10 years: £222,430

- 51. The substantive issue raised by this option includes the need to hold back payment of any dependency claims for 6 years whilst the affected group registers their claim with the Scheme. This will create a period of uncertainty and substantive delay in the payment of the financial loss award for affected persons. This may cause particular difficulty with regards to bereaved partners who would need to be supported by the IBSS or equivalents in the interim period (see Section 5). There is also a risk dependents may pass away during this period and lose their access and claim to dependency as the IBI has been clear that the estates of affected are not eligible for compensation. This is likely to be criticised by the community who already consider that compensation has been delayed for too long.
- 52. There would also be a risk, if the rules were not sufficiently clear and/or workable, that dependents who missed the time limit for registration, would challenge the Scheme successfully with the result that they would recover the value of their dependency claim at a later stage. Such litigation would have a financial cost to the Scheme as well as a time and reputational cost.
- 53. The one benefit of this approach would be the Scheme would more accurately reflect the common law approach to apportionment and therefore would prevent circumstances where the value of the dependents' financial loss claim is higher than the estimated value of the lost earnings of the deceased, on which those claims are based. On balance we do not consider this benefit to outweigh the significant risks and negative reaction of the community.

Recommendation

54. In the interest of speed and simplicity for applicants <u>we would recommend option 1</u> (tariff-based assessment of loss) as this would enable dependents to receive their

financial loss award independent of other dependents coming forward to the scheme and without delay.

55. Do you agree that a tariff-based assessment of loss is applied to calculate dependency awards (Option 1)?

Section 5: Transition of support schemes

Decision in original submission: 4.C

Transition arrangements:

- 56. You have agreed that the support schemes should be replaced by payments under the compensation scheme. We previously advised that transitional arrangements will need to be put in place to ensure no beneficiary of the current support schemes experiences a gap in payments. Continuity of support payments came up as a key area of concern and anxiety with the infected and affected community during recent engagement undertaken by MCO. It is therefore important that clarity is provided to beneficiaries under those schemes as part of the announcement of the Scheme.
- 57. **Proposal:** We propose the following steps for a transfer scheme to manage the change from IBSS support payments to compensation payments under the Scheme. The IBSS are already provided for, predominantly in DHSC with devolved administrations providing for some expenditure related to their own IBSS. The proposal below does not require new spending to continue IBSS or on transfer to the IBCA as these funds are already accounted for in government spending. However it will require CO having this provision. The timing of when the IBCA takes over administration of payments will depend on how quickly the IBCA has sufficient capability to do so.
 - a. Support payments continue on an ex-gratia basis operated by the current IBSS until 31 March 2025, as they will have already received information from the IBSS about their payments for 2024/25 and so have a legitimate expectation based on this information about what they will receive. Furthermore the Scheme will not be in place until legislative processes are completed later this Autumn and the IBCA is operational.
 - b. From 1 April 2025 beneficiaries continue to receive payments the same level via the IBSS, but these are no longer considered ex-gratia. It is made clear to beneficiaries that any monies received after this point will be deducted from their compensation payments.
 - c. This arrangement continues until the IBCA either completes assessment of an IBSS beneficiary's claim, or takes over management of their support payments while their case is assessed. This will need to be decided as part of plans for operationalising the Scheme, in consultation with the devolved administrations.
 - d. The IBSS will continue to accept new beneficiaries against their existing criteria until the IBCA is able to accept applications from beneficiaries not previously registered with an IBSS. At this point, new applications to an IBSS will not be accepted.

e. Once all beneficiaries who wish to be are transferred, the IBSS ceases to provide financial support. It may be that it is appropriate for each nation to continue to provide some non-financial support locally, particularly in terms of psychological support; but this will be a matter for DHSC and the Devolved Administrations. Should an IBSS beneficiary choose not to engage with the IBCA their payments would stop at this point.

