Role Description
Solid Organ Advisory Groups – Patient Representatives

What are the Solid Organ Advisory Groups?	One of the key roles of the Solid Organ Advisory Groups (SOAGs) is to advise NHS Blood and Transplant (NHSBT) in all aspects of organ transplantation, to ensure equity of access to transplant, and optimal outcomes for patients. Each SOAG provides a unique forum for all interested parties involved in organ transplantation nationally to come together, and discuss, debate and implement evidence-based improvements to positively affect patient outcomes. Transplant clinicians, scientists, commissioners, lay members, patients and NHSBT representatives form part of the key stakeholder configuration. The role of each SOAG is integral to organ donation and transplantation, and is therefore integrated into the structure of the Directorate of Organ Tissue Donation and Transplantation (OTDT) at NHSBT. There are 6 Solid Organ Advisory groups: Cardiothoracic – Heart Advisory Group (CTAG – Heart) Cardiothoracic – Lung Advisory Group (CTAG – Lung) Kidney Advisory Group (KAG) Liver Advisory Group (LAG) Pancreas Advisory Group (PAG) Multi-visceral and Composite Tissue Advisory Group (MCTAG) The Advisory Groups core business: Organ donation activity Transplant activity Waiting times Equity of access to transplantation Selection and organ allocation policies Transplant outcomes and research **Following a recent review of the Advisory Groups it has been agreed that each will have 2 Lay Member representatives and 2 Patient representatives.**
What is the purpose of Patient Representatives?	Patient representatives will assist the Advisory Groups to improve the experience and outcomes for patients through meaningful involvement in key decisions. They are expected to seek and be representative of the views of the wider patient population, as well as bringing their own experiences and perspectives to help make improvements for all patients.
Frequency and location:	The Advisory Group meetings take place 2- 3 times a year. Face to face Advisory Group meetings take place once a year in Central London), with the remaining meetings being held virtually via Microsoft Teams. Patient representatives will also be invited to join fixed term working groups/ subgroups of the Advisory Groups. These groups may include

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	future service planning and reviews, for example. Some of the group's activities may be face to face, however the majority will be via virtual meetings.
Who manages Patient Representatives?	The Patient Representatives will be supported in their role by the relevant Advisory Group Chair and wider OTDT clinical team.
What is the time commitment of a Patient Representative?	**Time commitment** The Advisory Groups meet between 2 -3 times a year. Dates for the Advisory Group meetings are scheduled a year in advance. Meetings are between 4- 6 hours and refreshments and lunch will be provided at the face to face meetings. Patient representatives will be invited to support fixed term working groups/ subgroups of the Advisory Groups. This could include be one-off tasks, once-a-quarter activities or regular meetings. **Term** Patient representatives are in post for 3 years. After this time, they step down to make way for other voices to be heard. A Patient representative may reapply after a 12-month period.
What does a Patient Representative do?	**Role duties:** • Be proactive, enthusiastic and inclusive participants within the Advisory Groups, fixed term working group/ subgroups. • Offer improvement ideas supported by their experiences as patients or family members / carers of patients. • Ensure the views of different patients are represented in the Advisory Groups, fixed term working group/ subgroups by liaising frequently with patients or family members / carers of patients from within the specialty. • Patient representatives should be focused on finding positive solutions which benefit all patients. • Connect with the opinions of the patient community by developing and leading a network of patients, their family members / carers. Patient representatives can take part in several different types of activities, such as: • Participating in surveys, focus groups, interview panels. • Participating in fixed term working groups/ subgroups and programmes of work. • Helping to shape the Patient Representative role and suggesting areas for improvement.
What does a Patient Representative not do?	• This role should not focus too heavily on individual experiences, and more a collection of opinions from the wider patient community. • Patient representatives must not breach expectations with regards to any confidentiality.
What training is required	There is no required training however we will support any training requirements identified.

What skills and qualifications do you need to be a Patient Representative?	This role is open to patients and carers/family members of patients who have received services from a transplant unit in the UK. **Essential criteria** • You must have a desire to improve quality and influence change in transplantation. • You should be interested in questioning information and explanations supplied by others, who may be experts in their field and to challenge constructively. • You should be able to consider issues from the perspective of the wider population • You should have good communication skills and feel comfortable sharing your views. • Personal integrity and awareness when dealing with issues where there could be potential conflicts of interest. **Non-essential criteria** • Comfortable communicating over email and using computers. • Have an understanding of equality and diversity issues.
What Patient Representatives can expect from us	• We will make you feel welcome, included and respected within the advisory groups. • You will be eligible to claim for travel and expenses associated with attendance at face-to-face meetings. • We will support you throughout your journey with us • We'll provide you with access to identified learning, development and engagement opportunities. • We'll make reasonable adjustments to enable people with different communication and access requirements to get involved e.g. using accessible premises for meetings if they do occur in person. • We will cover out of pocket expenses or reimburse out of pocket expenses for face-to-face core Advisory Group meetings, subgroup meetings and fixed term working group meetings • We will offer involvement payments for core Advisory Group meetings (£150 per day/ £75 per day for meetings less than 4 hours)
What is the application process?	Candidates should apply online, providing 2 references. We know an online form isn't for everyone so candidates can request a paper application or submit a video application if they would prefer. Candidates will be invited to an online interview with a member of the SOAG and members of the OTDT Clinical team.

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