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