

BTS ILD REGISTRY STEERING GROUP 2022 - 2025

CONSTITUTION

1. TERMS OF REFERENCE

The BTS ILD Registry Steering Group is responsible for the management and supervision of the Society's UK Interstitial Lung Disease Registry, which holds information regarding any ILD with evidence of fibrosis, as well as non-fibrosing sarcoidosis.

The project aims to provide a means of national data collection for these diseases through the development of the BTS online data collection system, based on the successful BTS Clinical Audit Programme. The Registry covers England, Scotland, Wales and Northern Ireland.

1.1 The Steering Group will meet a minimum of twice each year (with additional Teams meetings if required) with the following remit:

- To provide advice to the Society on the development of the BTS UK Interstitial Lung Disease Registry;
- To oversee the content and direction of this Registry, including advice on ethical issues;
- To advise on the development of online data collection systems;
- To oversee the application for ethical approval for the Registry;
- To advise on communication and dissemination of information to potential participants in the UK including the development of a network of ILD registry leads in centres across the UK;
- To produce regular progress reports from the Registry for:
 - BTS Standing Committees (Board, QIC)
 - The Research and Ethics Committee (REC)
- To advise on the content and format of reports to be produced from the data collected via the Registry as feedback to participating centres and for publication, recognising that additional expertise may need to be obtained for data analysis, etc.
- To advise on the criteria for approval of applications from external research bodies for access to the data collected through the Registry;
- To advise on any potential expansion of activity;
- To provide advice to the BTS Board and QI Committee on possible additional sources of funding for the future development of the Registry;
- To provide advice to the BTS Science and Research Committee on research opportunities presented by the Registry including sources of external research funding;
- To provide advice to BTS Trustees and to BTS Head Office staff on issues related to the operation and management of the Registry as required.

2. MEMBERSHIP

2.1 The membership of the Steering Group comprises the following:

- The Chair, who will hold a place on the BTS Quality Improvement Committee;
- Four consultant respiratory physicians;
- Two specialty trainees;
- The Chair or a member of the BTS ILD SAG;
- A respiratory nurse with an interest in ILD;
- A lay/patient representative;

- Representatives of appropriate patient charities

In addition to this, the Steering Group has the right to call on the expertise of other specialists as required (i.e. there is a provision to co-opt members to the Group whose expertise are required for a limited period of time).

2.2 All members, however selected and in whatever capacity, will normally serve for a maximum of 3 years from the date of taking up membership. The term of service is usually effective from the date of Society's Annual General Meeting in November each year.

2.3 The Chair-Elect will be appointed in the third year of the Chair's period of service, to allow handover, and will therefore expect to serve for no longer than 4 years, but exceptionally for 5 or 6 years. This will only occur if the Chair-Elect is already serving on the Committee at the time of the election.

2.4 Members of the Steering Group other than those who are members of the Group by virtue of their position as representative of an external organisation or member of the SAG, can apply to join by volunteering annually in response to a call for volunteers. This is circulated in the early summer each year to all BTS members. The call for volunteers will clearly state the vacancies that are available; the experience and special interests sought (if any) and the arrangements for selection. If there are more volunteers than places available, selection will be undertaken by the Chair of the Group and Honorary Secretary supported by the Chief Executive or Head of Clinical Programmes, based on the provision by volunteers of a short CV and supporting statement.

2.5 All members of BTS Steering Groups must be members of the Society unless they have been nominated by an external organisation or are acting as lay representatives.

2.6 If a Steering Group wishes to involve a member with specific skills, and that person is not therefore likely to be a BTS member; or, if a Steering Group wishes to vary the membership as outlined above, this MUST be discussed first by the Chair with the Chief Executive and the BTS Board of Trustees, and agreement of Trustees obtained.

2.7 Every effort is taken to agree dates of meetings one year in advance and notify these to all members as soon as they have been agreed. Dates agreed in advance will only be changed if there are exceptional circumstances, and then at least 8 weeks' notice will normally be given. If a member misses more than 2 meetings in succession, and there are no extenuating circumstances (in relation to sickness absence, for example), then the Society will ask that member to stand down.

2.8 All members are required to conduct themselves in accordance with the Society's policies and general procedures (e.g. for travel expenses), and in particular in relation to the policy about relationships with the bio-medical and tobacco industries, and the associated Declarations of Interest Scheme (DoI) (see section 4, following). Members are especially asked to note that efforts should be made to return a completed DoI form before the end of January each year, or prior to the first meeting of the Committee in every calendar year, whichever is earlier. If a form has not been completed after a reminder has been given at that meeting, the member concerned will be asked to withdraw until the information has been provided.

2 STANDING ORDERS

3.1 Role of the Chair of the Steering Group

The Chair of the Steering Group will be a member of the BTS Quality Improvement Committee and will be the main link between the development and execution of the Society's objectives for the BTS UK Interstitial Lung Disease Registry and the detailed work of the Steering Group. The BTS Quality Improvement Committee will provide overall direction and guidance in relation to the Registry's QI activities and its place within the wider BTS QI framework.

