

ELF involvement in EU projects

European Lung Foundation

The European Lung Foundation (ELF; www.europeanlung.org) was founded by the European Respiratory Society (ERS) and its mission is to bring together patients, the public and respiratory professionals to positively influence respiratory medicine. ELF works to communicate respiratory science to those outside the respiratory field. ELF also works to ensure that people with lung diseases and the general public have the opportunity to influence respiratory research and guidelines at the European level.

ELF interest

ELF is primarily interested in pan-European collaboration initiatives, with scope for improving the lives of people with respiratory conditions with tangible outcomes. Our goal in EU projects is two-fold:

- to facilitate and integrate patient involvement throughout the research process for the lifetime of the project
- to communicate the aims and results of the project to patients and the public in lay language

ELF is motivated to involve patients in all stages of EU projects. Involvement of those with expertise in living with a condition in research study design, on ethics boards and patient input groups can help ensure that recruitment targets are met and that the patients taking part in research can have a positive experience, that real-world outcomes are achieved by the project, appropriate communication and dissemination of the project to key stakeholders outside of the respiratory professional community and a legacy for the project.

Key facilities and infrastructure

ELF was founded and is funded in part by the European Respiratory Society (ERS). It therefore has a strong supporting network of respiratory societies and healthcare professionals across the globe. ELF has a network of >1500 patient organisations with whom it ELF work and collaborate with. ELF has a website with >40,000 unique visitors each month, ELF has a press team who run the press office for the ERS congress and journals, and has successful social media channels.

ELF also has an educational training programme for patients on how to get more actively involved in healthcare. This online training programme has been used by >800 patients to date.



EU project experience

ELF has been involved in four large European projects: UBIOPRED (www.ubiopred.eu), AirPROM (www.airprom.eu), EARIP (www.earip.eu) and FRESH AIR (improves health outcomes for people at risk/suffering from lung disease in low-resource settings www.theipcr.org/display/FRESHAIR/global+action+for+healthy+lungs). ELF has co-written and contributed to a number of European-level project proposals.

The experience of ELF in these projects has provided it with expertise in the following areas:

Project management
Participation in steering committees, advisory boards and project management
Set up of patient input platforms/patient advisory groups
Implementation
Conducting pan-European literature reviews on patient needs and experiences
Stakeholder engagement
Patient input into project implementation
Patient review of information and documents
Dissemination and promotion
Development of websites and social media presence
Communication to ELF network, patients and stakeholders
Lay summaries of project outcomes and publications
Public engagement and outreach
Advocacy

ELF criteria

ELF receives many requests to be part of EU projects. Criteria that a project would need to meet to be considered are listed in the document available on the "[EU Projects](#)" on ELF website, together with a form to be completed to request ELF involvement.