NHS BLOOD AND TRANSPLANT
ORGAN AND TISSUE DONATION AND TRANSPLANTATION DIRECTORATE

Terms of Reference for Pancreas Advisory Group

Introduction

The statutory obligations of NHSBT with respect to organ donation and transplantation are set out in the Directions. The Solid Organ Advisory Groups (SOAGs) play a highly valued and essential role in providing NHSBT with the necessary clinical advice on organ donation and transplantation. In addition, they work with NHSBT and other organisations to increase the quality and number of solid organ transplants in the UK.

Although the major role of the Solid Organ Advisory Groups is to advise NHSBT to help promote all aspects of organ transplantation and ensure equity of access to transplant and optimal patient outcomes, it is recognised that the SOAGs provide a much broader resource to help promote deceased and living organ donation and transplantation in the UK and internationally, and to provide a unique forum for all those involved in organ transplantation in the UK to meet and to discuss and promote evidence-based improvements in patient outcomes.

The work of the SOAGs is integral to organ donation and transplantation: the SOAGs are integrated into the structure of the Directorate of Organ Tissue Donation and Transplantation (OTDT) and to the Senior Management Team of ODT.

Role of the Advisory Group (AG)

The role of the Advisory Group will be to provide a forum whereby clinicians and other interested parties (including commissioners, regulators and non-clinical stakeholders) can work with NHSBT and other organisations to improve the number and quality of organs donated and transplanted; and improve the outcome of patients awaiting and following transplantation with a focus on access, outcomes and patient reported outcomes.

Delivery of this aim will include:

- Agree membership of Working Groups as required with additional expertise co-opted as required (it is not necessary that members of the Working Group are all members of the Advisory Group)
- Task the Working Group to investigate and report on specific issues in a given time frame
- Review, approve or amend recommendations from the Working Group
- Review relevant current guidelines and policies at least annually and advise NHSBT on operational aspects of transplantation
- Recommend, as necessary, promote and implement changes to the nationally agreed protocols
- Advise NHSBT and other bodies on appropriate methods of monitoring outcomes and interpretation of findings
- Monitor and report on clinical governance with special reference to outcomes and deviations from expected outcome, as well as deviation from agreed protocols in selection and/or organ offering
- Monitor deviation from agreed protocols in selection and/or organ offering
- Advise on equity of access of NHS-entitled patients to transplantation throughout the UK
- Identify and promote areas of audit, research and development
- Liaise as necessary with professional bodies in the development of national standards

Chair

Appointment - applications will be invited from transplant health care professionals (see the Role Summary and Person Specification in Appendix 1). The Chair will be appointed by NHSBT through a formal appointment committee with a panel of at least three people and will include the OTDT Medical Director and a member of a relevant Professional Society.

Tenure

- The Chair will be appointed for 3 years
- The Chair may apply and be re-appointed for a second and final two year-term
- A person who has been Chair may re-apply at any date more than three years after standing down

Remuneration

In recognition of the time spent working in the role of SOAG Chair, the Chair's employing institution will be reimbursed with 1 PA.

Appraisal

The Chair will meet the Medical Director or Deputy Medical Director of OTDT annually for a formal review of progress made and to agree future work plans and associated targets.

Role of Chair

- Chairing the twice-yearly meetings of the Pancreas Advisory Group
- Attending meetings of the Islet Steering Group (ISG)
- Attending meetings with patient partners/lay members
- Attending meetings of the Retrieval Advisory Group (RAG)
- Attending meetings of the Kidney Advisory Group (KAG)
- Attending other relevant SOAG meetings, if required
- Attending OTDT Clinical Team meetings
- Helping the MD of OTDT assess response to signals from outcomes monitoring
- Providing ad hoc advice to OTDT
- Review applications for national data and advise Statistics and Clinical Research on prioritisation of requests for data and general workload

Where appropriate, the Chair may nominate a Deputy to attend meetings on behalf of the Chair; the nominated Deputy will have the full authority of the Chair.