3.2 The Chair – working jointly with BTS Head Office – is responsible for the direction, conduct, moving forward and completion of Steering Group business, both during meetings and between the meetings. In this task s/he is supported by the Society's staff (who provide a full secretariat service) and other members.

3.3 The Chair will approve the Steering Group agenda and draft minutes, which are prepared by BTS staff. S/he will also prepare and/or commission papers from other Group members or BTS staff and will chair the formal meetings of the Group and any ad-hoc meetings and teleconferences.

3.4 While BTS staff can draft follow-up correspondence and deal with queries arising from the work of the Group on an operational level from day to day, it is anticipated that the Chair will provide advice on content and professional issues involved and, in particular, deal with peers and external organisations in relation to all areas where clinical leadership is required. Communications with external organisations that relate directly to the Registry should be conducted via BTS Head Office.

3.5 The Chair has an important role in ensuring that Declaration of Interest forms from all Committee members are scrutinised and any issue of concern discussed with the individual concerned and/or the Honorary Secretary. S/he must also ensure that at the beginning of each meeting members are asked to declare any additional recently-acquired interests, and is expected to exercise judgement in the conduct of Group business in the event of any potential conflicts of interest.

3.6 Succession planning for the Chair of the Group will take place as follows. In the spring of the year when the Chair's 3 year term in office is due to end, the Society will advertise that a vacancy for the Chair of that Committee will be coming up. A job description will be available. Members of the Committee plus any other member of the Society will be invited to apply. All applicants will be required to send a short c.v. and a statement outlining why they are interested in the position and what they feel they can bring to the post. Applicants will be shortlisted (if necessary) and interviewed by the Chair of the Board of Trustees and the Honorary Secretary, supported by the Chief Executive or Deputy Chief Executive. The panel's decision will be shared with the Officers' Group for ratification and made known to the successful candidate so that the Chair-elect can spend the remainder of the year before taking up post shadowing the incumbent and receiving information and training about being a Trustee of the Society. The appointment will also be reported to the next scheduled meeting of the Board of Trustees.

3.7 Before a Chair is appointed, s/he will be asked to submit an updated Declaration of Interest form, if this is not already available. This will be submitted to the Chair of the Board of Trustees and Honorary Secretary for approval before the appointment is confirmed.

3.8 Frequency and conduct of meetings of the Committee

The Committee will normally meet twice a year. Meetings will usually be held at the Society's headquarters building in London. These meetings may be held using Microsoft Teams technology.

3.12 The BTS staff member responsible for the Group will draft an agenda and discuss with the Chair no later than 3 weeks before the date of the meeting. The agenda and papers will be sent by email to all members no later than 7 days (and preferably) 10 days before the meeting takes place. It

is not good practice, and will not normally be possible, to table papers at meetings, especially those that contain detailed information except at the discretion of the Chair, and taking into account circumstances involved. Authors of papers are therefore asked to submit in time according to the date given by the secretariat, so that copying can take place.

3.13 A draft minute, including named action points, will normally be produced within 7-10 days of the meeting to be agreed by the Chair and then sent to members as an aide-memoire for those who may have been asked to carry out actions, or for the information of those who were not able to attend.

3 CODE OF CONDUCT

4.1 The Society values the contribution of those members who serve on its various Committees, Advisory Groups and Working Parties. Without this service, it would not be possible to carry out the great variety of work that is undertaken and which contributes to the raising of standards of care for people with respiratory disease. BTS has a justifiably high reputation for the quality of its activities and the advice it gives to external bodies.

4.2 The Society is also proud to have been a pioneer in a number of areas, including its Declarations of Interest scheme, which has been replicated by a number of other Societies in recent years. The probity of our actions is underpinned by a number of policies and procedures which are kept under regular (annual) review.

4.3 To ensure effective functioning of the Declarations of Interest process the Chair should proactively manage declarations from Steering Group members. This will include:

- Having declarations of interest as a standing item on all meeting agendas;
- Formally asking members whether anything has changed since they submitted their last declaration;
- Formally asking members at the start of each meeting whether there are any agenda items which may cause conflict or in which they have an interest;
- Seeking advice when required from the Honorary Secretary or Chief Executive if there are any concerns about new items mentioned under declaration of interest.

4.4 Consequently, we ask all members of Committees, Advisory Groups and Working Parties to note and abide by the following policy and procedures documents:-

- **BTS Policy on Biomedical Industries: Joint Working and Commercial Sponsorship and associated Declarations of Interest Scheme.** This is reviewed annually by BTS Council and Trustees.
- **Endorsement Policy** (reviewed in 2021)
- **Media policy** (reviewed in 2022)
- **Travel and subsistence policy** (reviewed annually by Honorary Treasurer and Chief Executive)

These documents can all be found on the BTS website in the “governance” pages of the section entitled “About BTS”

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