

ELF Patient Advisory Committee – Terms of Reference

The European Lung Foundation (ELF) Patient Advisory Committee supports ELF to deliver its mission and this document sets out the terms of reference for members of the Committee.

European Lung Foundation mission and vision

In partnership with European Respiratory Society (ERS), European Lung Foundation brings patients and the public together with healthcare professionals to improve lung health and advance diagnosis, treatment and care.

People living with lung conditions will be centrally involved in lung healthcare and research and everyone in Europe will have clear, reliable information they can trust about lung health and disease in their own language.

Purpose

The ELF Patient Advisory Committee is a sub-committee of the ELF Council and is one of the advisory bodies of ELF. The Patient Advisory Committee members elect one member of the Committee as Chair to represent them on the ELF Council; the ELF Chair is a member of both groups.

The purpose of the Patient Advisory Committee is to provide input to the ELF Council on all issues relating to patient organisations. The Committee also provides guidance and support to ELF in order to integrate the patient voice within ELF and ERS activities. Suggestions and recommendations from the Committee which require a strategic decision are brought to the ELF Council for consideration. The current [ELF strategy](#) is available on our website.

To understand where the Patient Advisory Committee sits within the overall ELF structure, please visit [our website](#).

Membership

The Patient Advisory Committee is comprised of representatives of not-for-profit respiratory health-related organisations, which represent individuals with respiratory diseases within Europe. The criteria for membership of the Committee are:

- Representative of a not-for-profit respiratory health-related organisation
- Organisation is based in the World Health Organisation (WHO) European region and/or represents patients in the WHO European region
- Committed to actively working with ELF and other organisations to improve respiratory health in Europe
- Member of [ELF patient organisation network](#).

A maximum of two representatives from any individual organisation can be members of the Patient Advisory Committee at any one time. Where an organisation has more than one representative on the Committee, the organisation will have one vote. If a representative is unable to attend a Committee meeting, they may nominate another representative of their organisation to attend on their behalf.

The Committee will have a maximum of 20 members at any one time. There is no limit to the length of time an organisation can be a member of the Committee.

Appointment process

Members are appointed for a three-year period. Every three years, ELF invites existing PAC members and interested organisations from the ELF patient organisation network to apply to join or remain on the PAC. Interested organisations are invited to submit a brief outline of their organisation's aims, remit and interest in joining the Committee.

Applications from existing and new organisations are assessed together. Patient Advisory Committee members will vote and new members will be selected to ensure a good balance of disease areas, European countries and expertise.

When a vacancy arises during the three-year term, ELF invites members of the wider ELF patient organisation network to apply to join the Committee. Recruitment will follow the appointment process outlined above.

Withdrawal and removal from the Committee

If ELF considers a member to be acting in a way that is detrimental to the reputation of ELF, inconsistent with the aims and remit of the Committee or to be in breach of these terms of reference, with approval of the ELF Council, they may remove a member of the Committee.

ELF understands that organisational priorities and capacity change and it may not always be possible for organisations to actively engage in the Committee. In order to facilitate a productive Committee environment, if an organisation is not able to play an active role in the PAC, they will first be asked if they still have the capabilities to do so and if this is not possible, with approval of the ELF Council, ELF will remove them from the Committee. Previous removal from the Committee does not prevent them from applying to join the Committee in future.

Roles and responsibilities

ELF values the commitment given by members of the Patient Advisory Committee and recognises that many of the patient organisations it works with are run by unpaid staff and volunteers, while many individual patients and carers also volunteer their time to support ELF. Membership of the Committee is intended to be mutually beneficial for both the member and ELF, supporting both organisations to deliver their aims.

Members of the Patient Advisory Committee are expected to:

- support the mission and vision of ELF, as outlined above
- actively participate in a minimum of two Committee meetings per year
- build relationships with members of the PAC to form a European network for all lung diseases as an opportunity to share best practice and experiences
- help identify and prioritise topics that need urgent inclusion in the ELF and ERS agenda
- work with ELF and ERS to help raise the profile of respiratory disease in Europe
- help to plan the annual ELF patient organisation networking day
- showcase the work of their patient organisation at the ERS Congress and relevant events
- propose patients to participate in the ERS Congress and other relevant events as patient speakers, chairs and representatives at public events

- input into the design of ELF and ERS projects to ensure a patient-centred approach
- input into ERS activities on patient-centred topics and propose patient representatives to participate, including in Task Forces to produce guidelines and statements, Clinical Research Collaborations, ERS Education Courses, ERS Symposiums and Research Seminars, and EU projects of which ELF is a partner
- assist with the development and dissemination of ELF materials to patients, the public and health professionals, in line with the organisation's own communication strategy
- promote the European Patient Ambassador Programme (EPAP)
- support the development of disease-specific ELF Patient Advisory Groups for lung diseases in Europe
- participate in working groups of the Patient Advisory Committee on specific topics relevant to their organisation
- recognise and promote ELF's activities where appropriate through the organisation's website and social media, in line with the organisation's own communication strategy.

In recognition of their significant contribution to ELF's activities, members of the Patient Advisory Committee receive the following benefits:

- one full free registration per organisation to the ERS International Congress, with the option to apply for a travel bursary (when available). Additional organisation representatives will be entitled to pay the patient registration fee
- free one-day registration to the ERS International Congress for additional representatives to take part in the patient organisation networking day
- opportunity to participate in the World Village at the ERS Congress to showcase their work
- opportunity to influence ELF and ERS strategy through regular Committee discussions and taking part in periodic strategic planning and priority-setting activities
- opportunity to increase the visibility of their organisation in Europe
- opportunity to engage with respiratory professionals
- opportunity to network and join forces with other patient organisations around areas of mutual interest to ensure the patient voice is heard.

Patient Advisory Committee Chair

The Patient Advisory Committee is chaired by a representative of one of the member organisations. The Chair is appointed for a period of three years.

The role of the Chair is to elevate the voice of patient organisations within ELF and ERS, thus ensuring that priorities for the patient organisation community are addressed at a strategic level. The Chair sits on the ELF Council, representing the Patient Advisory Committee, and works closely with the ELF Chair and ELF staff to develop new initiatives. The Chair oversees Committee meetings, including setting the agenda and identifying areas for strategic input.

At the end of each Chair's term, applications are invited from members of the Patient Advisory Committee to take on the role. Members of the Committee vote to select the new Chair.

Mode of operation

The Patient Advisory Committee meets four times per year via video conference. Members of the Patient Advisory Committee are expected to actively participate in at least two meetings per year, lasting up to two hours each. Some preparation and additional work may be required between meetings, for example, commenting on written documentation or circulating materials to the patient organisation's own members. Additional work is at the discretion of the individual Patient Advisory Committee member. The total commitment to carry out Committee-related responsibilities is likely to require a maximum of three working days per year.

Each organisation represented on the Committee will have one vote in matters put to them for approval. At least half of the Committee members must be present for there to be a quorum.

As with all ERS and ELF activities, the working language of the Patient Advisory Committee is English. As translation technology evolves, this may change.

Staff involvement

The ELF team is expected to play an active role in the Patient Advisory Committee's work; but they will not vote on items put to the Committee for approval. Secretariat support will be provided to the Committee by members of the ELF team.

Expenses

The costs of video conferencing will be paid by ELF. Members of the Committee are not expected to incur significant other expenses and will be entitled to one free registration for the ERS International Congress and can apply for a bursary to contribute to the costs of Congress attendance (when available). Members are expected to comply with ELF's expenses policy which is available on request.