

Infected Blood Inquiry Response Expert Group Work Programme: September- December 2024

For discussion on 12 September 2024

Context:

Regulations were made on 23 August 2024 to establish the infected blood compensation scheme and allow for payments to infected people through the core route to begin by the end of the calendar year. To fully establish the scheme, and so payments can be made to all those eligible for compensation, we need to develop and then lay further regulations including for:

- The core route for the affected
- The supplementary route for the infected and affected
- A number of further topics including: return to the scheme, support services, multiple awards, and a future review of the scheme.

The majority of scheme-related policy is settled, including in relation to the further regulations required. We do not intend to reopen these decisions. However, some policy questions remain and within these, areas where further input or clarification from the expert group is required to make final policy decisions, and lay the final regulations.

Current policy timelines aim to **lay these regulations in January 2025**. They will then be debated by Parliament before **coming into force around March 2025**. There is also work underway to develop guidance relating to the first set of regulations. On both matters, we plan to conclude the work and input of the expert group by 31st December.

The full scope of the further regulations is set out on **page 2** of this paper, alongside a high level 'status' rating for each, depending on whether there are: as-yet unresolved policy issues to be settled; refinements required to existing policies; or simply drafting questions to clarify the position for the CO legal team. Where we do not anticipate bringing the area to the expert group, we have indicated this.

On **pages 3-6** are:

- detailed reviews of each area and the outstanding policy questions, including early indication of the themes and questions on which we will look to the expert group for input
- Proposals for expert group engagement relating to the first regulations guidance
- An indication of how we intend to sequence the session between now and the end of the year.

In recognition of the more settled status of the work for this phase of work following intensive input by the Expert Group since January of this year, we have also tentatively proposed a 'minimum requirement' for expert group members relating to each topic, although each discussion remains open to attendance by all.

Status of policy areas in scope of second regulations

| Policy area | Sub-category (if relevant) | Status |
|--|----------------------------|--|
| Supplementary route | Evidence-led route | Amber: Policy development required on evidence criteria, interaction with core route, and caps for care award and financial loss award. |
| | Health impacts route | Green: criteria published; CO legal drafters to confirm any questions to clarify with expert group |
| Affected people | Eligibility and evidence | Amber: Policy development and refinements required on eligibility and evidence requirements (core route and supplementary route) |
| | Scheme delivery | Amber: policy questions outstanding, do not expect to involve expert group |
| Return to scheme | Core route | Amber/Green: refinements required to settle interaction with core route payment decisions and relationship with IBSS payments |
| | Supplementary route | Amber/Green: refinements required to establish accepted circumstances and likelihood of return to scheme under supplementary route |
| Unethical research award | - | Amber: further policy development required, role of expert group to be confirmed |
| Multiple awards | - | Green: no requirement for expert group involvement (unless we receive clarifying questions from CO legal drafters) <ul style="list-style-type: none"> • Proposal exists for infected and affected • Proposal exists for multiple affected |
| Review of scheme (and evaluation) | - | Amber/Green: expect reference in regulations to be brief/high-level. We would value comment on a proposal from the expert group in recognition of their professional expertise. |

| Topic/policy area: Supplementary route: evidence-led route | | |
|--|--|---|
| Scope | Key outstanding policy questions or areas for refinement | Matters for expert group input |
| Caps Evidence requirements Comparisons to core route awards | <ul style="list-style-type: none"> Consider how to compare the value of past financial loss and care to current rates to provide a comparison process against the core route Consider caps for financial loss and care awards Bereaved affected supplementary route for dependency payments | Input following policy team proposal for how to implement the evidence-led route - discussion and clarification |
| Work programme proposal (incl minimum requirement for each session) | | |
| Session one: <i>financial loss process and evidence</i> [Browne Jacobson, Alex McNeil, CO analysts] | | |
| Session two: <i>care award process and evidence</i> [Browne Jacobson, Alex McNeil, CO analysts] | | |

| Topic/policy area: Supplementary route: health impacts route | | |
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| Scope | Key outstanding policy questions or areas for refinement | Matters for expert group input |
| Evidence requirements for eligibility of health impact group Review of definitions of health impact groups in light of any comments from drafters | Policy team will review current definitions with CO Legal team; drafters will confirm any questions we need to clarify | Any clarification required on definitions of health impact group |
| Work programme proposal (incl minimum requirement for each session) | | |
| Session one: <i>Clarifications on health impact group descriptors</i> [Clinicians and Browne Jacobson] | | |

