

Policy for patient, carer, and public involvement

1. Introduction

BTS is committed to making sure patient, carer and public voice is embedded within our work. The publication of the BTS strategy and vision of 'Better Lung Health for All' has provided an opportunity to take a fresh look at our approach to ensure the way we include the voice of patients, carers, and the public is meaningful and effective.

1.1 Our Commitments to Patient and Public Voice

As a membership organisation the work of BTS is centred on support for health care professionals to achieve Better Lung Health for All. Our strategic intent with regard to patient, carer and public voice recognises the different perspectives of patients and carers and the wider public.

We define patient and carers as those people living with the impact of poor lung health and the wider public as people with an interest in lung health generally, or those who would benefit from greater awareness of lung health.

The following commitments to patients, carers and the public underpin our strategic approach.

- We will establish mechanisms that ensure we understand what is important from the patient and public perspective at a range of different levels within BTS.
- We will value, respect and support hearing diverse opinions to gain insight

and to facilitate more effective decision making.

- We will take a proactive approach to supporting the delivery of lung health services that meet the needs of all patients.

2. Our approach

Our approach to patient, carer, and public voice for BTS will help to deliver the strategic vision of Better Lung Health for All.

Patient, carer, and public voice allows BTS to gain insight from lived experiences, to understand what works, remove assumptions, and to ensure a focus on guidance, education, and impact in the appropriate places. It helps to raise the profile and awareness of lung health and the role of BTS in supporting this.

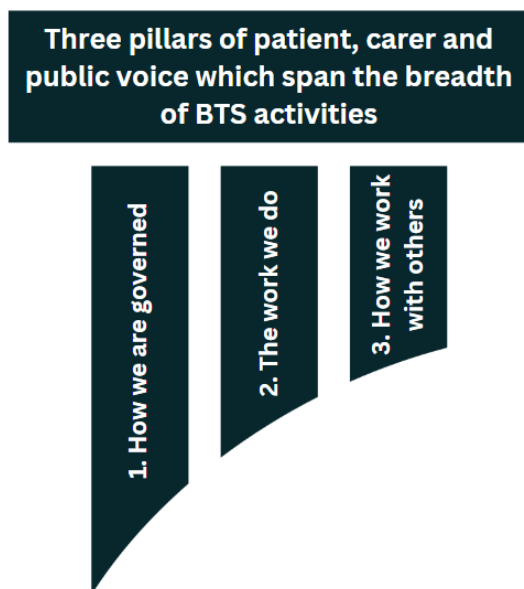
Our approach to patient, carer and public voice will enable the work of the Society to be effective, efficient, and deliver beneficial impact for patients with lung health conditions, and the wider public when it comes to increasing understanding of lung health.

To ensure the value of patient, carer and public voice is appropriate and meaningful, well understood, and focused, we will have in place mechanisms to ensure a range of perspectives are integrated throughout our work. It will enable influence at strategic and operational levels, within and across our organisation and work. To achieve this, we will focus on three main pillars of patient, carer, and public voice.

We fully recognise and value the unique contributions made by individuals who provide their lived and learned patient and/or public experiences to help us in our work. We acknowledge that no single person can be ‘representative’ of all patients, carers, or the public in any part of our work.

The three pillars include: how we are governed, the work we do and, how we work with others.

Figure 1



2.1 How we are governed

To ensure our overarching mission is achieved, a lay Trustee(s) sits on the Board. The purpose of the lay Trustee role is to provide an additional level of public accountability and strategic oversight. This role provides a different, more external, perspective, and useful challenge to discussions and decision making to ensure the work of the Society is always patient centred and that it is well governed, inclusive, and stable. The lay Trustee role(s), alongside other Trustees, is

fundamental in helping BTS to improve patient care, outcomes, accessibility, and reduce inequality, while ensuring its charitable and regulatory requirements are met.

We welcome expertise from our lay Trustee(s) in relation to the operational running of the Society, for example in areas such as charity finance, governance, communications, and HR.

Our refreshed approach to patient, carer and public voice will ensure we are clear on the expectations, purpose, and remit of this role and, explicitly acknowledge that an individual is not expected to represent any specific patient group or wider public view but will bring their own perspective, challenge, oversight, and guidance.

To support the lay Trustee role to be effective we will create a lay Trustee information, recruitment and support pack that will include:

- An introduction to BTS and our commitment to patient, carer, and public voice
- A role description to clarify the purpose and expectation. This will include information about number of meetings/time commitment and the purpose and format of meetings.
- A person specification to ensure any individual carrying out the role has the necessary skills and experience to participate effectively as part of the Board and to understand the role they are required to play. This will include details of the particular areas that the Board is seeking to cover such as charity governance and finance, human resources, communications.

- Induction information and access to training and / or shadowing in key areas of the Society and in lung health systems and structures.
- Tenure, i.e. 3 years.