58. Do you agree to the proposed transitional arrangements?

Beneficiaries "worse off":

- 59. We advised that there is the possibility of a legitimate expectation for support payments to continue, set by Matt Hancock when giving evidence to the IBI in his position as Secretary of State for Health and Social Care, who said that support payments would continue for as long as they are needed, for life if necessary. We expect that the majority of those on the IBSS will be net beneficiaries from the Scheme compared with a continuation of their current support payments: that is, the value of their compensation taken as a stream of payments will be higher than the support payments they receive now.
- 60. However, our assessment is that, subject to decisions you make regarding financial loss payments to bereaved partners, there may be a limited cohort of bereaved partners who would have less money under the Scheme, including for these purposes as a result of benefiting from the claim under the Scheme by the estate of the deceased infected person, than they would have expected to receive in support payments. This is most likely in cases where the following all apply: (1) the bereaved partner does not benefit from the deceased person's estate (for example where they were cohabiting and the infected person died intestate); (2) where bereavement is more recent to the opening of the Scheme; and (3) where the infected partner died closer to or beyond usual life expectancy, meaning that limited financial loss (dependency) payments are due to the bereaved partner in their own right. Where all these factors apply this gap would emerge over a relatively short time period (potentially less than 3 years in some circumstances).
- 61. We propose that we announce up front that bereaved partners in this situation will receive a top-up payment to bring the compensation they receive up to the level of their support payment. Partners would need to attest to what benefit they had received from the infected person's estate, that could be attributed to the estate claim under the Scheme, but otherwise the top-up would be automatic. This top-up would also need to be in place for the period until the estate claim is assessed. For this identifiable group of IBSS beneficiaries, we suggest this is better than a contingency fund to which individuals would have to apply. To give an illustration of the potential costs, if all bereaved partners currently registered with IBSS required a top-up the cost of this would be in the region of £12 million/year (based on 2024/25 rates).
- 62. The proposal to take into account the benefit of inheritance from the estate of the deceased infected person as a result of their claim under the Scheme in considering whether to provide a top up to be be argued partners carries increased legal risk. It could be argued that the legitimate expectation was in payments made to them in their own

right and therefore the estate amount (which is in the shoes of the infected) should not be taken into account. However, we consider that there are good public interest arguments in respect of proper administration of public money in taking into account the amount received by a person in the round from the Scheme. There may also be a risk from the delay of payment to the bereaved partners as it would mean finalising their total claim under the Scheme only once it was possible to assess the bereaved partner's share of inheritance that could be attributed to the claim of the deceased infected estate under the Scheme e.g. after the estate had been distributed. **GRO-D**

GRO-D

- 63. There may be other circumstances where an infected beneficiary of an IBSS receives less in compensation than they would in aggregate under the IBSS, if those payments were continued for their lifetime. For example, where a beneficiary of an IBSS is relatively young so could receive support payments for many years. The time-frame for this varies by severity band, but even for the lowest tariffs under the Scheme it would take approximately 30 years for the IBSS payments to exceed the compensation amount. Note that this is in nominal prices and does not consider payments rising by inflation, or the benefit of having a large lump sum growing in value. For these cases a contingency fund would be appropriate: we recommend the ICBA has such a fund to allow mitigations to be put in place should such circumstances arise. Further work is needed to understand circumstances in which the fund might be engaged and to estimate the cost of this, however this would be within the spending levels already allocated to IBSS.
- 64. Do you agree that top-up payments should be provided where a bereaved partner would receive less in compensation payments, either directly or as a beneficiary of an estate, than they would expect to receive in support payments?
- 65. Do you agree that a discretionary fund should be established to mitigate individual cases not yet identified?
- 66. As previously advised, transitional arrangements will require the consent of the Devolved Administrations. We therefore advise that you urgently write to the Devolved Administration Health Ministers to seek their views and suggest a meeting to obtain agreement in principle prior to any announcement.
- 67. Do you agree to write to DA ministers suggesting a meeting prior to any announcement?

Proposed lines to take for announcement:

- I recognise that people rely on the support payments they receive from the infected blood support schemes and people are keen to understand what the Government's intentions are.
- The Government intends to deliver justice for victims of infected blood and will pay compensation for both past and future losses. Once this compensation is in place, the support schemes will no longer be needed.