| Topic/policy area: Affected | | |
|---|---|--|
| Scope | Key outstanding policy questions or areas for refinement | Matters for expert group input |
| <p>Eligibility and evidence requirements for affected people</p> <p>Interaction with supplementary route</p> <p>Scheme delivery</p> | <p>Eligibility and evidence requirements</p> <ul style="list-style-type: none"> • Evidence requirements for care provision, sibling cohabitation, care for a child beyond 18 (disability) • Evidencing financial dependency, including appropriate categories of dependency • Caps: what is an appropriate cap on financial loss payments for dependency <p>Scheme delivery and interaction with other payments</p> <ul style="list-style-type: none"> • Infected/affected dispute implications (i.e.g where an infected person does not come forward to the scheme and claims by affected people are therefore blocked) • What happens if an applicant dies during the application process • Support scheme payments: what happens if an affected person dies before future financial loss has been paid out • Periodical payments: what happens if an affected person dies during the course of periodical payments being paid out | <p>Eligibility and evidence requirements (particularly relating to care provision and siblings; and evidencing financial dependency)</p> |
| Work programme proposal (incl minimum requirement for each session) | | |
| Session one: <i>eligibility and evidence</i> [clinicians, Browne Jacobson, Alex McNeil] | | |

| Topic/policy area: Return to scheme | | |
|--|--|--------------------------------|
| Scope | Key outstanding policy questions or areas for refinement | Matters for expert group input |

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|--|---|--|
| <p>Payment routes and choices following a return to the scheme</p> <p>Consideration of the circumstances under which someone can return to scheme under the supplementary route</p> <p>Interaction with IBSSs payments</p> | <p>Payments</p> <ul style="list-style-type: none"> • Can someone amend their payment route when returning to the scheme or choose a different route for any additional payments following return? • Interaction with IBSS tariffs, including offsetting of IBSS payments against future financial loss and care once someone returns to the scheme after a deterioration in their condition <p>Supplementary route</p> <ul style="list-style-type: none"> • Under what circumstances can you return to the scheme on the supplementary route? • Can you return to the scheme if you develop one of the additional health conditions and under which circumstances? • What is the likelihood that someone will develop one (or more) of the additional health conditions? | <p>Payment routes and interaction with IBSS</p> <p>Returning to the scheme under the supplementary route</p> |
| Work programme proposal (incl minimum requirement for each session) | | |
| Session one: <i>payment routes and interactions with IBSS</i> [Browne Jacobson, Alex McNeil, CO analysts] | | |
| Session two: <i>returning to the scheme under the supplementary route</i> [Clinicians] | | |

| Topic/policy area: Scheme review | | |
|--|---|--|
| Scope | Key outstanding policy questions or areas for refinement | Matters for expert group input |
| Design of scheme review and extent of detail provided in the regulations | <p>Review of the Scheme</p> <ul style="list-style-type: none"> • What will be the scope of the review of the scheme recommended by SRF? <p>Evaluation</p> <ul style="list-style-type: none"> • How will the success of the scheme be evaluated? | Approach to scheme review and approach to scheme evaluation, in acknowledgement of professional expertise of members |

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| Work programme proposal (incl minimum requirement for each session) |
| Session one: <i>Feedback on scheme review proposal from policy team (combined with session two on regulations guidance referenced below)</i> [All members] |

| Topic/policy area: First set of regulations - guidance | | |
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| Scope | Key outstanding policy questions or areas for refinement | Matters for expert group input |
| <p>Evidence - what kinds might we need to draw in, particularly in difficult cases (e.g destroyed medical records)</p> <p>Further detail on infection categorisation (e.g. guidance for where it is not immediately obvious what severity band someone is in)</p> | <ul style="list-style-type: none"> • What kinds of medical evidence exist beyond medical records? • Where might that evidence be found? • Is there anything that could be introduced where no medical evidence is available? • Are there details beyond the existing legislative definitions that would be useful for an IBCA assessor to consider when determining severity banding? (e.g. things that could guide them on a decision as to whether somebody has cirrhosis or decompensated cirrhosis) | TBD following proposed session one discussion below |
| Work programme proposal (incl minimum requirement for each session) | | |
| Session one: Initial review of outstanding questions, provided by policy team for expert group to determine their role in providing answers [All members] | | |
| Session two: Review and comment on draft final guidance (combined with session above on review and evaluation of the scheme) [All members] | | |

Timeline

Subject to your comments and approval of the above topics and proposed areas for expert group input, we will set out a detailed timeline and week-by-week session schedule. We expect to schedule topics that need fuller policy development earlier on in the work programme, followed by anything where refinements or clarifications for drafters are required, ending with a concluding phase that considers the first regulations guidance and proposal for review of the scheme.