

Stakeholder Forum Terms of Reference

PURPOSE:

The general purpose of the Stakeholder Forum is to ensure that the Organ Utilisation Group understands the views of key stakeholders and enables them to contribute to and / or influence the work of the Group, thereby contributing to the recommendations that will be delivered to Ministers.

ROLE:

The Stakeholder Forum will support stakeholders to:

- Articulate their views and their experiences.
- Provide advice, guidance and insight into organ transplantation including their views on the effectiveness of mechanisms for increasing the number of transplants.
- Support understanding regarding the barriers to transplants.
- Act as a 'critical friend' to challenge any issues and improvement recommendations.
- Provide an environment to consider and develop thinking about any recommendations or future service development.
- Inform the evidence base for any final recommendations made by the Organ Utilisation Group to Ministers.

The forum will also contribute to:

- Providing a mechanism to support stakeholder engagement, where appropriate.
- Providing feedback.

Abide by the Nolan Principles of:

- Selflessness.
- Integrity.
- Objectivity.
- Accountability.
- Openness.
- Honesty.
- Leadership

REPORTING:

The Stakeholder Forum Co-Chairs will liaise closely with the Organ Utilisation Group Secretariat and report to the Chair of the Organ Utilisation Group.

CHAIRS:

The Forum will have Co-Chairs to represent the transplant and patient communities. The Chairs will provide leadership to the Forum and speak on its behalf as appropriate to represent views of members.

DEPUTISING ARRANGEMENTS

In the absence of one of the Co-Chairs, the other Chair will chair the meeting.

MEMBERSHIP

The membership will not be restricted in terms of numbers or location.

The following stakeholder categories should be invited to attend either as permanent members of the Forum or on an ad-hoc basis:

- UK adult and paediatric transplant services
- Patient representative organisations (e.g. Cystic Fibrosis Trust; British Heart Foundation; Kidney Care UK etc)
- Organ donation service
- Organ retrieval service
- Diversity and inclusion representatives (e.g. NBTA)
- Government advisory groups (e.g. Scottish Donation and Transplantation Group)
- Relevant Royal Colleges and professional bodies

Each organisation will be invited to send a representative, who will articulate the views of their organisation.

Members are expected to make every effort to attend all meetings either in person or via online meeting. Attendance will be recorded formally through the minutes from the meeting.

In addition to the members of the Stakeholder Forum, it may be appropriate to invite subject matter experts to provide advice and information on an ad-hoc basis.

QUORUM

As the Stakeholder Forum is not a decision-making body, there is no specific quorum for its meetings.

MEETING FREQUENCY

The Forum should meet as often as necessary, as directed by the Co-Chairs.

MEETING ORGANISATION AND SECRETARIAT

- i. Meeting administration and secretariat support will be provided by NHS Blood and Transplant and NHS England & Improvement and shared with the Organ Utilisation Group
- ii. The draft agenda shall be compiled by the meeting administrator and agreed by the Co-Chairs