- However, receiving applications and paying full compensation will take time.
- Therefore, no immediate changes will be made to the support schemes. Payments
 will continue to be paid, at the same level, via the infected blood support schemes on
 an ex-gratia basis until 31 March 2025. This means these payments will not be
 deducted from compensation. This is in line with the commitment already made by
 Earl Howe that past ex-gratia payments would not be discounted by the Scheme.
- From 1st April 2025 beneficiaries will continue to receive payments until such time as
 their case is assessed by the Infected Blood Compensation Authority. At that point
 individuals will be able to choose whether to receive all their compensation as a lump
 sum, or to receive periodical payments as part of their compensation settlement.
- It will not be possible for the Infected Blood Compensation Authority to assess all
 cases at the same time. To ensure parity between individuals regardless of whether
 their case is assessed first or last, from 1 April 2025 any support payments received
 will be deducted from the final compensation settlement.
- As part of the assessment the Infected Blood Compensation Authority will consider the financial payment that an individual would have expected to receive from an infected blood support scheme and how this compares to the compensation they will receive, either in their own right or as the beneficiary of an estate. We have identified some limited circumstances in which bereaved partners who are not the beneficiary of their partner's estate could receive less in compensation than the value of the current support payments if those were continued for their lifetime. In these circumstances top-up payments will be provided. For other beneficiaries the value of the compensation they receive should exceed the lifetime value of support payments, but if there are any cases where this is not so the IBCA will have a fund to enable this to be mitigated.

Section 6: Interim payments

Decision in the original submission: 5.B

- 68. The Minister for the Cabinet Office has asked for further explanation for why option C (paragraph 132) on delivering two fixed payments to those infected with HCV or HIV is not preferable.
- 69. Our previous advice set out four options on the scope of interim payments to the infected (point 132, A-D). Our assessment was that a <u>fixed payment</u> to all infected IBSS beneficiaries of £210,000 (option B), equal to the minimum award for the chronic HCV severity banding (minus the first interim payment) was the preferred option. This was on the basis of balancing speed of delivery, legal risk and risk of overpayment. There is a risk in making interim payments that, where someone has already received compensation via the courts, interim payments result in double recovery.
- 70. We do not consider option C (of two fixed payments) to be preferable as:
 - a. Delivery confidence in this option is lower. While we have confidence that a fixed payment to all beneficiaries can be delivered within a short (c. 3 month) timetable by NHSBSA and the other IBSS administrators, because this has been done before, this is not the case for Option C. Payment of two, separate, fixed rates will create a risk to both the delivery timetable and require additional administrative processes which the schemes are not currently resourced to deliver.
 - b. NHSBSA have not been able to estimate with any certainty the additional time needed to deliver option C as compared to option B, or the additional resource required to reduce the timeline. We have not been able to test this with the Devolved Administrations, and so they have not factored this into their delivery plans. We are aware that the Devolved Administrations are already significantly concerned about the pressure on their Scheme administrators of delivering interim payments for estates. Indeed officials in Northern Ireland have written to DHSC on this matter.
 - c. The intention is that interim payments to infected beneficiaries would be prioritised over interim payments to estates. This means any additional time or administrative resource needed to deliver interim payments to infected individuals will have a knock-on impact on delivery of interim payments to estates. Under the VAP Bill the Government will now have a duty to make interim payment to estates.
 - d. There are additional handling risks to consider with Option C. Option C involves paying a flat rate for <u>all</u> HCV beneficiaries which is lower than the flat rate for HIV. It could be difficult to explain why those HCV beneficiaries who are very unwell, for example those with liver cancer, will receive a lower interim compensation payment compared to someone with HIV who may be relatively well. An explanation based on the inability of the IBSS to assess

differences in HCV severity (the reason we did not recommend Option D), is likely to attract significant criticism.

- 71. It should also be noted that not providing further interim payments to bereaved partners, when they were included in the first round of interim payments, could be criticised. However, given the significant health prognosis of many infected beneficiaries of IBSS we consider it appropriate to deliver interim payments to this cohort only. Further payments to bereaved partners at this stage outside of the Scheme and before transitional arrangements are in place for the IBSS creates a significant risk of overpayment.
- 72. Therefore, do you agree that the interim payment should be a fixed amount of £210,000 to both HCV and HIV applicants (option B)?
- 73. Delivery of interim payments to the infected will rely on the devolved governments agreement to distribute these payments on behalf of the UK government. We therefore recommend that you include this when writing to DA ministers regarding support scheme transition.
- 74. Do you agree to include the request to deliver interim payments to infected persons registered with the Scottish, Welsh and Northern Irish IBSS when writing to DA ministers?

