**Terms of reference: Taskforce for Lung Health, February 2019**

1. Purpose of group

The Taskforce for Lung Health was first proposed by the British Lung Foundation (BLF) in spring 2017. From January 2018 it embarked on a year-long project to produce a five-year plan for improving lung health outcomes. At the end of this first phase of the project, its terms of reference were reviewed to reflect the desire of members to continue to work together beyond the launch of the five-year plan, to ensure the implementation of the recommendations in the five-year plan, and to raise awareness of lung disease. The purpose of the Taskforce will be to:

* Campaign for the implementation of the policy recommendations set out in the Taskforce’s five-year plan, published in December 2018
* Monitor progress against the measures of success identified in the Taskforce’s five-year plan, as above
* Support the implementation of the respiratory clinical priority workstream in the NHS Long Term plan. This may involve Taskforce members beyond staff within the secretariat sitting on NHS England working groups. In such instances, Taskforce representatives will be expected to adhere to agreed Taskforce policy positions laid out in the Taskforce’s five-year plan, in addition to other organisational priorities, and to update the secretariat and the membership in a timely manner on developments within these working groups
* Raise awareness of lung disease, its causes and its effects.

1. Key activities

* Agree and support a programme of influencing work to support the implementation of the Taskforce’s policy recommendations. This work will take place within four working groups, focussing on four initial priority areas in 2019, operating within the Taskforce umbrella. These priorities have been agreed by Taskforce members as follows: early diagnosis; medicines management; pulmonary rehabilitation; and data tracking. See further detail on governance of working groups below
* Develop and support new principles and messages to underpin communications work to improve public understanding and awareness of lung disease
* Develop a set of metrics and monitor progress against the NHS long-term plan for respiratory disease and against the Taskforce recommendations. Develop a way of making these metrics accessible to member organisations and accessible and meaningful to those affected by lung disease
* Act as a forum for information-sharing between partner organisations.

While the Taskforce has selected the above policy recommendations to prioritise for influencing in year two, we recognise that other Taskforce members may wish to pursue campaigning and influencing work to implement other Taskforce recommendations, in line with organisational priorities and interests. If members wish to use the Taskforce name as part of their efforts, they will be expected to:

* Ensure that any influencing and campaigning materials using the Taskforce logo are in keeping with agreed Taskforce policy lines
* Ensure that use of the Taskforce logo and brand adheres to the Taskforce brand guidelines
* Share intelligence with the secretariat on progress.

1. Governance of working groups

Each working group will comprise of TF members and IF members interested in taking an active role in influencing for policy change in that particular area. There will be no upper limit on membership of working groups. Individual organisations and companies will be free to join a working group, but companies would have no editorial control over the output and would not be permitted to be a lead organisation. Each of the working groups will have at least one patient or carer representative. The secretariat will be represented on each working group and would have the final say if there were to be any dispute on any output.

Each working group will have one or two lead members. The role of lead members is to:

* Be the driving force behind the creation of influencing plans for recommendations relating to their workstream
* sign off communications plans, with the secretariat
* attend key stakeholder meetings with individuals/ organisations who are targets for that workstream
* help to develop briefing materials in support of the workstream’s key asks;
* advise on the development of key metrics for the data tracker for their workstream; co-chair, along with supporting communications agency, working group meetings and/or calls
* lead on external communications and be responsible for signing off all communications materials
* liaise with the secretariat and supporting communications agency outside of working group meetings to drive forward influencing
* and be responsible for reporting progress back to the Taskforce.

Non-lead members of working groups will be expected to:

* input into the influencing plan for the workstream, both in meetings (as availability allows) and off line
* attend key influencing meetings (as availability allows)
* communicate within their own organisations the work of the working group
* and update the working group and lead members on work of their organisation that is relevant to the working group.

1. Membership

The Taskforce will be formed of the following 30 member organisations and individuals:

* Action for Pulmonary Fibrosis
* Association of the British Pharmaceutical Industry (ABPI)- observing member\*
* Association of Chartered Physiotherapists in Respiratory Care
* Association of Respiratory Nurse Specialists
* Association for Respiratory Technology and Physiology
* Asthma UK
* British Geriatrics Society
* British Lung Foundation
* British Society of Thoracic Imaging
* British Thoracic Society
* The Chartered Society of Physiotherapy
* Cystic Fibrosis Trust
* Health and Safety Executive
* Interstitial Lung Disease Interdisciplinary Network
* Jay Dowle, patient representative
* John Conway, patient representative
* Julie Reynolds, patient representative
* Maxine Flewett, carer representative
* NHS RightCare
* Primary Care Respiratory Society
* Public Health England
* Respiratory Futures
* Roy Castle Lung Cancer Foundation
* Royal College of Anaesthetists
* Royal College of GPs
* Royal College of Nursing
* Royal College of Paediatrics and Child Health
* Royal College of Physicians
* Royal College of Radiologists
* Royal Pharmaceutical Society
* Society for Cardiothoracic Surgery, on behalf of the Royal College of Surgeons

\*The status of the ABPI as an observing member will be to actively contribute to the group through discussion and inputting of material, but will not hold voting rights in the event of any vote occurring. Any other trade bodies who sit on the Taskforce in the future will also have observer status.

There is no restriction on the number of Taskforce member organisations, but any further additions to the membership will be approved by a majority of the existing member organisations. Members of the public, beyond the four individual patient/ carer representatives, will not sit on the Taskforce.

Organisations represented on the Taskforce will nominate a main point of contact for communication and attendance at meetings. However, individuals attending taskforce meetings may change depending on which individual an organisation feels is best placed to represent them at particular events. In the event of a difference of opinion on the taskforce’s programme of activities, this will be resolved by a decision by the Taskforce chair.

Duration of membership of the Taskforce will be ongoing unless member organisations inform the secretariat of their intention to leave.

There are several organisations who have a strong interest in the Taskforce and have expressed an interest in supporting its work but are not taskforce members. The Taskforce will work closely with these members to ensure that they are consulted on areas which are of particular interest to them.

1. Secretariat

The Taskforce secretariat will be held by the BLF. The Taskforce will be chaired by Dr Alison Cook, Director of Policy and Communications at the BLF. The Taskforce is expected to meet approximately once every three months.

1. Ways of working

Member organisations will be expected to engage with the Taskforce activities outside of regular Taskforce meetings. This engagement may take the form of advocating for the Taskforce recommendations with relevant external audiences, or as a lead, or member, of a working group as detailed above. The Taskforce will work flexibly via face to face and virtual meetings to maintain momentum, ensuring the delivery of outputs to agreed timescales.

Member organisations are responsible for ensuring the right people within their organisations are abreast of the work of the Taskforce an involved in decision making where necessary. Where appropriate this should include colleagues working in comms and press.

Member organisations will be expected to take a role in communicating about the Taskforce within their organisations, with their members and with their wider stakeholder audience.

1. Working with industry

The secretariat of the Taskforce will chair a separate Taskforce Industries Forum (IF). The role of this group is to feed in intelligence to the Taskforce, and to act as a communications channel with forum members’ staff and stakeholders. Industry groups and companies may provide financial resources to the Taskforce which will be coordinated by the BLF. However, funding the Taskforce is not a condition of membership to the IF. Minutes of all IF meetings and decisions are available for publication if requested, though these will not be routinely published. For more detail on the role of industry, please refer to the separate terms of reference document for the IF.

1. Review period

This document will be reviewed in December 2019.