



The Voice of Transplantation in the UK

# **BRITISH TRANSPLANTATION SOCIETY**

#### **CHARTER FOR PATIENT AND LAY REPRESENTATIVES**

#### **JANUARY 2023**

#### **INTRODUCTION**

The British Transplantation Society (BTS) welcomes the opportunity to collaborate with patient representatives and lay members. We rely on many different partners to ensure that the society meets the needs of its membership, supports transplant professionals and, through them, offers the best care for patients and their families.

BTS must also remain financially viable to support its activities. In common with most professional societies, BTS has a paying membership and fees are aligned with salary. Executive, Council and Committee roles are voluntary; nominated and elected from the membership. We rely on financial support through our relationship with industry partners to run our Annual Congress and stand-alone meetings. These events are critical to give current and future generations of transplant professionals the opportunity to share knowledge and expertise, showcase research and innovation and network within the transplant community.

Many of our major industry supporters manufacture medicines for the benefit of transplant recipients and their transplanted organs. As such, they are members of the Association of the British Pharmaceutical Industry (ABPI), whose Code of Practice sets out the requirements for member companies to operate in a professional, ethical and transparent manner with respect to marketing of medicines and support of health professionals in providing the best care for patients.

For professional societies to partner with the pharmaceutical industry, we must work with them to make sure that the principles of the Code are respected and its requirements are met. One of these requirements is that the promotion of medicines is restricted only to professionals and that the public (including patients and lay people) are not exposed to product information/marketing. More information on the Code and ABPI's commitment to working with patients and professionals is available here <a href="https://www.abpi.org.uk/partnerships/working-with-patient-organisations/working-with-patient-organisations-2022-sourcebook-for-industry/">https://www.abpi.org.uk/partnerships/working-with-patient-organisations-2022-sourcebook-for-industry/</a>.

In drafting this initial document, feedback from the 2021 patient focus groups, advice from patient organisation representatives, industry partners and BTS Council has been included. Our aim is to create a framework for patient engagement and involvement (PPE/I) which will enable effective collaboration and appropriate representation to continue to evolve.





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### THE CHARTER

## BTS will ensure that

- 1. Collaboration with patients is reflected and clearly stated in the Society's strategic aims. Patients will be invited to engage with BTS activities where their involvement is of mutual benefit and supports transplant professionals in their roles.
- 2. BTS resources published on the public-facing website are accessible for patients and patient information resources/websites (e.g., NHSBT, patient organisations) are clearly sign-posted from the BTS website.
- 3. The option of Associate Membership of the Society, supported by two BTS members and approved by the Executive, for representatives of recognised patient organisations/charities is fully explored with the membership.
- 4. The requirements for membership of BTS and representation at Congress/events are clearly defined and published on the website and at meetings
- 5. A networking area with unrestricted access will be provided at Congress. This will be open to all attendees and clearly sign-posted so that anyone attending Congress can meet and interact with one another outside the exhibition area
- 6. This charter is reviewed at least annually and/or updated by BTS Executive in collaboration with relevant partners +/- approved by Council as required so that it remains fit for purpose. Any change requests that impact on the rules of the Society must be approved by Council and the BTS Annual General Meeting (AGM).

## Patient and Lay Representatives will ensure that they

- 1. Are aware of the role of BTS as a professional society within the transplant community, its strategic aims and the contribution that patients can make to BTS activities. Further information at www.bts.org.uk
- 2. Have read this Charter and understand their role and responsibilities in engaging with BTS and other partner organisations (e.g., industry see below) and/or as Associate Members of the society (pending AGM approval 2023)
- 3. Continue to collaborate with BTS to embed effective patient engagement and involvement in society activities, for the mutual benefit of transplant professionals and patients.





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# Special Considerations Related to Industry Partner and Public/Lay/Patient Interaction at BTS Meetings/Events

We are delighted to welcome patient/lay speakers and representatives of lay/patient organisations to BTS Congresses and meetings. The following measures are in place to ensure that everyone can enjoy BTS meetings and events and that industry partners are confident that the ABPI Code of Practice requirements are met:

- 1. All attendees are asked for their role, affiliated organisation and membership status to register for Congress or meetings.
- 2. All attendees are issued with a lanyard and badge on arrival at a congress/meeting, to be worn in the conference venue throughout the meeting. Patient and lay attendees are given lanyards of a different colour from transplant professionals to avoid any confusion. These are referred to on conference signage as a visual reminder for participants, other partners and conference venue staff.
- 3. The ABPI Code of Practice prevents patients and lay representatives attending industry sponsored symposia or entering the exhibition area if pharmaceutical companies are promoting their products. Signage will indicate where and when access is restricted and for whom according to lanyard colour. Conference venue staff and the BTS registration team are available to advise and, if patients and lay members inadvertently enter a restricted area, they will be redirected.
- 4. All attendees and industry partners are provided with a copy of this Charter at registration so that they are aware of on-site etiquette with respect to the ABPI Code of Practice
- 5. Please contact <a href="mailto:secretariat@bts.org.uk">secretariat@bts.org.uk</a> if you have any queries or concerns about this Charter or, during a Congress/meeting, please contact the registration desk directly.