

Infected Blood Reform: Scheme Project Group on UK Matters - Notes

Date: 25 January, 10.30 – 11.30.

Attendees:

Robert Girvan (SG)
Sam Baker (SG)
Karen Simpson (NI)
Catherine Cody (WG)
Ginny Belson (DH)
Donna McInnes (DH)

1. Introductions

- GB welcomed everyone to the meeting.

2. Note of previous meeting

- Note of the previous meeting had been circulated and was agreed.

3. Update from Scotland

- The financial support scheme (SIBSS) had still been running well. The number of new applications remained relatively high, both living and deceased cases.
- The clinical review of hepatitis C impacts was ongoing and was expected to report in April. There were challenges in coming up with realistic and evidence-based financial support options to account for the wide spectrum of impact in the Stage 1 group. It was likely that any change to these payments would be backdated to the date of the Ministerial decision.

4. Update from Northern Ireland

- The new scheme was progressing well. There had been one successful Stage 2 application, no appeals and some enquiries from estates. The discretionary grant policy still had to be decided.
- Officials were considering future policy and thinking on whether to adopt the special category mechanism. Beneficiaries still objected to filling in forms as part of the assessment process.

5. Update from Wales

- The new scheme was running well.
- There had been some correspondence regarding the new English special category mechanism; the Welsh Government was considering whether or not to adopt the special category mechanism and also needed to consider its plans for ex-gratia payment levels from next financial year.
- Some payments had been made to those resident in England to cover prescription costs.
- Discretionary funding applications were being considered on a case by case basis.

6. Update from England

- The special category mechanism process had entered the second stage. Applications or notes of intention to submit had to be received by 12 January, with a final deadline of 23 February.
- There were 708 applications received or submissions pending.
- There were fewer new applications to the BSA to join the English scheme than had been anticipated.
- On the UK Inquiry, it was noted that Brian Williams was the key Cabinet Office contact.
- SB commented that the Cabinet Secretary in Scotland had written to the Cabinet Office Minister to reinforce the need for keeping the devolved administrations informed as preparations for the Inquiry progress.
- There would be a period of consultation on the proposed Terms of Reference once a Chair was appointed and the intention was to progress that phase as quickly as possible. The previous consultation had provided some views from stakeholders on the possible ToR.

ACTION: Brian Williams would be invited to participate in the meeting in March and DM to remind him to contact DA officials.

7. Alliance House closure

- There had been a meeting with the Alliance House chairs and Jan Barlow regarding the future holding of the scheme files. DH Legal advice had been sought on the matter; if necessary, advice may also be sought from the Information Commissioner.
- A letter would then be sent to all beneficiaries regarding the situation with the files; DH were trying to push for legal advice as soon as possible given the time constraints for those who wished to submit a Subject Access Request.
- Jan had stated that the records must be held for a certain amount of time in secure storage.
- All of the organisations would close by end March/April except for the Macfarlane Trust.
- There had been discussions with AH on how the audits would be managed for 2017-18 following closure.
- There had been some queries regarding the additional grant process to disburse the Macfarlane Trust reserves. The grants would cover adaptations to property and specialist equipment linked to a disability, as well as energy efficiency measures. The deadline was end February and decisions would be taken by April.
- It was noted that it would be important for all the UK schemes to be notified of the grant awards to their beneficiaries to avoid duplication.
- There were also reserves remaining in the Honeycombe Fund and the Wilson Empowerment Fund which would have to be disbursed. This process had not been decided and would be discussed in July.

ACTION: each administration to make individual arrangements with Jan Barlow for the sharing of the Macfarlane Trust grant award information.

8. AOB

- RG noted that Haemophilia Directors in Scotland had recently commented that the Directors in England were struggling to provide robust supporting evidence for the Special Category Mechanism and this was causing some issues with patients.
- The decision on the applications still had to be made and any specific questions on the assessment process could be discussed at the March meeting.
- CC noted that Wales would need sufficient time to translate any letters to beneficiaries about the UK Inquiry into Welsh.

- Judicial Review – the hearing date was scheduled for 1st and 2nd May. DH would be busy in April preparing for the hearing. The other administrations would be kept updated on any developments.