

Terms of Reference

1st October 2025

COMMUNITY ADVISORY PANEL

Terms of Reference

Purpose

The creation of a Community Advisory Panel is a key part of IBCA's commitment to working with those who have been infected and affected by the infected blood scandal. The community's views are essential in shaping how the compensation claim service is developed and delivered. The Panel's particular role will be to provide independent, experience-led advice and guidance to the Board. They will contribute based on their personal lived experience, and are also welcome to share other views from community members (although they do not need to be representatives of any organisation).

The advice and commissions from and to the Panel will be included in a standard report to each meeting of the IBCA Board. Support will be provided by the Governance Team.

The panel will function solely in an advisory capacity.

Role and Scope

The Panel will, at the request of the Board or Chair:

- Advise the Board on concerns, expectations, and lived experience of those impacted by the infected blood scandal
- Provide feedback on a range of areas, including emerging policy proposals, engagement activity and operational practices.
- Highlight barriers or risks in how the delivery of the scheme may be experienced by the community.
- Any views expressed by members of the panel will not be published as attributable to named individuals.

• The Panel will receive such papers as the Board, Chair, or Chief Executive considers would assist them in their work.

The panel will not

Make decisions on behalf of IBCA.

Membership

The panel will comprise up to 15 members, including:

- Chair a Community Member (elected by panel members, on rotation)
- Community Members individuals with lived experience of being infected or affected by the infected blood scandal.

Membership will aim to reflect the diversity of backgrounds, geographies, and experience across the impacted community wherever possible.

The panel will also be assisted by an IBCA Non-Executive Director (appointed by the Chair of the Board) who will attend the panel to help facilitate discussions and to ensure clear communication between the panel and the Board.

Role Descriptions

Chair

- Lead the Panel, facilitate inclusive, respectful, and balanced discussion.
- With the support of the IBCA NED, act as the Panel's liaison to the Board, ensuring that the Panel's advice is clearly communicated to the Board.
- Attend public Board meetings as an observer.
- Ensure that Board decisions and relevant information on issues where the panel has provided advice are fed back to the Panel in a timely and transparent manner.

Community Members (Lived Experience of being infected and/or affected)

- Consider and comment on issues shared with the panel from the perspective of their and others' lived experience.
- Share insights that could further inform the Board's decisions based on lived experience, whether through personal infection, caring for someone affected, or being bereaved. Representing wider community views is also welcomed.
- Where relevant and possible, identify where there are different views among the community on issues, and provide guidance on how decisions could affect different groups.
- Constructively challenge and inform IBCA's thinking and proposals.

• Attend quarterly meetings and occasional additional meetings as required, without the Board present, to discuss and develop its advice.

Essential Requirements:

- Direct personal experience of being infected or affected by the infected blood scandal.
- Commitment to the principles of fairness, respect and compassion.
- Ability to listen to and draw attention to diverse perspectives across the community.
- Willingness to work collaboratively and constructively.

Appointment and Term

- Members will be appointed via an open recruitment process that is designed to be inclusive - it will actively seek to attract a diverse range of applicants and ensure that individuals from all backgrounds have an equal opportunity to apply and be considered.
- Appointments will initially be for an 18-month term with the opportunity to extend at the request of the Board.
- IBCA reserves the right to remove a member for breaches of conduct, persistent non-participation, or conduct incompatible with public service values.

Meetings and Ways of Working

- The Panel will meet quarterly, with additional meetings convened as needed at the request of the Board. There will be an annual joint meeting of the Community and Clinical Advisory Panels, and the expectation is that the Panel will attend one meeting a year of the IBCA Board.
- Meetings will be held virtually, with reasonable notice.
- IBCA will provide secretariat support for agenda setting, minute taking, and coordination.
- A Deputy for the Chair will be appointed in case of absence. They may attend
 meetings in place of the Chair when required and will be expected to work
 closely with the Chair to stay informed of Panel activities and discussions.

Payment and Support

Community members will be offered payment for their time and expertise in attending meetings. Accepting payment will be entirely discretionary and a decision for each individual, recognising that some may wish to contribute in a voluntary capacity. Payment arrangements will be confirmed prior to the appointment.

Reasonable travel and accommodation will be reimbursed in line with IBCA's expense policy.

IBCA will make reasonable adjustments and offer support to ensure that all members can participate fully and accessibly.

Conduct and Confidentiality

All members are expected to act in line with IBCA's Seven Core Principles: Integrity, Compassion, Candour, Transparency, Fairness, Efficiency, and Propriety in the use of public funds.

Panel members are expected to treat confidential or sensitive information with care and may be asked not to share details outside the Panel until the Board has been able to consider its advice and come to a decision.

For the avoidance of doubt, they will continue to be free to express their own personal opinions in public in relation to any matter or issue which is in the public domain.

Review

These Terms of Reference will be reviewed annually by the Board, in consultation with the Panel, to ensure they remain fit for purpose

