

European Lung Foundation patient input process

Initiation

- **Task Force (TF) application form:** TF applicants request patient input
- **ELF reviews accepted TF applications:** ELF contacts TF chairs to discuss patient input

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

- **PICO questions:** PAG inform the topics to be covered and development of questions
- **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
- **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)
- **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