<u>Membership</u>

- 1 representative per pancreas transplant centre, with 1 Deputy for each centre as needed
- The tenure for centre representatives should be for a maximum of 7 years, and be recommended by the relevant Centre Director (see below) or PAG/ISG equivalent

Voting members

- Chair of PAG
- Centre representative (Physician or Surgeon) from each designated pancreas transplant centre
- A member representing islet isolation centres (Physician or Surgeon), tenure as above

- A member representing the UK Islet Transplant Consortium, tenure as above
- Chair of the Islet Steering Group

If an agreement cannot be reached by consensus, a vote will be taken of the voting members; a majority will be binding. The Chair will have a casting vote but will not take part in the initial vote. Where a consensus is not reached on policies, the Chair must ensure that the Chair of the OTDT CARE Group is informed of the nature of concerns of those who did not support the policy.

Non-voting members

- One representative from each of the Commissioning groups for the four UK nations
- One representative from each of the national Departments of Health
- One representative nominated by the British Transplantation Society
- One representative nominated by the British Society for Histocompatibility and Immunogenetics
- Medical Director OTDT or their Deputy
- Relevant NHSBT Statistician(s)
- OTDT Histocompatibility and Immunogenetics Lead
- Associate Medical Director for Patient Safety (Clinical Governance)
- Associate Medical Director for Organ Retrieval
- Chair, Multi-visceral and Composite Tissue Advisory Group
- Chair, Kidney Advisory Group
- Chair, Retrieval Advisory Group
- Pancreas Lead CLU (Clinical Lead for Utilisation)
- OTDT Lead Recipient Transplant Co-ordinator
- Organ Donation Services Team representative
- Lead Nurse in Organ Donation representative
- OTDT Leadership Team representative
- Pancreas recipient co-ordinator representative x 2
- Lay member representative x 2
- Patient partner representative x 2
- Other members co-opted by the Group (may include representatives from relevant professional bodies, Societies and/or Colleges)
- Temporary members, e.g., reporting back from Working Groups
- The Chair, in discussion with members of the Group, may include other appropriate members (e.g., lead for Pancreas Collaboratives)

Representatives from the Republic of Ireland will be welcome as observers.

NB: All Advisory Groups must have at least one patient partner representative in attendance to be considered quorate.

Roles & responsibilities of members

- Bringing to the Advisory Group any relevant concerns or suggestions from the centres they represent; where possible this should be in writing so that the paper can be circulated prior to the meeting
- Circulating minutes and other discussion items and items of relevance within their organisations (to clinicians, managers and other relevant parties)
- Responding to relevant items on the agenda
- The Chair will appoint a Deputy Chair who may deputise for the Chair
    - The Deputy Chair must be an existing PAG pancreas centre representative
    - If there is more than one applicant, the candidates will be interviewed by the Chair and NHSBT representatives
    - The Deputy Chair will assume the role and duties of the Chair when the Chair is unavailable, when there are possible conflicts of interest, or at the request of the Chair. At present the Deputy Chair is not a remunerated post
    - On occasions when the Deputy Chair assumes the chairing role, it would be appropriate for their centre to be represented by another centre representative
    - The Deputy Chair will be appointed for the period of the Chair's tenure
    - When a Deputy Chair ceases to be the PAG representative for their own transplant centre, they will also demit from being Deputy Chair
- The representative from each transplant centre will be determined by the Centre Director(s) in collaboration with senior clinicians in their centre
- Members unable to attend should send a deputy who will have the same voting rights as the member
- Members will be expected to attend at least 80% of the meetings - if a member misses three consecutive meetings and has been unable to arrange a suitable deputy, then alternative representation may be sought
- The Minutes will record membership attendance
- Patient partners and lay representatives will be appointed through an independent process for an initial three-year term