2.2 The work we do

We recognise the professional experience and expertise our members have in delivering patient centred care. We encourage all our members who engage with and contribute to our work to consider the voice of the patient, carer and public in their roles on BTS Committees, SAGs, and other working groups. We will also seek to include the patient voice in our educational activities (for example in sessions at our Summer/Winter Meetings and short courses), and foster patient/carers/public input to scientific/research activities.

The development of clinical standards is a key part of the work of the Society. These outputs include internationally renowned clinical guidelines, quality standards and clinical statements. To ensure standards and information created by the Society is patient centred, the involvement of patients, carers and the public has been a feature of this aspect of our work for some time. As part of our refreshed approach to patient, carer and public voice we will work on ensuring involvement in standards development is consistent and uniform including the way people are recruited, supported and involved.

We will set out a minimum standard for supporting patient, carer and / or public involvement in the development of our standards documents and ensure this information is made available to all relevant working groups. This will involve guidance on patient, carer, and public

involvement in developing standards as part of an information and support pack. The pack will include:

- An introduction to BTS and our commitment to patient, carer, and public voice.
- A role description to clarify the purpose and expectation in relation to the activity concerned (Guideline/Quality Standard/Clinical Statement etc).
- Induction information and access to training and / or shadowing in relevant areas.
- Expenses policy.
- Time commitment and indication of the number of meetings.
- Named contact and contact information.
- Links to example BTS publications.

We will seek feedback from patients, carers and members of the public involved in developing guidelines and other guidance documents at the end of their involvement to see how well we are meeting our commitments. This learning will support regular review of the information and support pack. As part of this process, we will seek to understand the extent to which the people involved in helping to develop guidelines reflect the diversity of the lung health population.

Each BTS clinical guidance publication goes through a period of public consultation where the draft is available openly on our website for a specified period of time. Relevant patient-focussed partner organisations will be notified and invited to send comments. Any patient, carer or member of the public is able to engage with this process. All comments received are reviewed by the group tasked with

developing the document and specific approval processes are in place to ensure all consultation feedback is dealt with appropriately.

2.3 How we work with others

To achieve effective and meaningful engagement with people experiencing lung health conditions and to ensure we are able to extend our reach to a more diverse groups of people we will foster and strengthen our links with patient charities and continue to work closely with our key external partners. External partners include advocacy groups, disease specific charities and patient experience groups.

We will:

- Map our existing partners, identify any gaps, and establish regular communication with each.
- Seek the views of our partners on this framework and will be open to improving it based on any feedback received.
- Work with our partners on identifying lung health topics of relevance and importance for patients, carers, and the public (with both a research and clinical focus) and support our partners through our involvement in groups, wider discussions and lending our voice to relevant consultations.

3. Evaluation

In order to make progress with our refreshed approach to patient, carer and public voice, we aim to make a start at pace. However, we recognise to ensure any involvement is meaningful and effective, there is value and benefit in taking a quality improvement approach to evaluating the

steps taken and adjusting along the way based on our learning.

To achieve this, we will develop a workplan that has clear leadership within BTS Head Office/Officers/Board. We will build in regular 'check and review' points, using feedback from those involved in our work in this area and report progress on our refreshed approach to the Board annually.

4. Resources

To inform our work in this area and to ensure we are drawing from good practice elsewhere we have reviewed and considered information about patient, carer, and public voice from the following resources:

The UK Standards for Public Involvement in Research
<https://sites.google.com/nih.ac.uk/pi-standards/home>

The World Health Organisation
Framework for meaningful engagement of people with lived experience of non-communicable diseases, mental health and neurological conditions.
<https://www.who.int/groups/gcm/meaningful-engagement-of-people-with-lived-experience>

The NHS Constitution for England
<https://www.gov.uk/government/publications/the-nhs-constitution-for-england/the-nhs-constitution-for-england>

NHS England Working in Partnership with People and Communities
Statutory Guidance
<https://www.england.nhs.uk/long-read/working-in-partnership-with-people-and-communities-statutory-guidance/>

Community Engagement, Health
Improvement Scotland
<https://www.hisengage.scot/>

Public engagement and the NHS in Wales
[https://www.nhsconfed.org/publications/
public-engagement-and-nhs-wales](https://www.nhsconfed.org/publications/public-engagement-and-nhs-wales)

Personal and Public Involvement,
Northern Ireland
[https://www.publichealth.hscni.net/direct
orate-nursing-and-allied-health-
professions/allied-health-professions-and-
personal-and-publi-5](https://www.publichealth.hscni.net/directorate-nursing-and-allied-health-professions/allied-health-professions-and-personal-and-publi-5)

NICE Patient and public involvement policy
[https://www.nice.org.uk/about/nice-
communities/nice-and-the-public/public-
involvement/public-involvement-
programme](https://www.nice.org.uk/about/nice-communities/nice-and-the-public/public-involvement/public-involvement-programme)

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