

ELF Patient Advisory Committee – Terms of Reference

The European Lung Foundation (ELF) Patient Advisory Committee supports ELF to deliver its mission. 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 and / or Vice 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 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.

The Patient Advisory Committee should identify a concrete action or deliverable annually outside of its advisory function. This action, for example, could be a dedicated ELF event on a topic of focus, embedded into the outputs of a regular ELF activity, or be a joint statement, submission or publication. It is part of the Committee's purpose to identify such a project of collective interest and advance its progress whether via a smaller working group or collectively.

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 that is based in the World Health Organisation (WHO) European region and/or represents patients in the WHO European region
- Committed to meaningful and active work with ELF and other organisations to improve respiratory health in Europe, through contribution to collective work, discussion and initiatives.
- 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 from their organisation to attend on their behalf. This is encouraged as it ensures that the views of that organisation are consistently represented. Ideally each member of the Patient Advisory Committee would identify such an individual at the start of their term and keep them updated on a regular basis. If desired, ELF will include that individual on the Committee mailing list to ensure that minutes and other information are available to them in the event they are called upon to act as a proxy for the Committee member.

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 of their term (excepting the ten mentioned in the section below) 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 with an initial eligibility exercise being carried out by the ELF staff team. Patient Advisory Committee members will vote on the list of eligible candidates and the outcome of this will be taken into a further assessment process by a committee made up of the ELF Chair, PAC Chair and Core Council (the patient members / representatives of the ELF Council).

The selection committee will consider the strength of the application alongside the makeup of the overall list of candidates, giving weight to geographical spread, disease area, size of organisation and track record. This weighting fulfils an overall aim to ensure that the PAC is as broad and diverse as possible. Furthermore, where organisations are renewing their membership, consideration will also be given to the previous level of engagement and contribution to the work of the Committee.

In the event of deadlock or tied votes between two or more candidate organisations the selection committee will ask the existing members of the PAC to vote on that selection.

Of the twenty members selected in 2026, ten will be randomly allocated a three-year term. The remaining ten will be offered an initial two-year term to introduce a staggered three-year term henceforth, for continuity and good practice purposes.

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, and will follow the appointment process outlined above.

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. Many individual patients and carers also volunteer their time to support ELF

activities. Membership of the Committee is intended to be mutually beneficial for both the member and ELF, supporting both organisations to deliver their aims.

The strength and credibility of the Patient Advisory Committee depends not only on the diversity of the organisations represented, but also on the active contribution of its members.

As a minimum, members will:

- attend and actively contribute to at least three Committee meetings per year
- read relevant documents and prepare for discussions and decisions, including gathering insights from member's patient community as needed
- respond to important consultations and requests for input within reasonable timeframes
- contribute to at least one Committee initiative, working group or collective activity during their term
- connect ELF with members of the organisation's patient community
- assist with the patient-centred design, development and dissemination of ELF materials, events and projects to patients, the public and health professionals.

The level and nature of individual contributions may vary according to availability, resources and areas of expertise. These activities may include, for example, sharing good practice and identifying and prioritising topics for urgent ERS and ELF action.

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
- 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 and disease area 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.

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.

Whilst active participation is an essential condition of membership, ELF understands that organisational priorities and capacity changes may mean this is not always possible. In order to facilitate a productive Committee environment, if an organisation is not able to play an active role in the PAC, a discussion will be initiated with them to understand any difficulties and explore possible solutions. Where appropriate, the organisation may be invited to nominate another representative or agree a plan to resume active participation.

If meaningful engagement cannot be restored within an agreed and reasonable timeframe, membership may be terminated, subject to approval by the ELF Council. Such decisions will take into account personal circumstances, health-related limitations and the voluntary nature of participation. Previous removal from the Committee does not prevent an organisation from applying to join the Committee in future.

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 at least four times per year via video conference and one face-to-face meeting at the ERS Congress. Members of the Patient Advisory Committee are expected to actively participate in at least three 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.