Section 7: Validation with the community

Decision in original submission: N/A

- 75. You have requested further advice on options for validating the design of the Scheme with the community following the announcement. It is important that any engagement, regardless of whether this is as part of a formal consultation or not, does not ask for views on matters which are already settled by the Government. This is part of the Government's Consultation Principles and there is a very high risk of successful legal challenge if the Government seeks views on matters where it has no intention of altering its decision. The Government must properly consider the views of those it chooses to consult with in its decision making before the final decision is made.
- 76. This means that any validation engagement will need to be limited to matters where policy is still in development and views of the community are not already known.
- 77. The Scheme as proposed is based upon the recommendations of the IBI, which drew on both representations made directly to the IBI and the report of Sir Robert Francis who held focus groups with the both members of the community and legal representatives. Any engagement now should not repeat that work. You (DPM) have said that tariff rates with their direct impact on the overall cost of the Scheme must be a decision for Ministers and that direct consultation on these should be out of scope.
- 78. To the extent the resulting policy needs to be set out in regulations, engagement will need to take place in time for these views to influence drafting if required once the final decision is made. As the VAP Bill requires the scheme to be established through secondary legislation within three months of Royal Assent, and time is needed for draft regulations to be properly reviewed by the appropriate HMG committees before laying, our assessment is that any engagement which will influence drafting will need to be completed in June 2024.
- 79. Given these short timescales, we suggest engagement will need to be very focused if it is not to be tokenistic, and undertaken through community representatives rather than with the community at large.
- 80. Sir Robert Francis has been in touch with MCO about consulting on the scheme. Sir Robert is clear that some engagement on the terms of the scheme is essential if the scheme is to enjoy the community's trust, and that this would be a condition of his accepting the appointment of interim chair. He recommends an advisory group of beneficiaries be given the opportunity to review and offer observations on the Scheme before final decisions are made.
- 81. We have identified areas of scheme design where engagement with the community would be especially beneficial in terms of settling how the scheme will work in practice, and which taken together would give the community to validate the overall approach of the Scheme without directly seeking a judgement on tariff rates. These include:

- a. Scheme structure and relativities between categories of awards and severity bands: Whether the Scheme overall takes sufficient account of the full range of cases and experiences among the infected and affected groups.
- b. Care and financial loss awards: whether the patterns of experience which the Expert Group has used to set awards for the core routes for these heads of loss are sufficiently representative and cover a wide enough range of cases, so that the supplementary route is genuinely for special cases only.
- c. Evidence requirements: Whether evidential requirements have been set in the right place so that these are reasonable and practicable for applicants and wherever possible accept their statements on trust, where this can be done without laying the scheme open to fraud.
- d. Support Services: The VAP Bill provides for the IBCA to provide support services. It would be useful to understand what would be most beneficial to the community with regards to this, particularly around financial advice as this is not something currently provided by the IBSS.
- 82. Given the limited time for engagement during the drafting phase for secondary legislation we would propose that any engagement around aspects of Scheme design consists of focus groups with those individuals identified for the recent engagements held by MCO as these individuals were selected for their roles in prominent charities, campaign groups and support groups and consideration was given to ensuring balanced representation across the infected and affected community. Given the subject matter of these focus groups, we will need to consider whether it is appropriate for these meetings to also include legal representatives.
- 83. We think we could hold 4-6 focus groups by the end of June. We propose the details of the scope and approach to engagement are agreed with Sir Robert Francis, who could participate if he is appointed as interim chair.
- 84. There will be significantly more opportunities for community engagement related to the establishment and ongoing operation of the IBCA. David Foley and his team are working on ensuring that opportunities for community engagement are built into the IBCA as it is established. Initial advice about arrangements to allow interested persons to "sign-up" to be involved in service design is provided separately.
- 85. Do you support engagement with community representatives to take place in June, framed around the supplementary process, evidence requirements and support services, with the details to be agreed with Sir Robert Francis prior to 20 May?

Section 8: HIV financial loss (For information)

Decision: 2.J (Annex D)

Issue: Ministers previously agreed that eligible infected individuals should receive financial loss awards linked to infection severity. In line with this decision, the Expert Group has since amended the previous proposal for how this calculation should be applied to HIV and coinfection financial loss.

