

# ELF Youth Group: Terms of Reference

## 1. Introduction

European Lung Foundation (ELF) brings patients and the public together with healthcare professionals to improve lung health and advance diagnosis, treatment and care. ELF's vision is that 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. To ensure we can represent the voice of people of all ages, a decision was made by the ELF Council to form a Youth Group (hereafter the Group) to contribute to all aspects of ELF activities. These Terms of Reference set out the aims, membership and practical arrangements of the Group.

## 2. Roles and responsibilities of the Group

### *a. What is the role of the Group?*

The Group is a team of young people (from 16 to 24 years old), as well as representatives of young people, who have an interest in a particular lung condition or topic related to lung health. The Group is set up to focus on issues, policies and activities linked to this specific age group, but also to ensure ELF spends appropriate time and resources reaching young people. Key issues already identified include (but are not limited to): transition of care when moving from adolescence to adulthood, family dynamics, education in schools, social media and online activities.. While the Group functions as a team, individual members might also take special responsibilities regarding different projects.

### *b. What are the responsibilities of the Group?*

- Providing input into all aspects from a young person with a respiratory condition's perspective.
- Commenting on goals to ensure they are relevant to young people with lung health concerns.
- Providing input on aspects of living with a lung condition that are important to young people.
- Informing guideline recommendations and future research studies.
- Offering advice on the best way to hear the views of young people and include them in a project.
- Taking part in, and helping to develop, surveys and focus groups to provide the young patient perspective.
- Helping to disseminate the project findings through their networks to other young people, professionals and the public.
- Developing information materials, such as lay guidelines or factsheets, aimed at young people.

- Developing projects or initiatives to address young patients' priorities.

### **3. Membership**

#### ***a. Who can join the Group?***

The Group is open to young people with a lung condition (aged between 16 and 24). Representatives (parents, legal guardians, healthcare professionals) of patients under 18 will provide consent in sharing medical or other information of them and may accompany them during the meetings, events and activities if necessary.

#### ***b. How are members recruited?***

ELF recruits Group members via notices on its website and in social media, as well as through its patient and professional networks. For all members under 18, the consent of the parents or the legal guardians is necessary.

#### ***c. Are there any requirements for members?***

Members should be confident communicating in English, as English is the common language of all ELF activities and communications. We do try to facilitate the involvement of non-native English speakers as far as possible, and hope to eventually offer more opportunities for people to communicate in their native language as we develop the tools to do this. Members must sign a confidentiality agreement and conflict of interest declaration.

#### ***d. Are there any limits on membership?***

There is an age limit for people who want to be members of the Group. The age range is from 16 to 24 years old and there is no limit on the length of time they can be a member, as long as they remain within the relevant age bracket mentioned. No patient under 18 can participate in the group without the consent of their parents or legal guardians. For individuals that represent patients, there is no age limit. However, we will periodically review membership to ensure that the group remains relevant to the tasks required. A member that has reached and exceeded the defined age bracket could consider joining a Patient Advisory Group (PAG).

### **4. Confidentiality and conflict of interest**

#### ***a. What do members need to agree to?***

When joining the Group, members must sign a form agreeing to keep confidential all information related to the content and development of the projects they are involved with until the outcomes have been published at the end of the project. During the process, patients outside the Group may be consulted, in which case certain information can be disclosed.

All discussion in the Group meetings should be treated as confidential – particularly in relation to other individuals' health and personal circumstances.

The Group members are welcome to promote and discuss their activities with ELF through their own channels but should be conscious of confidentiality and privacy. If there is any doubt about whether something should be communicated, the ELF team should be consulted. The ELF team will contact individuals who post information that is deemed to be problematic.

The Group members that aren't under 18 must declare whether they have any potential conflicts of interest, for example, a relationship with the tobacco/e-cigarette industry or a pharmaceutical company. Members must also tell ELF if, at any point during their membership, a potential conflict of interest arises or may arise.

In order to comply with the funding agreement, EU projects may have additional requirements around confidentiality and conflicts of interest and may have a separate declaration form that the Group members are asked to sign.

***b. What if there is a conflict of interest?***

While a relationship with the tobacco/e-cigarette industry will usually prevent someone from being accepted as a Group member, other relationships, such as those with a pharmaceutical company, will not necessarily prevent someone from joining the Group. The issue will be discussed with the project's chairs or steering committee and decided on a case-by-case basis.

**5. Group meetings**

***a. When and how will members communicate?***

Group members will communicate by participating in online meetings, by joining messaging apps, such as what's app, and by connecting to social media platforms.

***b. Who attends the meetings?***

All members are expected to attend the Group meetings, where possible. An ELF representative normally attends these meetings and will take the minutes. Meetings can be chaired by the ELF representative, or the Group may choose to nominate a member to chair each meeting. The minutes will be circulated after the meeting for those who were unable to join. Participants under 18 can be accompanied by their parents or legal guardians during the meetings.

**6. Communication**

***a. How do the Group members communicate with each other?***

Members are encouraged to exchange email addresses so they can share ideas and experiences between meetings. Other methods of online communication can also be used, as described above.

**7. Expenses**

**a. *What expenses can Group members claim?***

Membership of a Group is a voluntary role. ELF/ERS will cover the cost of telephone calls and video conferencing, if needed.

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