Guide for chairs on involving patients in your Task Force

How the European Lung Foundation can assist you

1. A resource for your Task Force

The European Lung Foundation (ELF) provides the patient voice in the activities of the European Respiratory Society (ERS).

ERS recognises that patient and public input into Task Forces is often valuable and appropriate and we can help to facilitate this for you. We work closely with the chairs of Task Forces to ensure that patient issues are highlighted in the work of Task Forces.

We can discuss patient input options with you and provide just the level of support that you require. Please get in touch to discuss how we can best support your activities. ERS/ELF will cover and manage the costs for patient involvement once your application is approved and the patient input approach has been agreed.

2. How we involve patients

Based on our experience of including patient perspectives in Task Forces to date, we have developed a patient input process (see page 4). We will discuss and tailor these options to ensure that any activities complement the aims of your Task Force.

We recruit and involve people with experience of lung conditions through our European patient and healthcare professional networks and provide training for them through our European Patient Ambassador Programme (EPAP). This gives the introductory knowledge required to participate in Task Force meetings effectively.

For joint Task Forces with other professional societies, ELF works with the patient involvement leads of the partner society and the Task Force chairs to agree a plan for patient input.

3. Why involve patients in your Task Force?

ERS promotes patient and public input into Task Forces when appropriate and recognises that this will help to:

- Ensure that guidelines address key issues of concern to patients that may be overlooked by healthcare professionals.
- Highlight areas where the patient’s perspective differs from health professionals.
- Underpin guidelines with patient experience.
- Provide input from individuals across Europe to increase the transferability of guidelines to different settings.
- Ensure that patients will support the outcomes of the guidelines.
- Disseminate the guidelines more widely, including to patient groups.
Checklist for Task Force chairs

Pre-application stage:

- Contact ELF as soon as possible (ideally at the pre-application stage) to discuss potential options for involving patient perspectives in your Task Force.

- If you decide that it is desirable for patient representative(s) to be involved as full members of the Task Force, then note this on the application form and add the number of patient participants to the appropriate patient input budget section.

Active Task Forces and ongoing liaison with ELF:

- An ELF staff member will participate at the Task Force kick-off teleconference to talk about the patient input process. This is a good opportunity for discussions to start if you have not made contact previously.

- It can be helpful for an ELF staff member to attend the first meeting with Task Force members (and possibly subsequent meetings) to present an overview of plans for patient input into the Task Force and to provide support to any patient representatives in attendance.

- Ensure that all Task Force members understand the role of patients in the project and address any initial concerns they may have. We can provide guidance on this and work with you to ensure that patient representatives also understand exactly what is expected of them.

- Ensure that your named ELF staff contact is included in all email communications about Task Force teleconference/meeting dates, minutes and working documents, so that we can keep track and plan for patient input activities.

- If patient representative(s) will be attending meetings, we recommend arranging a short teleconference/meeting for an introductory conversation in advance, to help clarify their understanding of the Task Force, and reveal how they can best input on the day and after. ELF can arrange and facilitate this call.

Responsibilities for chairs in Task Force meetings:

- Give an introduction explaining the role of the patient representative(s) and encouraging all Task Force members to involve them.

- Discuss with patients their role in the task force and your expectations of their involvement as soon as possible.

- Prompt patients to provide input where appropriate e.g. especially when their views may differ to the professionals’ opinion.

- Use natural breaks in the discussions to explain to patients what is being discussed. Debrief with patients after meetings to make sure they have understood the discussions.
➢ Consider lay versions of important documents. These should be developed with patient representatives, chairs and other panel representatives where appropriate.

➢ Be aware of some challenges patient representative(s) may face during meetings:
  o May not be used to attending formal meetings.
  o May not feel part of the group initially e.g. Task Force members may already know each other well.
  o May be unable to participate fully during in-depth scientific discussions.
  o Some discussions may touch on sensitive or potentially upsetting issues e.g. mortality rates, serious complications or ineffectiveness of certain treatments.

➢ Maintain patient confidentiality at all times.

➢ Involve patient representative(s) in any social events that you are holding alongside the meeting so that they can get to know other Task Force members in a more relaxed setting.

➢ Give regular feedback to patient representative(s) and ELF on how their involvement is affecting the project.

Next steps

Please contact Courtney Coleman, ELF patient involvement and engagement, at courtney.coleman@europeanlung.org to discuss your patient input options further.

Read about Task Forces that patients have been involved in previously, such as chronic cough, severe asthma, and smoking cessation for people with lung conditions, on the ELF website: http://www.europeanlung.org/en/projects-and-research/task-forces/
ELF patient input process

**Initiation**
- Task Force (TF) application form: Chairs contact ELF for discussions about patient input
- ELF reviews accepted TF applications: ELF and TF chairs finalise patient input activities

**Patient-centred literature review**
- ELF undertakes a literature review to explore how patients experience the condition/issue, their perception of unmet needs and possible improvements. Gaps in key themes/knowledge identified

**Patient Advisory Group (PAG)**
- ELF forms a patient advisory group (PAG) of 8-10 dedicated patients/caregivers from across Europe to inform the work of the TF at all stages. 1-3 members may be included as TF members
- Training provided through our online European Patient Ambassador Programme (EPAP)

**Consultation**
- Online survey: to gather the perspectives of the widest possible number of patients and carers across Europe (developed with PAG/TF and translated into a range of languages)
- PICO questions: PAG helps to inform the topics and identify outcomes alongside TF members; and in particular, to define within each PICO, the values and preferences of patients.
- GRADE process: PAG help identify the outcomes that the evidence is graded against using the GRADE approach e.g. quality of life measures
- Focus groups: patients come together to discuss topics defined by the PAG/TF. Can be held in different countries or one focus group of patients from a range of countries
- Ongoing consultation: ad hoc engagement of PAG on issues arising from literature searches, TF discussion and patient perspectives on topics covered in the manuscript etc.

**Integration of patient input**
- Final manuscript: patient perspectives included in the final manuscript (as a specific section or alongside each of the recommendations). Patient input also outlined in the methodology
- Separate paper: presents the findings of patient consultation in greater depth. Cross-referencing between the final manuscript and the patient paper if possible

**Review**
- Review of the recommendations: PAG checks and validates the patient perspectives findings
- Review of the final manuscript: PAG checks patient perspectives and assesses which sections should be disseminated to patients
- Review process: PAG/TF evaluate the patient input process

**Dissemination**
- Lay version: ELF develop a plain language version of the manuscript (in several languages)
- ERS members and ELF network: through ERS weekly, ELF newsletter (featured interview), ELF website news and social media channels
- Breathe patient-professional perspective: an article on the TF topic with a reference to the final manuscript, ideally with a TF member and PAG representative as the interviewees