

Scottish Infected Blood Support Scheme Advisory Group

Background for potential members

Aims

The Scottish Infected Blood Support scheme (SIBSS) began operation in April 2017 and is administered by NHS National Services Scotland (NSS). It provides support to those infected via infected NHS blood or blood products in Scotland and their close relatives. SIBSS has been created as a result of the recommendations of the Contaminated Blood Financial Review Group, and will continue to take account of the conclusions and recommendations in the Final Report of that Group.

However, the Clinical Review of the current assessment criteria that was recommended by the Review Group is a separate workstream which will be managed by Scottish Government, with a report submitted to Scottish Ministers. It will be taken forward in 2017 by a separate Clinical Review Group.

Sustaining confidence in the scheme will mean that beneficiaries or potential beneficiaries, along with others who will work with the scheme, need to be assured that, when there are significant problems with service delivery, their concerns will be listened to and acted upon and that they will receive timely explanations from the scheme. A strong advisory group will ensure that the Scottish scheme takes account of beneficiaries' concerns and views on areas for operational scheme improvement, in light of the budget available. It will provide advice on positive action to ensure that lessons are learned, that trust in the scheme is maintained as far as possible and that the available budget is targeted effectively.

The Group should ensure respect and courtesy between beneficiaries and scheme administrators and others involved in contributing to the scheme, such as medical professionals. The Group will need to sustain the confidence of the public, beneficiaries and the NHS through demonstrable impartiality.

The Group should be sufficiently flexible to work effectively for the different needs and

approaches required for different categories of beneficiary and be able to adapt to future changes. For example, the Group may need to hold an extra meeting if a particular issue of concern is identified.

Independence

In order to exercise their functions effectively, the Group needs to be seen to be independent and impartial in their actions. To ensure that this is the case, we would propose that:

- As far as possible, there should be a range of members with direct or indirect interest in the scheme, including beneficiaries/their relatives, representative bodies, lay members and NHS professionals, to ensure that purely personal or financial concerns do not dominate the Group's work and that it takes on board the full range of perspectives.
- To prevent the perception that the Group is overly focused on certain groups of beneficiaries, members will be appointed by NSS, who will also accept applications from individuals who are not affiliated to the major third sector organisations involved.

Terms of Reference

The Advisory Group is not a decision-making body, but it will play an important role. It will:

- Take on an independent role in providing advice on service delivery and exercise these functions fairly and effectively, without undue regard to any one particular interest or any personal concerns.
- Advise on the development of processes and procedures, particularly as the scheme is initially being established, but also in the event that the scheme is changed over time.
- Provide a strong and clear voice for all beneficiaries and applicants to promote best practice in service delivery.
- Advise on measures to ensure any beneficiary concerns and operational problems are handled appropriately.
- Facilitate greater openness in the delivery of the service.
- Promote cooperation between the scheme administrators and beneficiaries/their

representatives.

NSS will review these arrangements periodically. It will not be the Group's role to consider individual decisions made by the scheme, except where, for example, that raises concerns about inconsistent approaches being taken to service delivery. The Group will be separate from the Scottish Government, although government officials may occasionally attend as observers where appropriate.

Strategic policy decisions related to the level of payments, eligibility conditions and scheme funding are a matter for the Scottish Government to consider separately. This includes the areas for future review highlighted in Proposal 5 of the Financial Review Group report.

Members

Members should have the appropriate knowledge and skills for their roles. They should be objective in their discussions. A proportion of members will be non- beneficiaries. All members should share a commitment to the fair treatment of beneficiaries.

There will be a focus on operational issues with the aim of assuring good practice in service delivery. Members should ensure that the interests of all stakeholders are considered in their deliberations.

Those appointed to the Group should demonstrate that they have the time and commitment to attend meetings twice per year. The composition of the Group will be reviewed periodically.

Chair

The Group will be chaired by a member of NSS staff.

Invitation to apply

A number of people will be invited to attend as a representative of a particular organisation. Anyone else who is interested in becoming a member of the group should submit a short application letter or email for consideration, highlighting their personal

experience and relevant knowledge. Applicants should commit to attend and to adhere to the principles outlined above. Members will be selected according to merit and the qualities required, bearing in mind the need to represent the different categories of beneficiary in a proportionate way.

It will also be open to other interested parties to attend meetings as observers where appropriate.

Members of the public are also welcome to attend the monthly NSS [board meetings](#).

Frequency

The Group will normally meet every six months, unless there is a compelling reason for an additional meeting. However in 2017 it is likely that meetings will be needed every three months.

Location

Meetings will be held in Edinburgh and are expected to be held during working hours. Reasonable travel expenses will be reimbursed.

Organisation Chart