- 86. Since advice was sent to Ministers on 1 May the Expert Group has updated the proposal for HIV and co-infections financial loss formula. Unlike HCV and HBV infections, the Expert Group has linked impact on financial loss for HIV and co-infections of HIV and HCV/HBV to the infected person's diagnosis status as introduction of effective treatment is not considered to have resulted in a significant improvement to the quality of life and work capacity of individuals considering side effects.
- 87. The proposal assumes a 50% financial loss from date of infection to diagnosis followed by 100% financial loss following diagnosis. The Expert Group has advised this acknowledges infected individuals are likely to have had an asymptomatic period following infection. The Expert Group has noted that age at infection was a significant factor for determining rate of HIV disease progression to symptomatic disease. As this will vary across individuals the Expert Group have advised the simplest milestone to recognise a step change in impact on earning potential would be to link this to receiving a diagnosis. This will of course not reflect the experience of all infected individuals and the supplemental route will offer claimants an option for claiming financial loss impacts not reflected in this formula.
- 88. In regards to financial loss for co-infected, the Expert Group has advised this is calculated in the same manner as injury awards. For people co-infected with HIV and HCV or HBV, the Expert Group considered HIV the primary disease in terms of impact. Financial loss awards are therefore awarded on the basis of full HIV award and a percentage uplift of the relevant severity of HCV or HBV infection, with the percentage increasing with severity.

Milestones for step	% of full financial award received (approx £29,657 per annum from infection)				
change in earning impacts	HIV	HIV & Acute HCV/HBV	HIV & Chronic HCV/HBV	HIV & Cirrhosis HCV/HBV	HIV & Decompensated cirrhosis/ liver cancer HCV/HBV
Following diagnosis	100%	100%	100%	100%	100%
Point of infection to diagnosis	50%	62.5%	62.5%	75%	75%

ANNEXES

Annex A Initial Public Sector Equalities Duty Assessment: Infected Blood Compensation Scheme

Introduction

Under the public sector equality duty you are required to have due regard to eliminate discrimination and harassment, advance equality of opportunity between those who have a protected characteristic and those who do not and foster good relations between persons who share a protected characteristic and those who do not.

You have been provided with advice regarding the design of a compensation scheme for those infected with HIV, HCV and/or HBV as a result of NHS treatment with infected blood or blood products and those who were affected as a result of their relationship to the infected person. The below discusses the equality impacts of the proposals contained within the advice.

This is an initial assessment only. Further assessment will need to be undertaken before secondary regulations setting out the details of the Scheme are finalised.

Impacts of the policy

<u>Persons with an infection:</u> Those with HIV are likely to fall within the definition of a person with a disability under the Equality Act, this is also likely to be the case for those chronically infected with HCV or HBV. The scheme is intended to compensate individuals for the impact on their lives caused by, or related to, the infection. Although the scheme will compensate those infected and affected, we consider it justified that those who were infected receive different levels of payment than those who were not; and that the level of payment varies according to the health impacts an individual has experienced. We are aware that the proportion of applicants that are male may be higher because of the increased likelihood of haemophiliacs being male. We do not consider this will have an impact.

The Government has indicated that it will prioritise under the Scheme assessment of claims from infected persons, who are more likely to be disabled than affected persons. This is also the intention with regards to interim payments. We consider this difference of treatment to be justified given that these individuals may have ongoing costs associated with their care needs and are at greater risk of dying.

Data available on the age profile of beneficiaries of EIBSS suggests that people who receive payments under the Scheme are more likely to be elderly. Age will be taken into account when calculating awards for past and future financial loss and care needs. We consider any resulting difference in treatment that results from this approach to be justified as it will reflect the likely loss experienced by an individual.

We do not have any statistical information on other protected characteristics of these individuals including marital status, pregnancy and maternity status, race, religion or belief, gender reassignment, sexual orientation. The proposals do not suggest any difference in

treatment based upon these characteristics, however this will need to be kept under review as secondary regulations are developed.

Affected persons: The definitions of affected persons have been deliberately drawn to recognise a wide range of different family relationships by allowing access to the scheme of "those in the position of" a child or parent, rather than limiting to biological relationships. The definition of partner includes co-habitation so there is no difference of treatment between those who were married and those who were not. However, given that some relationships will have existed before same-sex marriage or civil partnership was possible, and same-sex couples may have experienced discrimination that would discourage co-habitation this may result in the scheme design perpetuating historic discrimination for a bereaved partner where the infected person died during this period. This will need further consideration before the eligibility criteria and evidential requirements for persons to demonstrate their relationship are finalised in the secondary regulations.

There is limited data available on the protected characteristics of those affected. Given the time period in which individuals were infected (1970s and 1980s) we expect parents to be elderly. Data from EIBSS suggests that bereaved partners are also more likely to be older. We do not have any information about the marital status, pregnancy and maternity status, race, religion or belief, gender reassignment, sex, sexual orientation of those affected. Overall the proposals do not suggest any difference in treatment based upon these characteristics, however this will need to be kept under review as secondary regulations are developed.