Fixed Term or other Working Groups reporting to PAG

- It is anticipated that the Advisory Group will have Working Groups to address specific aspects of transplantation or issues; the nature, membership, frequency, lifetime and venue of these meetings will be at the discretion of the Advisory Group. Virtual meetings are encouraged
- The Chair of the Advisory Group, or nominated deputy, will chair the Working Group
- Members of the Working Group are expected to attend at least 80% of the meetings
- Members of the Working Group will not act as representatives of their own centre
- Members unable to attend may nominate a Deputy who will have the same rights as the member
- The relevant statistical lead will attend as a non-voting member
- The Working Group may invite other members of NHSBT, and others as required to consider specific topics

<u>Additional AG-specific items</u>

Islet Steering Group (ISG)

- This is a long-term sub-group of PAG, enabling additional focus on, and support of, UK islet allo-transplant centres. Patient selection and organ offering policies, and clinical governance (patient safety) issues remain under the remit of PAG.
- The PAG Chair will appoint the ISG Chair from islet centre representatives
    - If there is more than one applicant, the candidates will be interviewed by the Chair and NHSBT representatives
    - The ISG Chair will be appointed for the period of the PAG Chair's tenure
    - When the ISG Chair is appointed a replacement from their islet centre will be appointed. At present the ISG Chair is not a remunerated post
    - The PAG Chair will meet the ISG Chair annually to discuss a review of progress and agree future work
- Voting membership (voting rules as per PAG)
    - Chair of ISG
    - One clinical representative per islet transplant centre (tenure as per PAG members)
    - One managerial representative per islet isolation centre (tenure as per PAG members)
    - PAG Chair
- Non-voting membership
    - UK Islet Transplant Consortium representative
    - One representative from each of the Commissioning groups for the four UK nations

- One representative from each of the national Departments of Health
- Relevant NHSBT Statistician
- Pancreas Lead CLU (Clinical Lead for Utilisation)
- One islet transplant centre manager representative
- Organ Donation Services Team representative
- Recipient co-ordinator representative x 1
- Lay member representative x 2
- Patient partner representative x 2
- Other members co-opted by the Group (may include representatives from relevant professional bodies, Societies and/or Colleges)
- Temporary members, e.g., reporting back from Working Groups
- The Chair, in discussion with members of the Group, may include other appropriate members

Meeting practicalities

Meeting frequency

The Pancreas Advisory Group will meet twice a year, one will be held virtually, and one will be a face-to-face meeting. ISG will meet twice a year; one meeting will be held jointly with the PAG.

Meeting Minutes, Papers, and administrative support

- The Minutes of each PAG and ISG meeting will be taken by the NHSBT Advisory Group Support
- The Agenda, Papers and agreed Minutes of the PAG meetings will be published on the OTDT website
- Meeting papers for the working groups will not be published as these will be work in progress, although reports to the Advisory Group will be included in the Minutes of the Advisory Group Meeting
- PAG Agenda and Papers will be published on the ODT website when these are circulated to members of PAG. Minutes will be published after they have been approved
- Redacted papers will be published only if the originals contain patient-identifiable material, commercially sensitive or published details would preclude publication in a peer-reviewed journal
- Minutes will be circulated electronically

Budget

PAG will be allocated an agreed budget, administered by OTDT, which will include travel expenses, hosting of meetings, working parties, consensus meetings and other relevant activities. Accountability for the budget will be with the Chair, but the budget will be held within OTDT.

Statistical and analytical support

PAG will be allocated an agreed level of support from Statistics and Clinical Research to support the activities of the group: this support will be used for analysis of outcomes, audit, governance issues, service evaluation, modelling of alternative methods of service delivery and other projects, agreed with the Chair, the Assistant Director of Statistics and Clinical Research, and the Medical Director OTDT.

The PAG Chair and the relevant statisticians will meet at least every three months to agree the agenda, new projects and assign priorities.

Appendix 1

Advisory Group
Chairs Role Summar