We do not consider that any negative impacts on equality, as above, are disproportionate and we have considered appropriately the need to advance equality and foster good relations.

Engagement with the community:

Engagement with the community to inform decision making could result in the views of groups with protected characteristics not being properly considered. This might occur in circumstances where engagement is by invitation only and those invited are not able to represent the views of those with certain protected characteristics. This is more likely to be the case if insufficient notice of a meeting is given which limits the ability of representatives to seek views from others, for example their members, prior to the meeting. This could also happen if the engagement is by open invitation but is structured in such a way as to exclude certain groups; for example meetings in London which may be more difficult for someone with a disability to travel to. This could mean that policy decisions do not properly consider the impact on those with protected characteristics.

Last Reviewed: 12.05.2024

Annex B New Awards for affected of HCV/HBV Cirrhosis, HCV/HBV Decompensated cirrhosis, HIV and Co-infected

Heads of Loss	Partner	Parent (where child's infection started before age 18)	Child (where parent's infection started before the child turned 18)	Siblings	Carers / parents where infection started after child turned 18 / adult children (where infection of parent started after child turned 18)
Injury Award	£86,000	£65,400	£40,400	£22,000	£22,000
Social Impact Award	£8,000	£8,000	£8,000	£8,000	£8,000
Autonomy Award	£16,000	£6,600	£6,600	£0	£0
Financial Loss	Where the infected is deceased: Past financial loss from point of infection to death paid to the estates of the deceased. Financial loss from point of death to life expectancy paid to the affected dependants registered with the scheme akin to dependency payments. Where the infected are living: Past and future financial loss paid to the infected either in lump sum or periodical.				
Care Award	Care costs currently modelled into care award of infected				
Total (w/o financial or care)	£110,000	£80,000	£55,000	£30,000	£30,000

Awards for affected of HCV/HBV chronic

Heads of Loss	Partner	Parent (where child's infection started before age 18)	Child (where parent's infection started before the child turned 18)	Siblings	Carer/ Parent of child over 18 at time of infection/ adult child	
Injury Award	£34,000	£20,000	£20,000	£20,000	£20,000	
Social £8,000 £8,000 Impact Award		£8,000	£8,000	£8,000	£8,000	
Autonom y Award			£6,600	£0	£0	
Financial Loss	Where the infected is deceased: Past financial loss from point of infection to death paid to the estates of the deceased. Financial loss from point of death to life expectancy paid to the affected dependants registered with the scheme akin to dependency payments. Where the infected are living: Past and future financial loss paid to the infected either in lump sum or periodical payments.					
Care Award	Care costs currently modelled into care award of infected					
Total (w/o financial or care)	£58,000	£34,600	£34,600	£28,000	£28,000	

Annex C Compensation Scheme Heads of Loss

Heads of Loss - IBI Description	Paid to the infected	Paid to the affected
Injury	Yes	Yes
For past and future physical and mental injury, emotional distress and injury to feelings caused by the infection and treatments for it, or being affected by them or by the death of an eligible infected person, including an award for loss of society of the deceased.		
Social impact	Yes	Yes
For past and future social consequences of the infection including stigma and social isolation.		
Autonomy	Yes	Yes
As additional redress for the distress and suffering caused by the impact of the disease, including interference with family and private life (e.g. loss of opportunity to have children). This should include sums for the aggravated distress caused by interferences in their autonomy and private life such as lack of informed consent in regards to their treatment.		
Care	Yes	Awarded to infected, living or estate, to distribute amongst the affected
For the future care needs of the eligible infected person, and to compensate for past losses in respect of care necessitated by their infection (to be paid directly to the infected person where they have paid for care, and/or directly to an affected person who has provided care).		Infected person or estate representative able to request the Scheme ALB pay a portion of the care award directly to a nominated affected person.
		The affected person would not be able to claim this independently of the infected person.

Financial loss	Yes	Yes where the infected is deceased
For past/future financial loss suffered as a result of infection.		Where the infected is deceased: Financial loss from point of infection to death: paid to the estate of the infected Financial loss from death of the infected person to healthy life expectancy: Paid first as financial loss to dependents (akin to dependency). If no dependents come forward, paid to the estate of the infected.
		Where the infected is living: Financial loss for past financial loss: paid to the infected person Future financial loss: paid to infected person as lump sum or periodical payment